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PhD Thesis

An evaluation of the development and implementation of individualised funding for people with a disability

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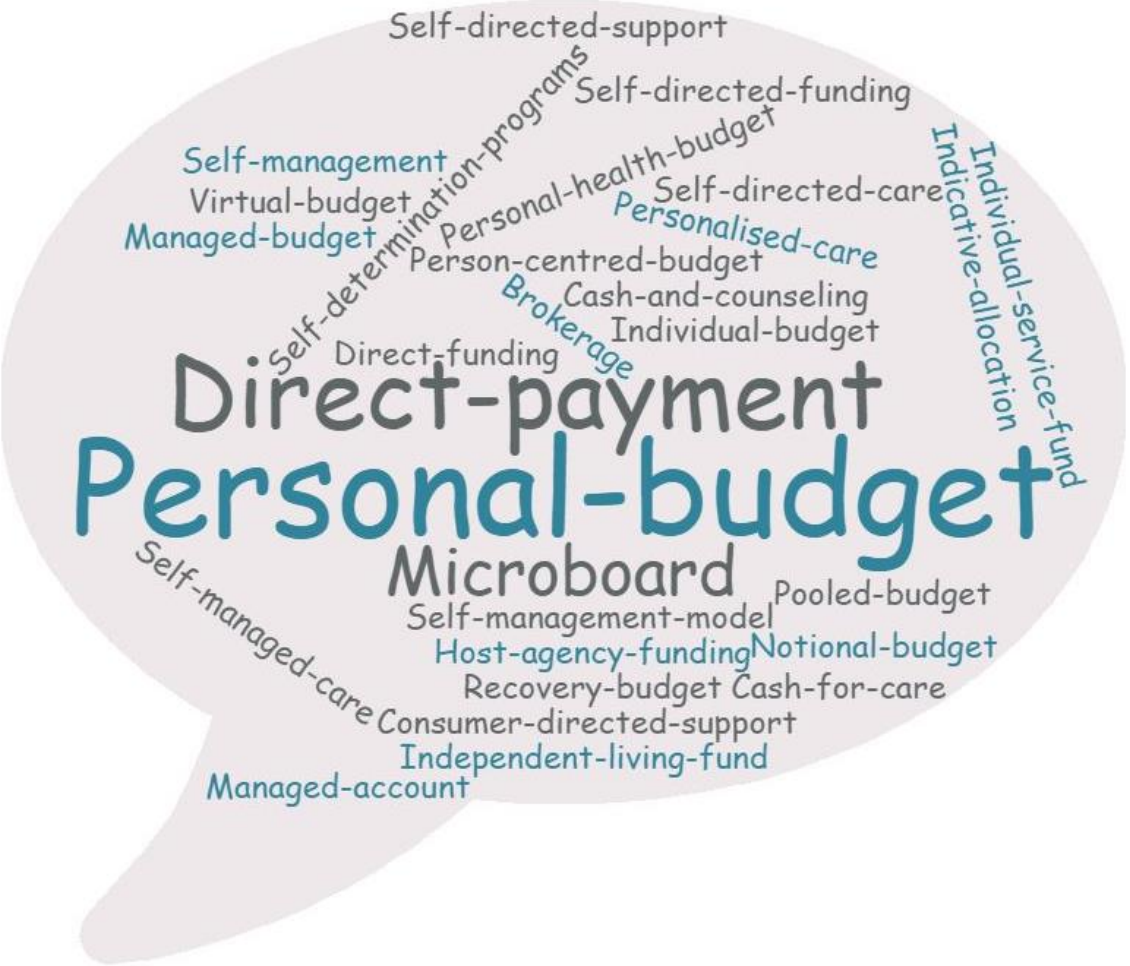

Dissertation

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ACRONYMS

AC	Assessment Criteria
ADL	Activities of Daily Living
ASCOT	Adult Social Care Outcomes Toolkit
ASSIA	Applied Social Sciences Index and Abstracts
CAHPS	Consumer Assessment of Healthcare Providers
CASP	Critical Appraisal Skills Programme
CEA	Cost-Effectiveness Analysis
CGT	Constructivist Grounded Theory
CINAHL	Cumulative Index of Nursing and Allied Health Literature
CMO	Context, Mechanism, Outcome
CRPD	Committee on the Rights of Persons with Disabilities
CSO	Central Statistics Office
DLA	Disability Living Allowance
DP	Direct Payment
EASPD	European Association of Service Providers for Persons with Disabilities
ENIL	European Network on Independent Living
ESF	European Social Fund
GHQ	General Health Questionnaire
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HIQA	Health Information and Quality Authority
HR	Human Resources
HRB	Health Research Board
HSE	Health Service Executive
IADL	Incremental Activities of Daily Living
IBSEN	Individual Budgets Evaluation Network

ICD	International Statistical Classification of Diseases
ICERs	Incremental Cost-effectiveness Ratios
ICF	International Classification of Functioning, Disability and Health
ILF	Independent Living Fund
INFINITE	INdividualised FundINg ImplemenTation framework
LA	Local Authority
NCSE	National Council for Special Education
NDA	National Disability Authority
NGO	Non-governmental Organisation
NHLBI	National Heart, Lung and Blood Institute Health Information Center
NIDD	National Intellectual Disability Database
NORART	Norwegian and Nordic index to periodical articles
NRCPDS	National Resource Center for Participant-Directed Services
PCP	Person-centred Plan / Personal Care Plan
PSSRU	Personal Social Services Research Unit
PwD	People with a Disability / Person with a Disability
QoL	Quality of Life
RCT	Randomised Control Trial
SDS	Self-directed Support
SPHeRE	Structured Population and Health-services Research Education
SRESC	Social Research Ethics Subcommittee in Maynooth University
UNCRPD	United Nations Convention on the Right of Persons with Disabilities’
WHO	World Health Organisation
WHOQOL-DIS	WHO Quality of Life Disability module

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ABSTRACT

Background

Since the 1970s, there has been an important and continuing shift within the disability sector toward self-determination and independence for people with a disability. Individualised funding provides one way of achieving such self-determination by providing personalised and self-directed supports for people with a disability. Such supports have become globally recognised as a viable alternative to traditional group-orientated and centre-based 'service provision'. Typically resourced from public funds, individualised funding initiatives aim to empower individuals with a disability to envision the life they want and purchase the necessary supports they need to enable them to reach their short and longer-term goals and aspirations.

Objectives

The research reported in this thesis was designed to: (1) map the historical and political context within which disability service provision has emerged in Ireland and to examine, in particular, trends in, and funding of, day service provision within the disability sector; (2) explore the perceived effectiveness of individualised funding in Ireland and the extent to which it might be an appropriate, feasible and acceptable mechanism for supporting people with a disability; and (3) to undertake a comprehensive mixed methods systematic review in order to examine the actual and perceived effectiveness of individualised funding initiatives for adults with a lifelong disability in terms of improvements in their health and social care outcomes, as well as the lived experience of implementation.

Methods

Three separate but related studies were conducted using mixed methods approaches within a pragmatic framework. **Study One** was retrospective in nature and used secondary national data to examine day-service utilisation in Ireland during a 15-year period (1998 to 2013). **Study Two** involved an in-depth national evaluation of four individualised funding pilot initiatives in Ireland. This study incorporated an extensive documentary analysis, in-depth interviews, secondary analysis of qualitative data and a participatory workshop. **Study Three** involved a mixed-methods systematic review of international data from 1985 – 2016, comprising a narrative analysis of quantitative data and a meta-synthesis of qualitative data.

Results

Study One) The findings of the initial mapping exercise indicated that day services in Ireland did not change substantially during the period 1998 to 2013 and often did not reflect demand. Statistically significant changes between uptake of services over the 15 year period, in addition to other pertinent socio-demographic information indicated: fewer people availing of day-services as a proportion of the general population; more males; fewer people aged <35; a doubling in person-centred plans; and an emerging urban/rural divide. These findings provide historical context/background to the development of four pilot individualised funding initiatives in Ireland, which were evaluated in Study Two.

Study Two) The individualised funding pilots in Ireland - characterised by independent-skills development and community integration - have been welcomed as a progressive development beyond traditional service provision, with reported improvements across a range of personal, health, social care and organisational domains when compared to more traditional forms of provision. These include: improved self-image, personal and social skills, new opportunities and increased community engagement. The findings also point to the importance of 'natural supports', who underpinned the process, and how overly-protective behaviour on the part of both paid and unpaid carers, may unintentionally pose a barrier to full implementation. Organisations achieved value for money; challenged the status quo and reportedly improved outcomes. The findings indicate further that unnecessarily complex and overly-bureaucratic systems can lead to individual burn-out. For organisations, challenges included access to funding and resistance to change. Administration, money/time/people management and accessing community based activities also challenged the process.

Study Three) A total of 73 unique studies (113 titles) were identified including four of a quantitative nature, 66 qualitative and three based on a mixed-methods design. The collective quantitative findings demonstrated statistically significant improvements in a number of domains for people utilising individualised funding when compared to a control group; these included better quality of life, higher levels of satisfaction and safety, and fewer adverse effects. For the latter, it should be noted that one out of 11 measures (collected across five studies) indicated fewer adverse effects in the control group. Similarly, cost-effectiveness data were inconclusive with no differences detected in one study and inconsistent findings between three sites in a second study. The qualitative data highlighted a number of implementation facilitators and challenges as outlined below.

Implementation facilitators included: freedom to choose 'who' supports you, 'when', 'where' and 'how'; needs-led support; strong, trusting and collaborative relationships; flexibility; support with information sourcing, staff recruitment, network building, administrative and management tasks; community integration; social opportunities; improved self-image and self-belief; perceived value for money; and timely relevant training for all stakeholders. *Implementation challenges* included: lack of trusting working-relationships due to previous negative experiences; overly complex, rigid, and bureaucratic assessment, administrative and review processes; cumbersome systems that duplicate work; inaccurate or inaccessible information; inconsistent approaches to delivery; difficulties with finding and retaining suitable staff; hidden costs or administrative charges; risk aversion by paid and unpaid supports; and logistical challenges in accommodating a wide range of support needs in an individualised way.

Conclusion

The collective findings from this research suggest that individualised funding should not be shoehorned into existing systems, processes and procedures that have been developed for a time when societal perspectives and understanding of disability were very different from those that are in evidence today. These initiatives should, instead, be facilitated by a needs-led, person-focused, aspirational resource allocation system that is flexible and capable of adapting to various, dynamic and changing contexts.

The results from Studies Two and Three provide a number of important policy and practice insights. With regard to the latter, individualised funding should perhaps be introduced on an incremental basis, starting with school leavers and, in time, moving to a 'whole society' approach, including disabled children, adults and older people receiving supports within traditional services. Implementation should be accompanied by the provision of necessary resources, (human, time and financial) to facilitate the transition from a traditional paternalistic model of service provision to one that is truly person-focused, needs led and community-based. This should include educational and training opportunities for all stakeholders.

Ideally, implementation should also be supplemented with robust, mixed-methods evaluations which focus, not only on outcomes over time but also the context of, and mechanisms for, success into the future. With these in mind, the research findings were used to outline various options that might help to promote and support the implementation of individualised funding in Ireland. This is particularly timely and important given the plans that are currently underway for national roll-out, as evidenced by unique policy dialogue opportunities involving, for example, the National Taskforce on Personalised Budgets and a high level of interest from, and consultations with, the Health Research Board and the Department of Health in Ireland.

CHAPTER ONE: INTRODUCTION

1.1 INTRODUCTION

The World Health Organisation (2013) estimates that 15% of the world's population currently live with a disability, a proportion that is thought to be increasing due to population ageing and a greater prevalence of more chronic health conditions (WHO, 2013). Disability is extremely diverse and complex and defining it, therefore, can be contentious (Leonardi, Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006). As a result, there are a number of ways in which disability is defined and described in the literature. For example, the 'International Classification of Functioning, Disability and Health' (ICF) defines disability very broadly as encompassing impairments, limitations in activity and restricted participation (WHO, 2002). By contrast, the United Nations (UN) (2006) defines people with a disability more specifically as "*those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others*". According to the WHO (2013), disability may be conceptualised as the interaction between individuals with an impairment (e.g. muscular dystrophy) and a range of personal, social and environmental factors (e.g. stigma, workplace discrimination, or inaccessible public transport), which, in turn, can limit a person's social, educational and economic opportunities. The concept of disability is further explored and developed in later chapters.

For the purposes of this research, it should be noted that the term 'people with a disability' will be used throughout because this is in line with the 'United Nations Convention on the Rights of Persons with Disabilities', as well as Irish policy and practice. An exception to this can be seen in the publication presented in Chapter Four, in which the term 'disabled people' is used; this was recommended by the international peer reviewers because this term and its derivatives , are seen as more consistent with the social model of disability and the ethos of the journal in question.

The remainder of this chapter presents a brief background to the research which includes an overview and 'signposting' of the relevant bodies of literature which are developed in later chapters, as well as key policy developments in both an Irish and international context. Given that this thesis is 'by publication', three publications are presented in Chapters Three to Five; these are referred to below where appropriate. More specific detail on the content of the thesis is provided in Section 1.5. A description of the study and its aims and objectives are also described in the sections that follow.

1.2 BACKGROUND

Historically, service providers have focused primarily on meeting the medical needs of people with disabilities, but more recently, the importance of social care needs, such as keeping active and socialising, has been recognised (Malley et al., 2012). For example, most international policies on disability now advocate for greater autonomy and self-determination for people with disabilities, such that they feel more empowered and can be as independent as possible, choosing their own supports and self-directing their lives (Perreault & Vallerand, 2007; Saebu, Sørensen, & Halvari, 2013). One way to achieve such self-determination is by means of 'individualised funding' – a mechanism to provide personalised and self-directed supports for people with a disability, placing individuals with a disability at the centre of decision-making around how and when they are supported (Carr, 2010).

Individualised funding emerged as part of a significant paradigm shift that had its origins in the Independent Living Movement in the USA during the 1970s. Then, during the 1980s, the Independent Living Fund was established in the UK to enable people with a disability to be supported within the community rather than move into residential care (Jon Glasby & Littlechild, 2009). By 1989, a campaign for legislative change, led by the 'British Council of Organisations of Disabled People', was set up to facilitate individualised funding in the UK. A national rollout followed and by 2005, 89% of local authorities in the UK were offering 'direct payments' with over 10,500 users of direct payments by 2003 (Riddell et al., 2005). This was in direct response to the broader European Network on Independent Living (ENIL) agenda which aimed to provide greater independence, choice, control, self-determination and empowerment to an historically vulnerable and ill-served population (Evans, 2003).

1.2.1 Individualised funding: definitions and historical context

The popularity of individualised funding continues to grow internationally and so too does the pool of terms used to describe it (Pike, O'Nolan, & Louise, 2016). As will be noted throughout this thesis, the descriptions of various models and modes of individualised funding vary greatly within the international literature due, in large part, to country-specific contextual factors and the ever evolving use of language within the disability sector (Table 1.1). These variations are often descriptive in nature and typically reflect the different funding mechanisms or level of support accompanying the funding package.

The most commonly used models of individualised funding in the UK and Ireland involve a 'direct payment' or an 'intermediary' service. The first of these involves funds being given directly to the person with a disability. This includes the self-management of funds and often the direct employment of a personal assistant. A 'brokerage' model or 'managed' personal budget provides a similar amount of choice and control in relation to services utilised, but a third-party acts as an intermediary between the state provider of public funds and the recipient, offering attendant administrative support. The intermediary support can also provide guidance and individually tailored information to enable the person to successfully plan, arrange and manage their support services or person-centred care (Carr, 2010). Many variations of these two models exist depending on a range of factors including, for example, the age of recipients and whether they have a physical or sensory disability, as opposed to a mental health, intellectual or developmental disability. Other vital contextual considerations include country-specific cultural and political factors, such as pre-existing health and financing systems and models of service delivery which often involve many heavily invested stakeholders.

Table 1.1 Examples of terminology used globally

Country	Terms used	Source of money	Support / Care mechanism
U.S.A	○ Self-Determination programs ○ Cash and Counseling ○ Consumer Directed Care / Support	Medicaid waivers at State level	○ Independent consultant ○ Fiscal intermediary services
U.K.	○ Direct Payments	Local Authority	Personal assistant
	○ Individual Budget	Local Authority	Package of care from multiple sources
	○ Block funding from the Social Care budget	Social Care budget	Residential costs and associated care costs
	○ Independent Living Fund	Department for Social Security	Care from agency OR personal assistant
Other terms used	○ Recovery Budget ○ Personal Budget	○ Personal Health Budget ○ Microboard	
Other funding sources:	○ Supporting People fund ○ Access to work funding ○ Disabled Facilities Grants		
Netherlands	Person-centred budget	Dutch Welfare State	Package of self-determined care. Assisted by employed care worker (Often Informal (family) carers)
Ireland	Independent Support Broker / Brokerage	Innovation funding for pilot Ongoing funding from HSE	Package of care from multiple sources / residential costs
	Direct payments	Innovation funding for pilot Ongoing funding from HSE	Package of care from multiple sources / residential costs
	Self-management model	Innovation funding for pilot	Community Connector
Canada	Direct Payment / Direct Funding	Community Living British Columbia (CLBC)	Supports and services for the individual as agreed to by the individual, agent and CLBC facilitators and CLBC analysts
	Host Agency Funding	CLBC	
Other terms used	○ Self-managed care ○ Individualised funding program ○ Support for Interdependent living		
Australia	○ Local Area Co-ordination Program ○ Shared management model ○ Self-management (direct payments) ○ National Disability Insurance Scheme (NDIS)		○ Microboard ○ Self-directed funding ○ Consumer-directed care
Other terms used internationally	Indicative allocation; Individual service fund; Managed account; Managed budget; Notional budget; Personalised care; Pooled budget; Self-directed care; Self-directed support; Virtual budget; Cash-for-care		

International data sourced from: (Carter Anand et al., 2012; A. Power, 2010; Webber, Treacy, Carr, Clark, & Parker, 2014)

The concept of individualised funding is mentioned throughout this thesis and necessarily so in the Introductory sections to each of the three publications (Chapters Three to

Five). The historical context is also articulated and described in Publications Two and Three whilst some critiques of individualised funding, and/or its implementation are explored, based on a critical appraisal of relevant studies.

1.2.2 Key concepts/themes associated with individualised funding

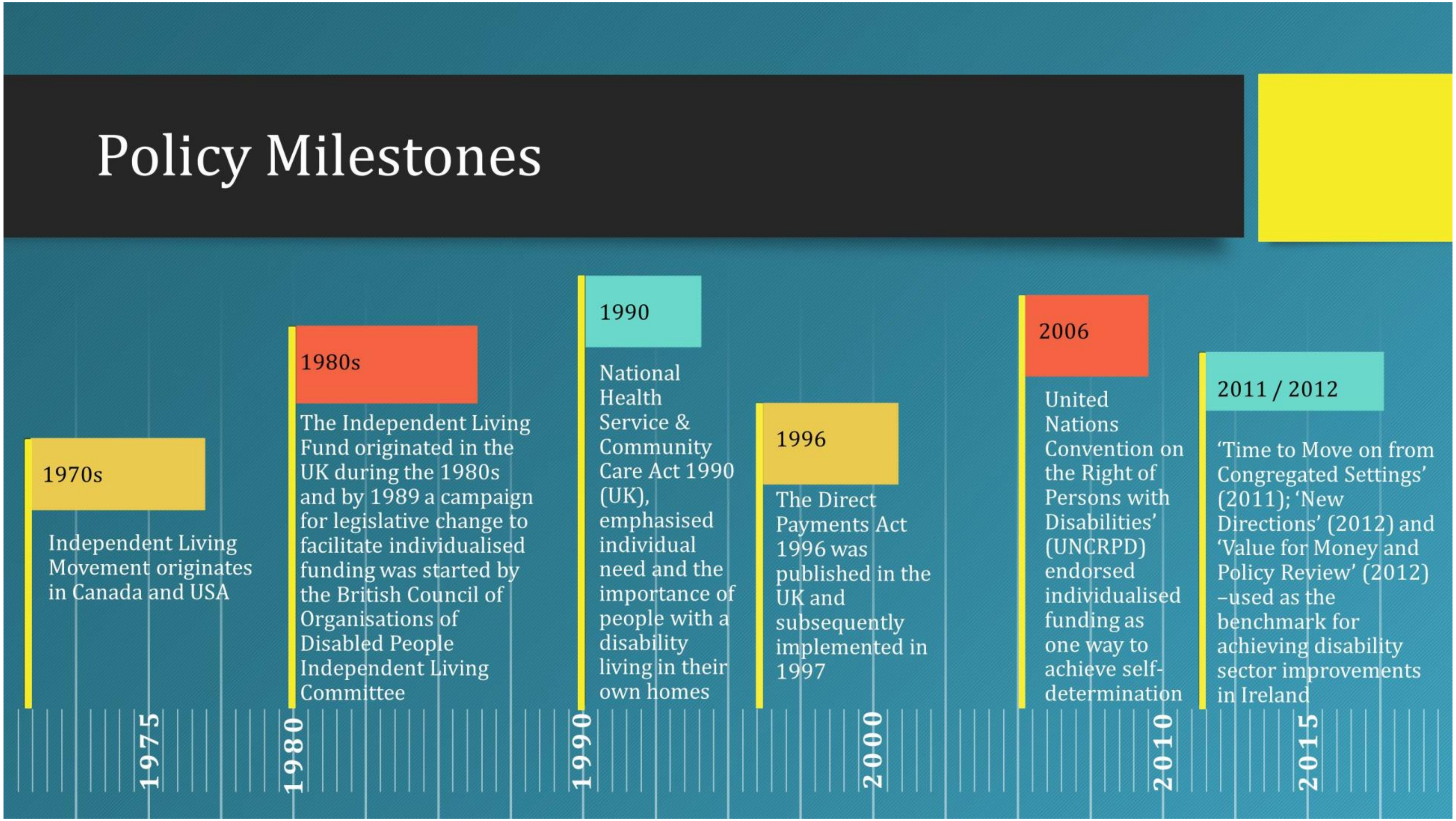
Several core concepts of individualised funding or personalisation (a term often used interchangeably within the literature) are also discussed throughout the thesis (Table 1.2). The first of these - 'self-determination' - is defined as "determination of one's own fate or course of action without compulsion", which can be interpreted, in relation to people with disabilities, as a process, outcome, set of skills, indicator of independence or just choice (Wehmeyer, 2005). Self-determination is discussed in more detail in the Introductory section of Publication Three. The second core concept - 'resource allocation' - is a contentious mechanism for assessing need and for subsequently allocating funds on an individual basis. This is also explored at various junctures including the concluding sections to the first two publications as well as throughout the third publication. A third key concept in the literature, which usually occurs in parallel to (or after) resource allocation, is person-centred-planning. Again, this is discussed at various junctures including each of the three publications presented later in the thesis.

Other relevant concepts and themes are also explored throughout the thesis (Table 1.2). These include the shift identified in the literature, from professional-led services to individualised supports and the impact that policy and legislative changes have had on younger people with a disability (particularly school leavers), as well as indicators of capacity and the role of socio-demographic factors in the utilisation of individualised funding (Publication One). The key concept of 'group orientated activities' and their associated advantages and disadvantages are explored, as well as the importance of: 1) training; 2) information provision; 3) positive risk taking; and 4) the availability and impact of a network of support for the person with a disability (Publications Two and Three).

1.2.3 The implementation of individualised funding: key policy developments

International policy has been promoting independent, self-directed supports for people with a disability for several decades. This began in the US and Canada when the first independent living movements emerged during the late 1960s / early 1970s, but it was not until the 1990s when, in the UK, a critical legislative milestone was reached with the National Health Service and Community Care Act; this emphasised the importance of people with a disability living in their own homes and was followed by the Direct Payments Act 1996, which saw UK national implementation commence in 1997. (Figure 1.1) On foot of the successes of these legislative changes and the increasing evidence in support of individualised funding (Brown et al., 2007; Duffy, 2012b; Glendinning et al., 2008; Rabiee, Moran, & Glendinning, 2009), the 'United Nations Convention on the Right of Persons with Disabilities' (UNCRPD) endorsed individualised funding as one way to achieve self-determination (United Nations, 2006). (Table 1.2)

However, as previously mentioned, an important gap exists between policy-based aspirations and the lived experience of people with a disability. For example, this gap in Ireland is considerable because, whilst national policy recommendations are in line with international best practice, the objectives of the 'Disability Services Programme' are still being pursued largely through *"a resource-intensive approach, based on a medical model of disability, delivered in segregated settings with high-staff/client ratios and skills mix designed for group rather than individual need"* (Department of Health, 2012, p. 160). The '*Value for Money and Policy Review of Disability Services in Ireland*', conducted in 2012, left no uncertainty about the unsustainability of the current system, indicating that: 1) the cost of delivering services is high and even with efficiencies will remain high; 2) increasing demographic pressures cannot be met within current model; 3) resources are not allocated according to need or linked to outcomes; and 4) the achievement of personal outcomes is not compatible with services delivered in group settings (Department of Health, 2012).



Policy Milestones

1970s

Independent Living Movement originates in Canada and USA

1980s

The Independent Living Fund originated in the UK during the 1980s and by 1989 a campaign for legislative change to facilitate individualised funding was started by the British Council of Organisations of Disabled People Independent Living Committee

1990

National Health Service & Community Care Act 1990 (UK), emphasised individual need and the importance of people with a disability living in their own homes

1996

The Direct Payments Act 1996 was published in the UK and subsequently implemented in 1997

2006

United Nations Convention on the Right of Persons with Disabilities' (UNCRPD) endorsed individualised funding as one way to achieve self-determination

2011 / 2012

'Time to Move on from Congregated Settings' (2011); 'New Directions' (2012) and 'Value for Money and Policy Review' (2012) –used as the benchmark for achieving disability sector improvements in Ireland

Figure 1.1 – International and National Policy Milestones

Unlike the 'block grant' funding model currently in place, the review recommended that "*all funding should be allocated on the basis of a standardised assessment of individual need, which should be linked to the resource allocation methodology. Recommendation 7.14*" (Department of Health, 2012, p. 212). This endorsement was directly linked to earlier and concurrent policy recommendations, specifically focusing on 'residential' and 'day service' improvements respectively, as outlined in the '*Time to Move on from Congregated Settings*' (HSE, 2011b, p. 19) and '*New Directions*' reports (HSE, 2012b, p. 140) (Figure 1.1).

Despite these robust, evidence-based recommendations, progress in Ireland has been slow. This is due, at least in part, to concerns that individualised funding may prove too much too soon, with supply unable to meet demand. However, these concerns appear to be unfounded since experience from other countries (e.g. Northern Ireland, Scotland, British Columbia and Toronto in Canada) would indicate a very slow uptake of individualised funding (Carter Anand et al., 2012; Isaacs & MacNeil, 2015), to the extent that a number of studies have been commissioned to examine the reasons underlying this trend (Bahadshah et al., 2015; Social Interface, 2007).

Indeed, critics of individualised funding have raised concerns about the potential adverse implications of commodifying care and of turning people with a disability into consumers of basic life needs (Pedlar & Hutchinson, 2000; Clare Ungerson, 1997). For example, Peter Beresford, a leading social work academic, questions whether individualised funding would, in fact, close the gap between policy-based aspirations and the lived experience of people with a disability, or whether profits would continue to be channelled to large service providers at the expense of quality for the end users (Beresford, 2009, 2014). Whether individualised funding is successful or not, may depend on the extent to which it is effectively implemented. A number of international experts - including Michael J Kendrick (USA), Tim Stainton (Canada) and Simon J Duffy (UK) - have warned against becoming overly focused on governance issues and the associated processes and mechanisms of allocating and monitoring funds – an emphasis that may lead to a loss in the core values associated with individualised funding (Kendrick, Stainton, & Duffy, 2015).

Regardless of these criticisms, most international and national disability policy makers would agree that the historical 'one-size-fits-all' model of group-based, segregated services is not fit for purpose. However, in Ireland, this traditional model of service provision remains the status quo and is financed through 'block grant' funding to service providers to deliver a suite of day, residential or personal assistance services. The calculation of this block grant for each upcoming year is based on adjustments to the baseline figures from the previous annual spend by a service provider (NDA, 2011). Despite the lack of progress on the ground, a number of key research activities have taken place in order to inform the future direction of national implementation, such as feasibility studies pertaining to various resource allocation tools (NDA, 2015). These have been consistent with key policy recommendations such as recommendation 7.11 in the *Value for Money and Policy Review* which states:

> "*An individualised supports model has many facets and may be implemented in a number of ways. Further work should be undertaken by the HSE and the Department of Health to identify the precise features of the model proposed…*" (Department of Health, 2012, p. 175); and "*The HSE should… arrange for piloting of selected systems to promote person-centred budgetary control [and] arrange for monitoring and evaluation of pilot projects*" (HSE, 2012b, p. 176).

The research pertaining to the history and development of the disability sector both in Ireland and elsewhere - including key national and international policy developments – are outlined at several junctures throughout the thesis including each of the three publications presented in later chapters (see also Appendix 3.4). This literature includes the historical development of 'services' from largely, church-run institutionalised foundations, to the recent global shift toward community-based and person-centred approaches to disability supports (including individualised funding).

1.2.4 Previous research on individualised funding in other countries

Considerable research on individualised funding has been conducted in numerous countries throughout the world (e.g. Australia, Canada, New Zealand, UK and USA) and has focused on many different aspects including descriptive exemplars, factors affecting uptake, implementation, impact and the various mechanisms of support. For the reasons described below in section 1.4.3, we were particularly interested in research which had explored the effectiveness of individualised funding in improving health and social care outcomes for people with a lifelong disability across the world. These outcomes – described in more detail in Publication Three - include quality of life, client satisfaction, physical functioning, adverse impacts, safety/security, community participation, community integration and self-perceived health. Diverging arguments, such as the reported benefits of individualised funding, or the perceived risks and emergent tensions between advocates of individualised funding and traditional service providers, are explored in the Introduction to this paper after which key quantitative and qualitative findings from previous reviews relating to outcomes and implementation successes and challenges respectively.

Table 1.2 – Introduction and discussion of key literature: an overview

Key literature	Chapters	Appendices
Defining disability	1 , 3, 5,	
History of disability sector	3, 4, 5	A3.4
Traditional service provision	3, 4	
Individualised funding	1, 3, 4, 5	
Divergent terminology	1, 4, 5	A3.4, A3.5
Criticisms of individualised funding	1, 4	
Key policy developments	1,3	A3.4
Self-determination	5	
Resource allocation	3, 4, 5	
Person-centred planning	3, 4, 5	
Key support themes include: **1) Training; 2) information provision; 3) positive risk taking; and 4) the availability and impact of a network of support**	4, 5	A3.4, A3.6
Implementation successes and challenges	4, 5	A3.5, A3.6
Previous research evidence / outcomes / effectiveness data	5	A3.5

1.3 THE CURRENT STUDY

Although various national policy recommendations for individualised funding in Ireland were outlined as early as 2011, there was little political engagement until recently - with the announcement of a Personalised Budgets Taskforce (Department of Health, 2016) - and even less actionable progress or reformist plans. Nonetheless, several pioneering pilots were conducted in the interim, on foot of policy recommendations (Department of Health, 2012; HSE, 2011b, 2012b). For example, the Genio Trust[1] provided 'innovation funding' to support the implementation of four national individualised funding pilot initiatives. This organisation was also keen to evaluate the pilot initiatives (as well as individualised funding more generally) in line with both international best practice and national policy recommendations (Department of Health, 2012). To this end, the Genio Trust offered to fund a PhD scholarship, in conjunction with the well-known SPHeRE[2] programme funded by the Health Research Board (HRB[3]) in Ireland. This provided the impetus for the present study. However, as indicated below, the study was extended to incorporate additional work in order to provide a more holistic and detailed perspective on individualised funding both in Ireland and across the world.

1.4 AIMS AND OBJECTIVES

The research reported in this thesis comprises three separate, but related studies which were undertaken to: (1) map the historical and political context within which disability service provision has emerged in Ireland and to examine in particular, trends in, and the funding of, day service provision within the disability sector; (2) explore the perceived effectiveness of individualised funding in Ireland and the extent to which it might be an appropriate, feasible and

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[1] Genio Trust works to bring Government and philanthropic funders together to develop better ways to support disadvantaged people to live full lives in their communities (www.genio.ie).

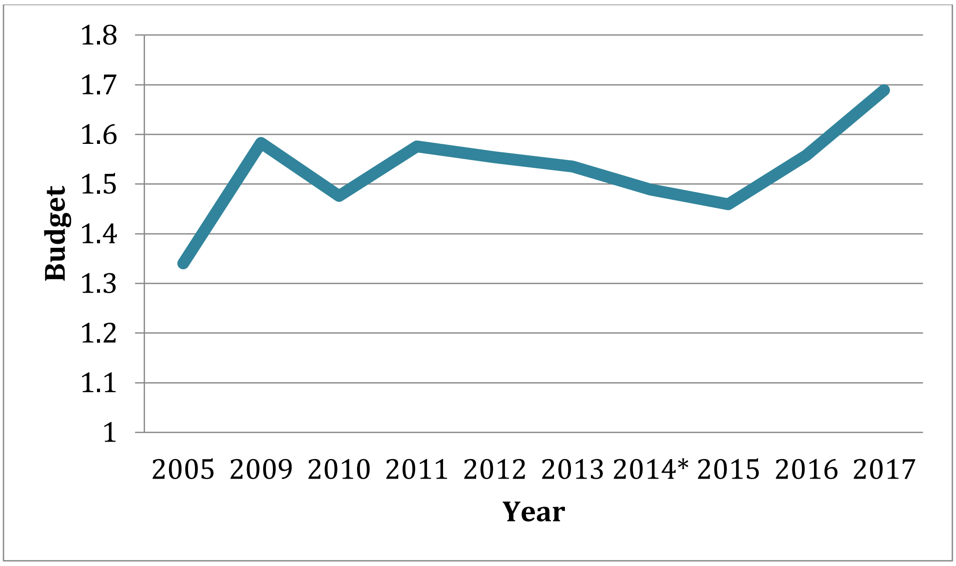
[2] The SPHeRE (Structured Population and Health-services Research Education) Programme (formerly the HRB Scholars Programme) is an innovative and ambitious research programme in population health and health services research (PHHSR) funded by the Health Research Board (HRB) (www.sphereprogramme.ie).

[3] The Health Research Board (HRB) is a statutory agency under the aegis of the Department of Health. As the lead agency in Ireland responsible for supporting and funding health research, information and evidence (ww.hrb.ie).

acceptable mechanism for supporting people with a disability to gain independence and self-determined, fully integrated lives within the community; and (3) to undertake a comprehensive mixed methods systematic review in order to: (a) examine the actual and perceived effectiveness of individualised funding initiatives for adults with a lifelong disability (physical, sensory, intellectual, developmental or mental disorder) in terms of improvements in their health and social care outcomes; (b) to explore stakeholder perspectives/experiences; and (c) assess overall cost-effectiveness. Each of the three studies is described in more detail below.

1.4.1 Study One

Study One was undertaken to gain a better understanding of the historical and political context within which service provision had emerged in Ireland, with an initial focus on how monies are generally spent within the disability sector. A national review of disability expenditure and policy, completed in 2012, showed that the funding of specialist disability services reached a high of 1.789 billion in 2009, having increased by roughly 34% since 2005, but had fallen again by an estimated 5.7% from 2009 to 2011 (Department of Health, 2012). These services were primarily funded by the health service in Ireland (Health Service Executive - HSE). Recent trends in HSE budget allocation are illustrated in Figure 1.2.



*extrapolated from 2015 data

Data source: (HSE, 2005, 2009, 2011a, 2012a, 2014b, 2015, 2016)

Figure 1.2 – HSE budget allocation (in billions) for disability services

The 2012 review clearly indicated that the vast majority of disability funds are spent on intellectual disability services (73%) (Department of Health, 2012). Likewise, the '*Time to Move on from Congregated Settings*[4]' report, showed that 93% of people availing of residential services had an intellectual disability (n=3,802), while the *'New Directions*[5]' report also indicated that the majority of day service users had an intellectual disability as a primary disability (n = 13,720, 54%) (HSE, 2011b, 2012b). Thus, given that the vast majority of disability funding is spent on services for people with intellectual disabilities, it was decided that Study One should focus only on this sub-group, with a particular emphasis on 'day services'. As outlined above, these accommodate considerably more people than residential services whilst, arguably, they also offer more scope to achieve the goals of individualised funding (i.e. choice making, achievement of personal goals and aspirations, and being independent, active community members (HSE, 2012b)). Furthermore, a trends exercise previously carried out using the National Intellectual Disability Database (NIDD[6]), had focused primarily on residential services during 2003-2007.

The specific objectives of ***Study One*** were to:

- map any changing trends in day service provision in Ireland;
- highlight where national policy changes, driven by international best practice, may be influencing service delivery; and
- identify potential future service needs and lessons for similar high-income, under-performing countries in Europe and elsewhere, based on emergent patterns and changing demographic trends seen in an Irish context.

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[4] Report of the Working Group on Congregated Settings, initiated by the Primary, Community and Community Care Directorate in 2007 to develop a national plan and associated change programme for moving people from congregated settings to the community in line with Government policy (HSE, 2011b).

[5] Report of the Working Group set up to conduct the National Review of HSE Funded Adult Day Services based on a recommendation from the National Review of Sheltered Services which had been completed in 2007 (HSE, 2012b)

[6] The NIDD is a national database that collates a minimum set of information, for all people in Ireland who receive or are in need of intellectual disability services.

1.4.2 Study Two

Study Two involved an evaluation of four individualised funding initiatives, which had been implemented, on a pilot basis, during an initial one-year period and before national implementation commenced (still pending at the time of writing). The specific objectives of ***Study Two*** were to assess whether individualised funding was perceived to be:

- effective at improving health and social care outcomes in Ireland;
- acceptable and feasible within the Irish context; and
- an appropriate mechanism for supporting people with a disability to gain independence and self-determined lives, fully integrated within the community.

1.4.3 Study Three

During the early stages of this research, the extent to which individualised funding was effective at improving outcomes for people with a disability was the subject of fierce debate, particularly in the UK with many conflicting views in the literature (Beresford & Stansfield, 2013; Duffy, 2012b). For this reason, it was decided to undertake a systematic review to assess the extent to which individualised funding is effective at improving health and social care outcomes for people with a lifelong disability across the world. This review covered the period from the 1980s, when individualised funding initiatives first emerged, to the present day. The specific objectives of ***Study Three*** were to:

- examine the effectiveness of personal budgeting interventions for adults with a lifelong 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

- 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 (D. Fixsen, Naoom, Blase, Friedman, & Wallace, 2005).

1.5 THESIS OUTLINE

Chapter Two provides an overview of the design and attendant methodological issues pertaining to each of the three studies. This outlines: (1) the epistemological and ontological framework to the research; (2) the key methods adopted in each of the three studies; and (3) other overarching methodological issues such as ethical considerations and researcher reflexivity.

Chapter Three presents the first of the three peer-reviewed publications (Publication One) which was based on Study One. This paper - entitled 'Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland' - was accepted for publication in the *Journal of Applied Research in Intellectual Disabilities* on the 24th January 2016.

Chapter Four presents the second peer-reviewed paper (Publication Two), entitled: 'The successes and challenges of implementing individualised funding and supports for disabled people: An Irish perspective', which outlines the literature and key findings pertaining to Study Two. This paper was accepted for publication in '*Disability & Society*' on the 14th November 2016.

The third and final publication (Publication Three) is presented in **Chapter Five**. This comprises a detailed systematic review which was successfully registered with the Campbell Collaboration[7] following the preparation of a Title Registration Form and a detailed (published) protocol (Fleming, Furlong, et al., 2016). This review report entitled: 'Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review' - presents a synthesis of results from a range of quantitative (n=4), qualitative (n=66) and mixed method (n=3) studies undertaken in ten countries across the world. Eleven appendices accompany this chapter including: detailed search strings; an outline

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[7] The Campbell Collaboration is a voluntary, non-profit, international research network that produces and disseminates systematic reviews of the effects of interventions in the social and behavioural sciences (www.campbellcollaboration.org).

of the search-results refinement process; characteristics of included and excluded studies; quality and risk of bias assessments; description of outcomes reported; and a full list of qualitative codes utilised in the qualitative analysis.

The concluding chapter, **Chapter Six** presents a synthesis and critique of the key findings from all three studies framed around the context, mechanisms and outcomes associated with individualised funding initiatives. In addition, it outlines an implementation framework for facilitating the assessment of the various options available to policy makers planning the roll-out of individualised funding on a national scale.

CHAPTER TWO: METHOD

As indicated previously, this chapter begins by outlining the epistemological and ontological approach underpinning the research as well as the overall study design. Methodological details are then provided for Studies One and Two as well as a summary of the method for Study Three with the necessary detail provided later, as appropriate, in Chapter Five. The chapter concludes with a brief discussion of other cross-cutting methodological issues.

2.1 EPISTEMOLOGICAL AND ONTOLOGICAL APPROACH

This research adopted a mixed methods approach and therefore, was conducted within an overall framework of 'pragmatism'. Pragmatism has formed the basis for much philosophical discussion for well over a century (Dewey & Bentley, 1949; James, 1907; Mead & Morris, 1997; Peirce, 1905; Rorty, 1991), but essentially pragmatists reject the forced choice of either constructivism or positivism (i.e. subjective, inductive, narrative driven qualitative research on the one hand and objective, deductive, statistical driven quantitative research on the other). Johnson and Onwuegbuzie (2004) sum up the debate by suggesting: 1) that pragmatism is value-driven (e.g. helping to reduce societal discrimination); 2) that research methods differ based on circumstances; and 3) that empirical findings have practical consequences, which can shed light on the progression of real-world phenomena (including psychological, social and educational).

Johnson and Onwuegbuzie (2004) also argue that mixed methods researchers have not yet uncovered the perfect solution to settle the philosophical debates and therefore an approach must be adopted to accommodate the insights from both quantitative and qualitative findings into a workable solution. As such, the current research tentatively blends two approaches across the various stages of research (Tashakkori & Teddlie, 1998), with "research design" and "data collection" driven by pragmatism and adopting both quantitative and qualitative methods as appropriate. The analysis and interpretation of findings, on the other hand, was strongly influenced by 'critical realism' which acknowledges that there is a 'real world' - independent of our perceptions and social constructions - whilst also utilising a form of epistemological constructivism and relativism whereby our understanding of the world is constructed and contextualised based on our own experiences and perceptions (Maxwell, 2011). Here, we can clearly see the parallels with Pragmatism, since John Dewey pointed to the importance of linking beliefs and actions in the process of inquiry and knowledge acquisition. Interpretation of beliefs generates actions and vice versa. While some actions and beliefs are habitual, others require self-conscious decision making (D. L. Morgan, 2014).

Thus, critical realism adopts both an inductive and deductive approach, such that the cyclical relationship between pre-existing structures and processes in society, and how these affect, and are affected by, human action – individual, group and organisational - can be acknowledged and explored (Gilson, 2012). In line with this thinking, Pawson and Tilley (1997) developed a theory driven approach to evaluation called 'realist evaluation' which aims to understand what works for whom, in what circumstances and to what extent (Pawson, 2006, 2013; Pawson & Tilley, 1997). Thus, it focuses not only on outcomes, but also the context and mechanisms under which certain outcomes are achieved. This is often referred to as the "CMO configuration". According to Jagosh (2017), context may be interpreted as anything in the background that may not formally be part of, but can impact upon, the intervention, such as cultural norms and values, history, existing public policy and/or economic conditions. Mechanisms can be defined by underlying entities, processes or structures (Astbury & Leeuw, 2010). In the case of social interventions, mechanisms refer to cognitive processes which stimulate or demotivate stakeholders, including those delivering the intervention (Jagosh, 2017). Context and mechanisms can, in turn, produce and/or affect the outcomes or effectiveness of an intervention.

A relatively recent review of empirical studies on health systems found that realist evaluations have been gaining traction in health services research (Marchal, van Belle, van Olmen, Hoerée, & Kegels, 2012), particularly in the assessment of complex interventions, such as smoking cessation (Douglas, Gray, & Van Teijlingen, 2010). Furthermore, the Medical Research

Council (MRC) guidance on developing and evaluating complex interventions, supports the use of realist evaluations in recognition of the fact that: (a) the phases of evaluation may not be linear; (b) experimental designs while preferable are not always practical; (c) locally tailored interventions may work better than standardised ones; and (d) context is key (Peter et al., 2008). For these reasons, a realist evaluation is often considered more appropriate than the traditional and better known formative and/or summative evaluation because it supports an ongoing and evolving process of organisational innovation which typically takes place within an unpredictable "real world" environment, rather than a linear and logical one (Gamble, 2008).

This approach was considered to be well suited, therefore, to Study Two because the individualised funding initiatives, which are the subject of this evaluation, were highly complex whilst the study participants varied considerably in terms of type and level of disability, age and geographical location. Furthermore, the four pilot initiatives evaluated in Study Two were all at different (early) stages of implementation. A realist evaluation provides an appropriate way of describing and capturing "real world" implementation (Gamble, 2008). For the same reason, the evaluation itself was conducted within, and guided by, a broader implementation science framework, with key questions designed to address the various stages of the implementation process, with one pilot initiative in particular starting its transition between "initial implementation" and "full operation" (Figure 2.1).

Figure 2.1 - Stages of the Implementation Process

Source: (D. Fixsen et al., 2005, p.15)

According to Fixsen et al., 'implementation' is defined as "*a specified set of activities designed to put into practice an activity or program of known dimensions*" (D. Fixsen et al., 2005, p.5). 'Exploration and Adoption' describes the period when organisations make a decision based on needs, evidence-based practice and available resources. 'Program Installation' relate to tasks that need to be completed before any end-user is seen. 'Initial Implementation' describes an often turbulent period, where for example, organisational change is tackled. ‘Full Implementation’ can occur once transitionary periods have ended and new learnings are integrated into policy and practice. Finally, ‘Sustainability’ examines the training, resources, political alliances and other components required to ensure longevity (D. Fixsen et al., 2005). All stages of the implementation process were the focus of, and guided, the research design.

2.2 Research Design

This research was conducted in three separate, but related studies, each of which is described in more detail in the sections that follow. **Study One** (Publication One) was retrospective in nature and examined service utilisation in Ireland by means of a secondary data analysis during a 15-year period (1998 to 2013). This was important in contextualising the research, both historically and in terms of more recent patterns of service use for people with disabilities in Ireland.

Study Two (Publication Two) involved an in-depth national evaluation of four individualised funding initiatives which were set up, on a pilot basis, in various parts of the Republic of Ireland between 2010 and 2013. This study incorporated an extensive documentary analysis, in-depth interviews, secondary analysis of qualitative data and a participatory workshop. Exploratory qualitative methods were adopted since the individualised funding initiatives were at very early stages of development, the numbers involved were small and little was known about the structures, processes, funding mechanisms, or successes and challenges being experienced.

Study Three (Publication Three) adopted a broader global perspective and sought to address, in parallel, the ‘effectiveness’ question which has emerged in national and international debates on individualised funding in recent years. As such, this study involved a systematic review undertaken to examine the effectiveness of individualised funding in improving health and social care outcomes for people with a disability.

2.3 STUDY ONE

Study One involved a secondary analysis of data from the National Intellectual Disability Database (NIDD) for the period 1998 to 2013. The paper pertaining to this study is presented in Chapter Three. This current section provides further methodological details not presented in the paper.

2.3.1 The National Intellectual Disability Database (NIDD)

The National Intellectual Disability Database (NIDD) comprises a minimum set of information for all people in Ireland who receive, or are in need of, intellectual disability services, including day, residential and multidisciplinary service provision. As outlined in Chapter One, day services account for the vast majority of disability funding and arguably provide more scope, therefore, to achieve the goals of individualised funding than other forms of service provision (e.g. residential, therapeutic services). Therefore, day services were the main focus of this study. Individual data forms are used by the NIDD to gather three basic pieces of information including: demographic details; current service provision; and future service requirements. Diagnostic or medical information is not gathered as the database is not intended to be an epidemiological tool. Cross-sectional data are collected at a specific point in time and are updated annually. The data forms are generally completed by a service provider, rather than the individual with a disability.

A potential limitation of the database relates to registration, which is voluntary, whilst data are only captured for people who avail of specialised services. Therefore, the database may not capture *all* people with intellectual disabilities living in Ireland. This may be particularly true for those with a mild intellectual disability, since they tend to use more mainstream services and activities. Nonetheless, the database contains the most accurate data available for people with an intellectual disability in Ireland. Furthermore, coverage and comprehensiveness are considered very good since service providers themselves return the information (Kelly, Kelly, & Craig, 2009). However, there may be some degree of response bias due to uncertainty as to whether people with a disability contribute to the completion of data forms.

2.3.2 Access to data

For purposes of this study, a standard data request form was submitted to the NIDD (following the strict database policy regarding access to and analysis of data) including, amongst other things, a detailed rationale and declaration of confidentiality. Due to national data protection regulations, individual level statistics were unavailable. Therefore, only aggregate secondary data was requested. Demographic summary statistics were also provided for each year based on: sex; age group; degree of disability; and receipt of a person-centred-plan. The data request was reviewed and approved by a national committee. For comparative purposes, general population statistics were sourced from the Central Statistics Office (CSO), Ireland's national statistical office. Data were requested for six specific years between 1998 and 2013, covering a 15-year period at three yearly intervals. At the time of the study (2015), no data were available beyond 2013.

2.3.3 Study population and settings

As outlined in the opening chapter, Study One focused on people with an intellectual disability due to the fact that intellectual disability is the primary recorded disability (although multiple disabilities may co-exist) and, therefore, the vast majority of disability service funding is spent on this group. Although the NIDD includes data for all people registered as receiving or in need of services, including children, the current study focused only on adults aged 18 years and over. Although not explicitly stated in early documentation, the Irish Government are focusing only on adults during initial implementation planning for individualised funding (Department of Health, 2016). Therefore, adults are the focus of this and the two subsequent studies.

Study One focused on day services, since these services have been shown to accommodate considerably more people than residential services (Chapter One). Also, when compared to residential supports, day services arguably have more scope within which to achieve the goals of individualised funding, (i.e. choice making, achievement of personal goals and aspirations, and being independent and active community members (HSE, 2012b)). In addition, it should be noted that the NIDD supplies data not only for the main or primary day service that is used, but also use of the second and third day services. However, for the purposes of this study, only *primary* day services were compared since every individual on the dataset had availed of at least one primary day service, whereas only 5%-18% of people had used a second day service during the 15-year period with even fewer availing of a third.

It should be noted that an audit of the NIDD in 2007 – focusing on residential services - showed an overall accuracy of 72.2%, with 19.3% of data considered to be inaccurate, and 8.5% of the sought audit data not returned (Dodd, Craig, Kelly, & Guerin, 2010). Data relating to the future demand for services was found to be the most inaccurate (50.4%) due to confusion around contingency and future needs. Therefore, it is possible that a similar level of inaccuracy may apply to day services, whilst the database also only records need in terms of existing service options.

It was possible to analyse the data according to either 'county of residence' or the 'local health office' (i.e. within which services were registered). However, due to the shifting parameters of local health authorities over the 15-year period (i.e. the move from 11 Health Boards (1999) to 4 regions within the new Health Service Executive (2005)), it was deemed more appropriate to map trends based on the unchanging geographical county borders. Furthermore, this also allowed for better comparisons with other national databases (i.e. data from the CSO).

2.3.4 Analysis

Over the 15 year period, 32 separate day services were recorded on the NIDD. In the 2013 data file, 28 of these services were utilised and the number participating ranged from 1 to 7,353; the latter is referred to here as the 'Activation Service' (see Table 3.1 for definitions). The most popular day services (i.e. those with 500 people or more attending or wishing to attend) were examined in order to map trends in a concise and meaningful way. However, the aggregation of data restricted the complexity and depth of statistical analysis. The analysis was conducted using WINPEPI, a computer programme specifically developed for epidemiologists conducting health research (Abramson, 2011). Upton's chi-square was used to test for statistically significant differences when comparing proportions of two independent samples (I. Campbell, 2007). The data were collated and mapped using QGIS Geographic Information System (QGIS, 2015) and various trend visualisation tools in Microsoft Excel (2010).

2.4 STUDY TWO

As stated earlier, Study Two involved an evaluation of four individualised funding pilot initiatives which have been implemented in various regions across the Republic of Ireland. The paper pertaining to Study Two is presented in Chapter Four. Additional methodological detail is provided here. Each of the four initiatives is described below as a stand-alone case-study. Case studies - which are becoming increasingly popular within health services research - use multiple sources of evidence to examine contemporary phenomena within the context of 'real world' differences (Gilson, 2012). In line with this approach, multiple sources of data were utilised in the current study including: a documentary analysis, a series of in-depth interviews, secondary analysis of qualitative data and a participatory workshop.

2.4.1 Site recruitment

Four individualised funding initiatives (cases), located in four nationally dispersed organisations, were identified through a process of purposive sampling, with the support of the

Genio Trust. Prior to the research commencing, informal discussions were held with the initiative lead or with the CEO, around the planned preparatory work (e.g. proposal development, ethics application and potential start dates). During this scoping period, two additional organisations - that were not part of the Genio-funded pilots but which were anecdotally piloting individualised funding within their organisation - were contacted to determine their interest in participating, but no response was received despite several follow-ups. Once ethical approval was granted (Section 2.5.1), each of the four initiative leads was formally contacted with a letter of invitation to participate in the evaluation (Appendix 1.1), all four of whom subsequently agreed to do so. This organisational consent was one of two phases of the consent process; the other involved the individual research participants themselves.

The four participating organisations were awarded "Innovation funding", from the Genio Trust, after a competitive open application process. The funding was provided to pilot individualised funding initiatives in Ireland, for a one year period (initially). It should be noted that only two of the four pilots were in a position to continue the initiatives once the innovation funding / pilot period had finished. The pilots were geographically spread throughout the country, with an urban / rural and socio-economic mix - including the densely populated counties of Dublin and Kildare (along the east coast), as well as the low density (primarily rural) counties of Kerry (south west) and Donegal (north west) (Figure 2.2).

2.4.1.1 Participant recruitment

A letter and information sheet to all prospective participants were devised in line with research and ethical best practice, taking into account, for example, the potential literacy limitations of the intended population. All materials were scored against the 'Flesch Readability Ease' index in order to assess overall accessibility (Flesch, 2013). The results indicated that documents performed well (scores noted at the end of relevant documents in Appendix 1). Organisational staff members were also asked to read through the information pack with potential participants and their representatives (e.g. a family member or other advocate).

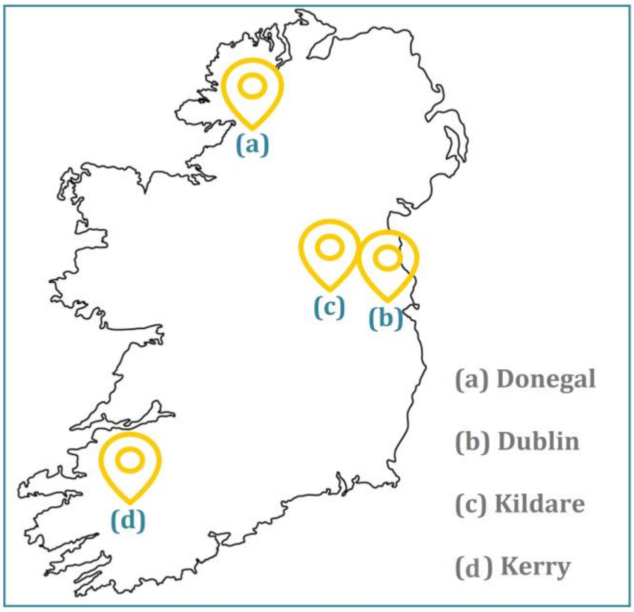


Figure 2.2 – Location of Pilots

2.4.2 Description of each case study

Each of the four initiatives (case studies) will be described below, including the target population, initiative description and process of implementation.

2.4.2.1 Case study 1 – 'Bridging the Gap'

This pilot initiative was described (by staff) as a "direct payment using a broker". It aimed to provide support to young adults in order to arrange and access services/training opportunities within a community setting. The initiative provided an individualised package of support to 11 individuals during the research period (November 2014 – September 2015). Those involved in the initiative had physical, intellectual and/or developmental disabilities. The direct payment was held centrally and managed on behalf of participants using pre-existing financial systems. The broker and individual with a disability developed a person-centred plan (PCP) together, while the broker (generally) identified and costed various elements of plan, sometimes negotiating the price of services. This initiative also utilised a 'finance group' (consisting of four organisational staff including an accountant) who reviewed and signed-off the PCP and associated budgets and spending plans, in addition to monitoring progress in terms of outcomes and goal attainment. The process is outlined in Figure 2.3 below. No funding was available to continue the initiative after the pilot funding had expired (end of 2015) and, therefore, the initiative was put on hold until existing funds could be released from traditional services or until such time as national implementation commenced.

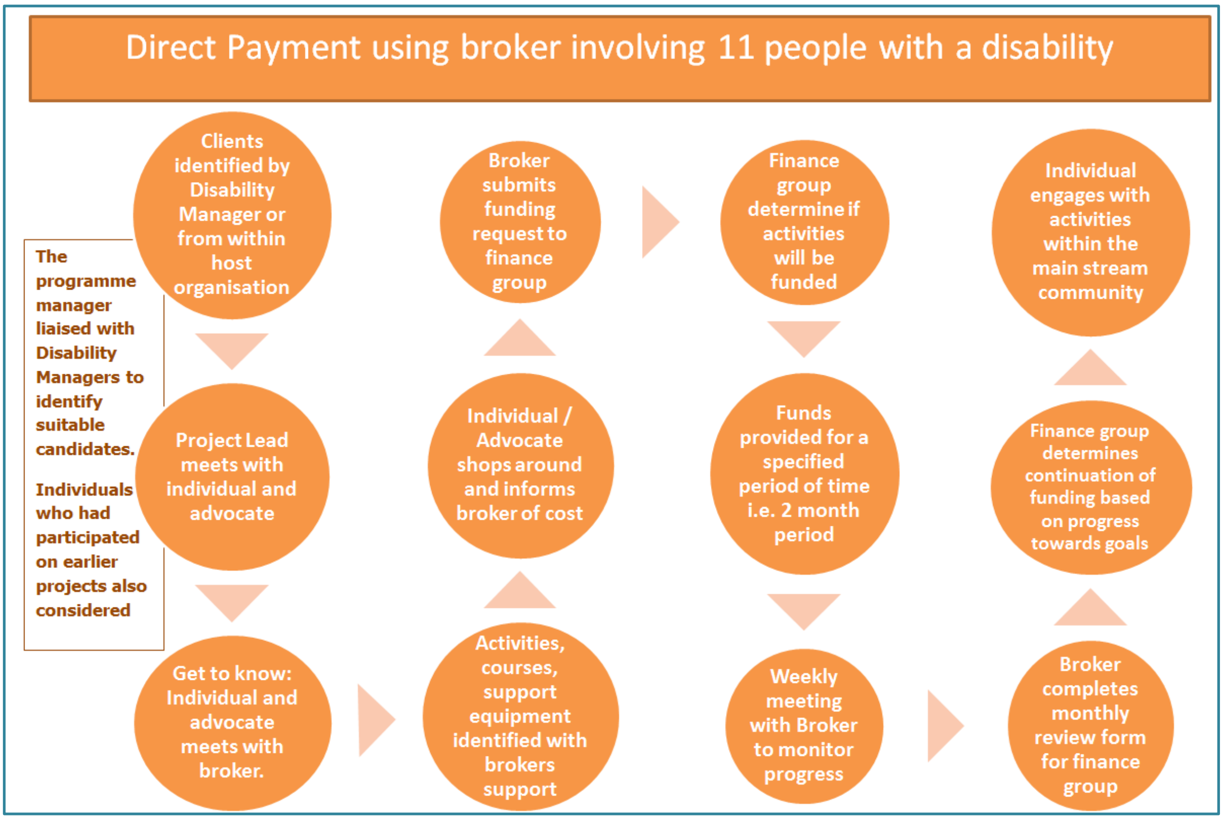


Figure 2.3 – Process flow chart for case study 1

2.4.2.2 Case study 2 –'The ÁT Network'

This second initiative was primarily described by staff as a "direct payments" initiative, although it also involved centralised support, particularly during initial set-up. Ongoing support was offered where necessary. This initiative provided direct payments to 20 individuals (at the time of the research) in order to enable them to purchase their own services, which primarily involved (although not limited to) the direct employment of a personal assistant. This initiative involved mainly people with a physical disability, although people with other disabilities were also involved. In this initiative, individuals set up their own company allowing them to manage their own finances, hire necessary staff and purchase services directly from providers. Centralised staff (within the host organisation) acted as an intermediary between the individual and the Health Service Executive (HSE). During the initial set-up, in-house support included provision of administrative support, training and mentorship from other company owners. The process is outlined in Figure 2.4 below. At the time of the research, the ÁT Network was exiting the pilot stage and was beginning to receive HSE funding on a case-by-case basis, with plans for national expansion underway.

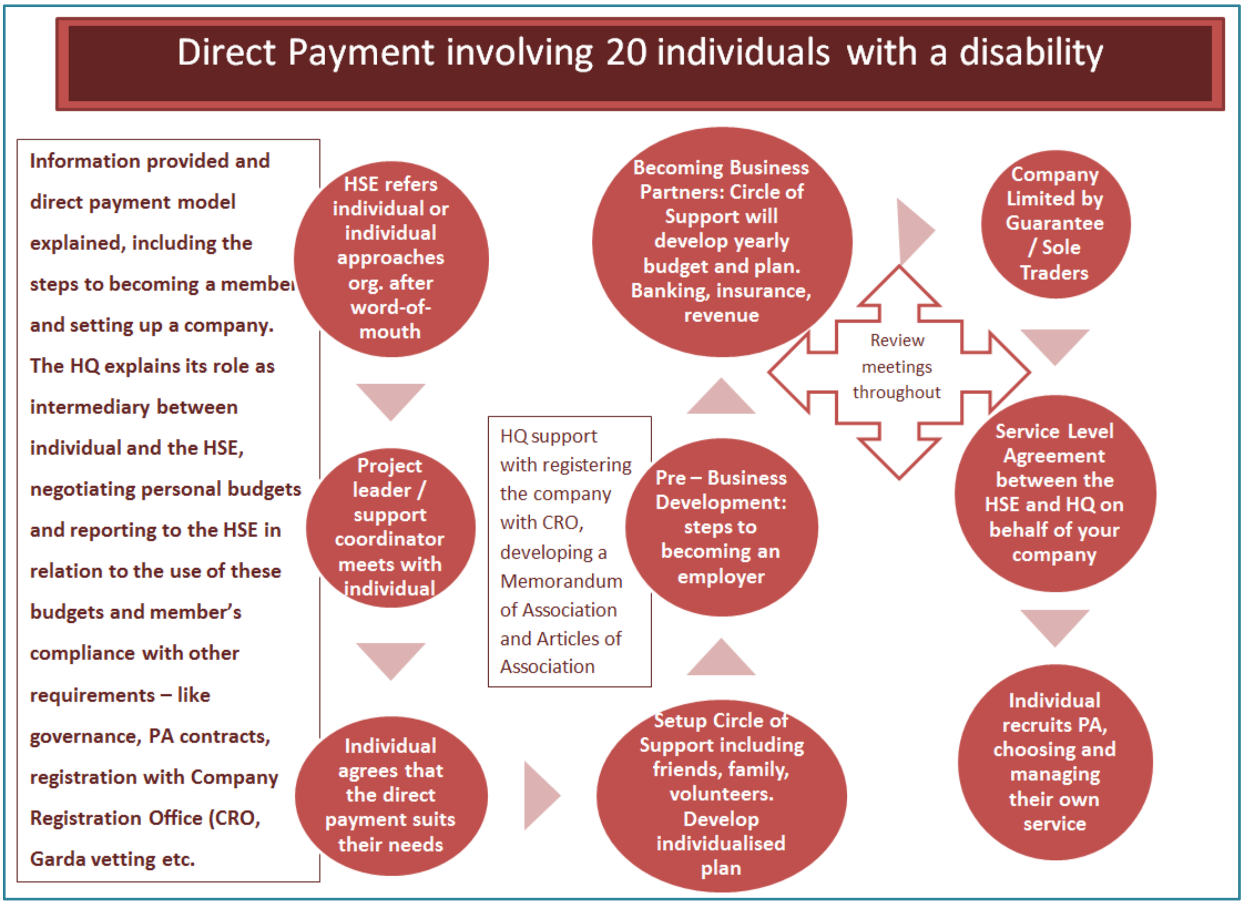


Figure 2.4 – Process flow chart for case study 2

2.4.2.3 Case study 3 – 'ConnectAbility'

This initiative was described by staff as a "self-management" model using a "community connector" to support individuals plan and manage their training, work, education and recreational activities. The initiative involved five individuals with an intellectual disability and/or mental health problems. The budget was held centrally and managed within the organisation using pre-existing financial systems. The community connector assisted individuals to design their own programme, choosing activities and providers that best met their needs.

This process was facilitated by helping individuals to identify their goals and necessary steps to achieve those goals. Community- based training activities - often freely available through adult education centres and involving, for example, money management skills and driving lessons - were identified to help individuals manage community participation (Figure 2.5). Again, as in case of Study One above, no funding was made available to continue once the innovation funding had expired.

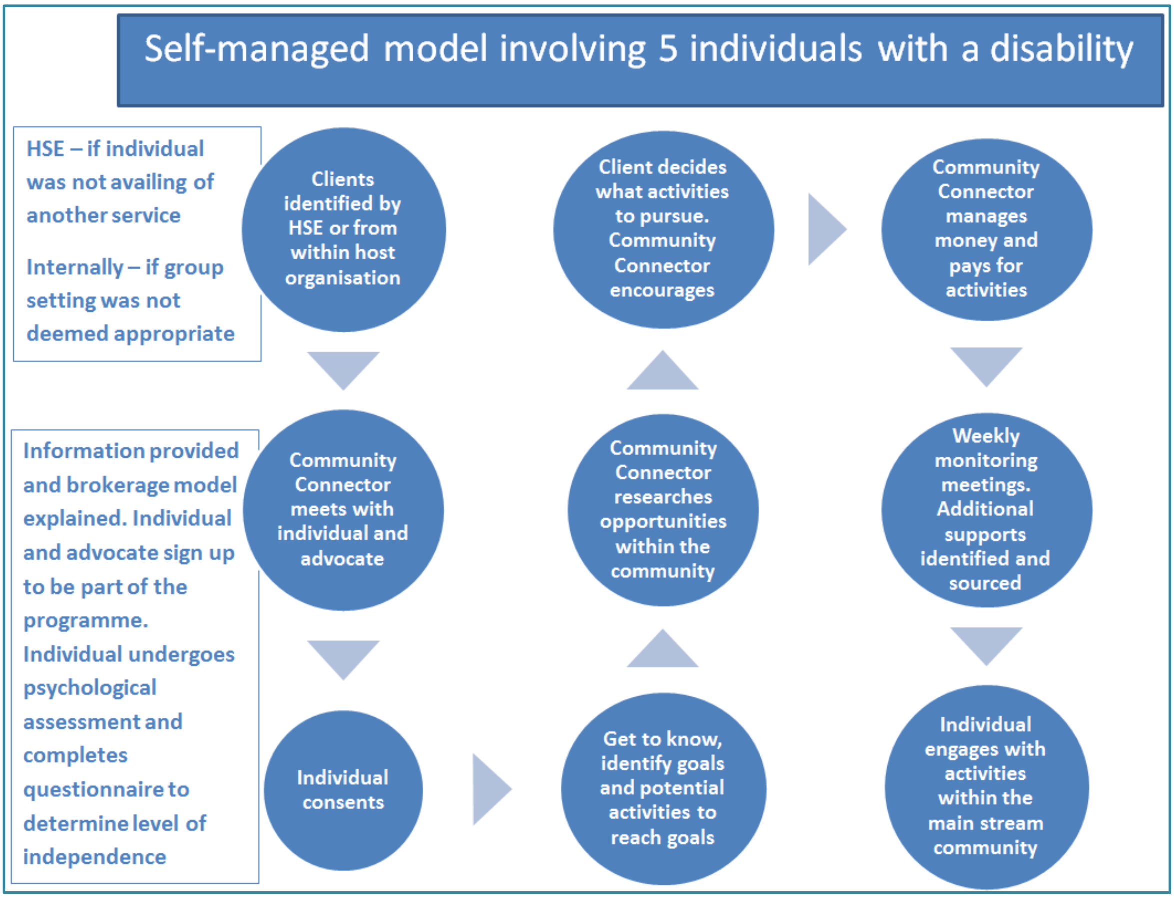


Figure 2.5 – Process flow chart for case study 3

2.4.2.4 Case study 4 – 'PossibilitiesPlus'

This initiative was described by staff as an "independent support broker" model. It was designed to support people with disabilities to live self-directed lives by negotiating with the HSE to release funds, usually allocated to traditional service providers, for use as personal budget. The nine individuals involved in the initiative had a physical, intellectual and/or a developmental disability. Finances and human resources were managed centrally - utilising pre-existing systems within the host organisation's traditional service arm (i.e. day and residential services). All other mechanisms were independent of the traditional service arm (e.g. broker/facilitator, circle of support, community based supports/activities). An agreed sum of ‘petty cash’ was provided to individuals for daily expenses, although not all individuals wished to avail of this facility. Newly recruited, independent support brokers acted as an intermediary between individual/their family and the HSE to determine: how much money would be allocated; whether the amount was adequate to meet their needs; and whether it was available to use as personal budget. Other than these administrative tasks, the broker spent time getting to know the individual and their support structure. They subsequently assisted with developing and formalising a ‘circle’ of (informal) supports. Furthermore the broker assisted with the recruitment of support workers where necessary (Figure 2.6). Towards the end of the research (2015), PossibilitiesPlus was exiting the pilot phase and had begun receiving HSE funding on a case-by-case basis.

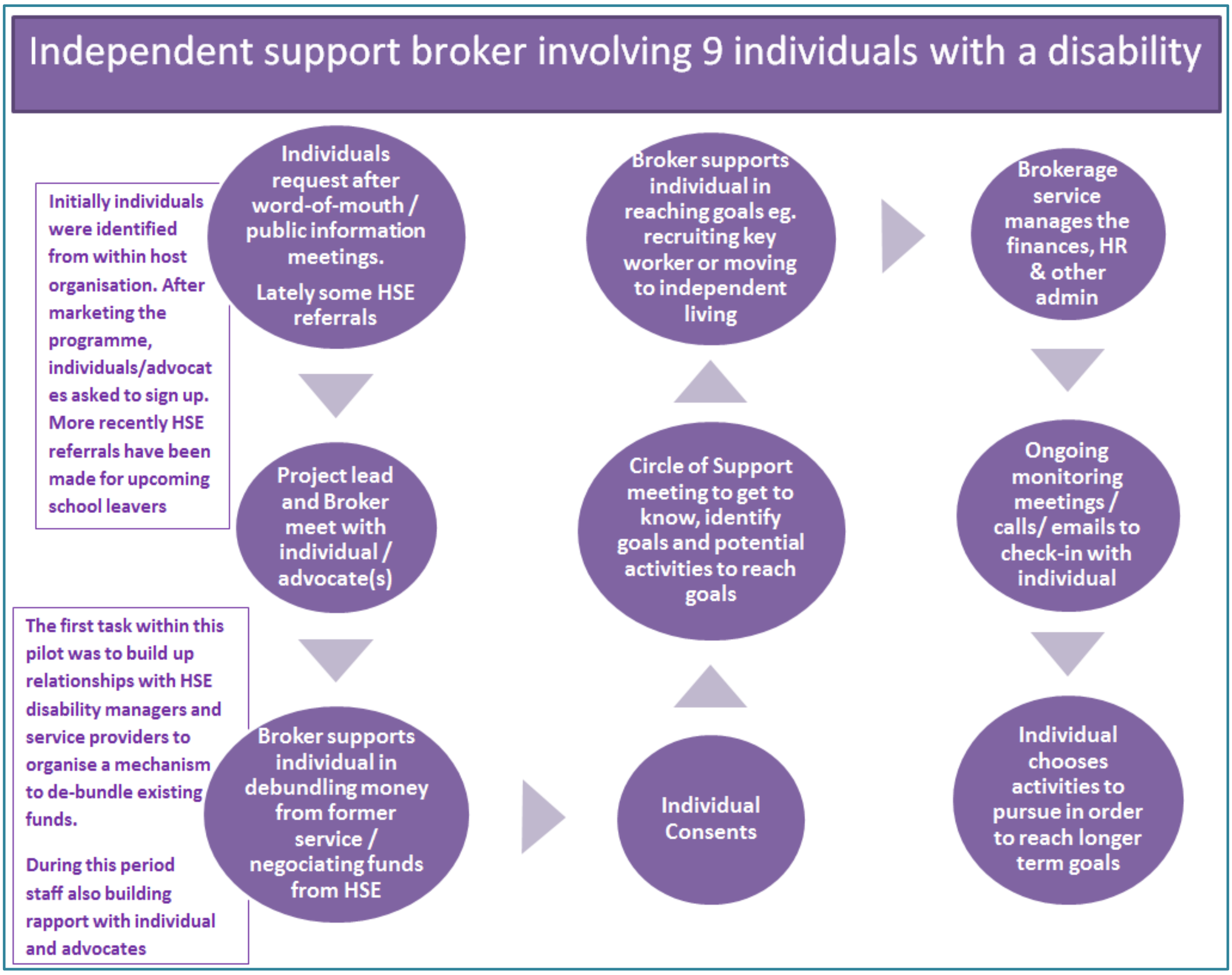


Figure 2.6 – Process flow chart for case study 4

2.4.3 Materials and measures

2.4.3.1 Documents used in the documentary analysis

As part of the consent process, all four organisations were asked to nominate a main point of contact to supply key internal documents that were produced in the lead-up to, and implementation of, each of the four initiatives (Appendix 1.2). These included, among others: meeting minutes; administrative forms; correspondence; annual reports; strategic documents and action plans; policies; contracts and agreements; person-centred plans and weekly schedules; presentations and other informational materials.

A total of 571 documents were shared with the researcher most of which (82%) were from Case-studies Three and Four (Figure 2.7). These provided the researcher with useful insights into the structures, processes and context under which each of the initiatives was operating, whilst also facilitating the identification of relevant concepts to explore, such as sustainability, conflict of interest and organisational change. This process was important in informing the development of the interview schedules which are described below. The process of analysis is described later in section 2.4.6.1.

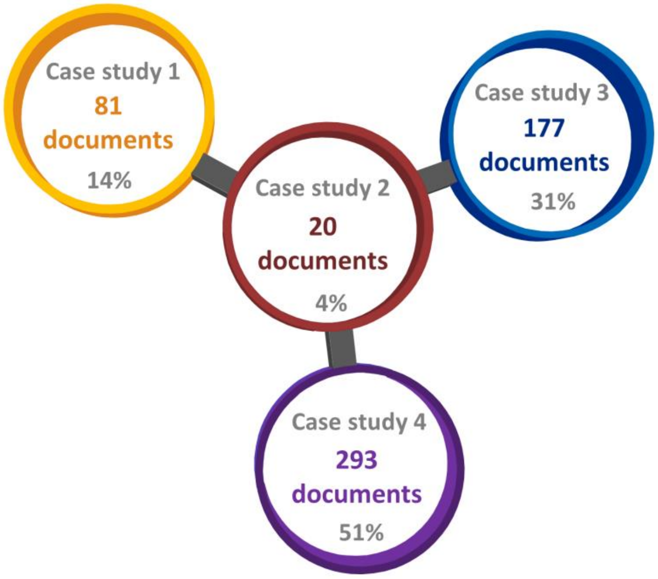


Figure 2.7 – Breakdown of documents

2.4.3.2 Interview schedules

The interview schedules were devised using open-ended questions to allow for organic and free-flowing conversation. Separate schedules were developed for staff and initiative participants (Appendix 1.3 and 1.4 respectively), but were generally guided by the various stages of the implementation process, namely: exploration and adoption; programme installation; initial implementation; full operation; innovation; and (plans for) sustainability (D. Fixsen et al., 2005). Data collection and analysis were informed by constructivist grounded theory, commencing with inductive gathering of data but supplemented by the non-linear movement back and forth between data gathering and analysis (Charmaz, 2011). Therefore, interview schedules were adapted to explore emergent themes, an approach which is consistent with critical realism.

Prior to commencement of the fieldwork, a pilot interview was conducted with a typical staff member within a national service provider organisation. The participant was an acquaintance of the researcher who had worked in the disability service for over a decade and was very familiar with policy and practice in Ireland. This showed that the expected timing was a little longer than anticipated, lasting about 1 hour in total rather than the anticipated 45 minutes. The conversation flowed naturally, aided by the flexible use of the interview schedule, moving to pertinent subject prompts as each topic arose. Additional prompts were added to the final interview schedule, based on the pilot interview. These prompts came naturally at the time, but were added to the guide in order to utilise, in a potential scenario, where an interview may not flow as well. Examples of additional prompts included:

- Decision to develop initiative
- Impact on organisation
- What are the processes from start to finish?
- How is funding allocated to individual?
- Personnel involved throughout the process
- Broker – Quality of their work / training

2.4.4 Data collection/procedure

Contact with prospective interviewees was facilitated by a gatekeeper in each of the four initiatives. For data protection reasons, the gatekeeper was asked to circulate the letters of invitation directly to the initiative participants along with an information sheet and consent form (Appendix 1.5 and 1.6). At the same time, staff members, whose names were provided on the organisation's initial consent form, were also sent a letter of invitation and information and consent form (Appendix 1.2, 1.7 and 1.8). Where individuals were unable to read the materials, either a staff member or advocate read and explained the research project. Project participants were also given the option to have an advocate present with them during the interview. Interested parties were asked to complete the participation form, indicating suitable day, time and location for interview, along with follow up contact details (Appendix 1.9).

Interviews took place in the host organisation office or the participant's home, whichever was most convenient for the individual. Before commencing the interviews, the researcher once again went through the information form - reiterating assurances of confidentiality and anonymity, answering any outstanding questions and completing the consent form. Once participants were happy to proceed, the interviews commenced. All interviews were audio recorded, with consent, using a digital dictaphone and lasted on average 70 minutes.

Secondary data were also used for a small number of participants who were unavailable for interview (n=9), but where publicly available online video files were obtainable; these contained footage in which individuals were discussing their experience of the individualised funding initiative. The content of these video files was prepared in advance and they were, therefore, very focused and concise, lasting approximately 8 minutes on average. The use of secondary data files was necessary because the gatekeeper, for one organisation, reported 'research fatigue' from prospective participants and therefore did not wish to over-burden potential participants. While additional participants and staff members were available to be interviewed in the remaining three organisations, data collection ceased once saturation point was reached and no new themes were emerging. All primary and secondary data were transcribed verbatim and anonymised.

A total of 24 interviews were conducted with 35 individual participants and, in some cases, project participants and advocates were interviewed together (Table 2.1). As mentioned above, secondary data pertaining to nine individuals were also utilised. The largest proportion (45%) of individuals involved had some form of intellectual, physical, developmental or mental health impairment, while the remaining participants involved staff members and advocates (27% in each group).

Table 2.1 - Profile of study sample

N=44	Staff (n=12)		Project Participants (n=20)		Advocates (n=12)		TOTAL	
	Male	Female	Male	Female	Male	Female	Male	Female
Case Study 1 (CS1)	2	1	3	2	2	4	7	7
Case Study 2 (CS2)	1	1	4	3	0	2	5	6
Case Study 3 (CS3)	1	3	3	1	0	2	4	6
Case Study 4 (CS4)	1	2	1	3	0	2	2	7
Total n (%)	**5** **(11)**	**7** **(16)**	**11** **(25)**	**9** **(20)**	**2** **(5)**	**10** **(23)**	**18** **(41)**	**26** **(59)**

[CS1] Brokerage service supporting 11 individuals with a physical or intellectual disability*
[CS2] Direct Payment service supporting 20 individuals with a physical or sensory disability*
[CS3] Brokerage service supporting 5 individuals with an intellectual or mental health disability*
[CS4] Brokerage service supporting 9 individuals an intellectual or developmental disability*
*Services were not limited to these disabilities but reflected majority of participating individuals

2.4.5 Participatory workshop

On completion of the analysis (described in next section), the validity and acceptability of the research methodology and findings were tested by soliciting feedback from key stakeholders in a participatory ‘Sharing and Learning’ workshop involving people with disabilities, family members, advocates and staff members from the four individualised-funding initiatives (n=20) (Figure 2.8). The workshop (based around the preliminary findings from the in-depth interviews) was delivered interactively to study participants in order to encourage evaluative feedback; this is integral to realist evaluation in that it helps to identify avenues that are worth exploring (or not) into the future (Pawson & Tilley, 1997). Furthermore, the event was intended to be (and was received as) a shared learning experience for participants, an opportunity to network, to hear about other models of individualised funding and to build a network of advocates.

This kind of participatory approach is often recommended for population-based research and, arguably, enhances the ethical aspects of disability-related research (Good, 2009). Heron and Reason (1997) argue that participatory inquiry involves researcher and participants working collaboratively together, rather than the researcher conducting the research on, or about, other people.

Figure 2.8 - Participants of 'Stakeholder Sharing and Learning' workshop

The workshop took place in the Department of Psychology, Maynooth University on September 4th 2015 (Appendix 1.10 and 1.11). A total of 20 people attended, consisting mainly of interview respondents, but also including the PhD supervisory team and five family members/advocates not previously involved in the research. The workshop itself lasted 3.5 hours with a coffee break and lunch included. It was multi-faceted with: 1) learning objectives outlined at the outset; 2) individual presentations from the four pilot organisations; 3) presentation and discussion of preliminary findings from interviews; and 4) group work and discussion to address key question emerging from the research. The discussion of findings and the group work were audio-recorded using a dictaphone. The questions addressed during the group work, which were informed by preliminary analysis of in-depth interviews, can be seen in Box 2.1 below.

Box 2.1 – Questions addressed during the group work

1. Given the importance of ‘natural supports’, how can we ensure that supports will not have a disabling effect?
2. How can we collaborate together to strengthen the case for HSE systematically de-bundling money?
3. How can we ensure that individuals remain the leading force, especially as numbers increase?
4. Should we be pushing for Resource Allocation Systems as the mechanism for allocating money to individuals?
    i. If yes, how do we go about that?
    ii. If no, what are the alternatives?
5. How do we ensure that all possible options / activities are made available to individuals, especially those who are unsure what they want to pursue?

Each of the four groups was asked to nominate a member to capture feedback from the team and flipcharts were supplied. Ten minutes was allocated to each question, after which time respondents were asked to move on to the next question. (Figure 2.9) The researchers facilitated the group discussion by moving around the groups, encouraging discussion and gathering flipchart sheets after each 10-minute period had elapsed. These sheets were then displayed on the walls around the room in order to encourage a broader group discussion (which was also audio-recorded and transcribed verbatim, Appendix 1.12).

Figure 2.9 - Group work during participatory workshop

2.4.6 Analysis

2.4.6.1 Documentary Analysis

The goal of the documentary analysis was to build organisational context, to explore processes and create a narrative of the "how's" and "why's" of moving toward individualised funding, thereby informing the development of interview schedules for the next phase of the evaluation research. Once the documents (described earlier) were received, they were transferred to the lead researcher's encrypted laptop. They were then manually scanned for sensitive information and anonymised using fictionalised names. These names were kept in a password-protected coding plan (Appendix 1.13), to which only the lead researcher had access. PDF and JPEG documents were opened in Microsoft Paint where sensitive information was redacted. Once documents were anonymised, they were imported into MAXQDA. Where additional sensitive information was discovered within MAXQDA, the researcher further anonymised the information according to the coding plan.

All documents were read at least once, and line by line coding was commenced for the first batch of documents received. However when subsequent files were delivered, it became apparent that line by line coding would be too resource intensive, with little additional benefit in terms of informing the development of the interview schedules. Therefore, a decision was made to use MAXQDA to conduct a content analysis to identify frequently used words within the documents. Non-descriptive words (such as pronouns) were excluded. The results of this process are shown, for case study four, in Figure 2.10. The top ten, most frequently occurring, words are depicted. The outer ring represents the number of times a (colour coded) word appeared across the 293 documents, while the inner ring reports the percentage. (See Appendix A1.14 for full results)

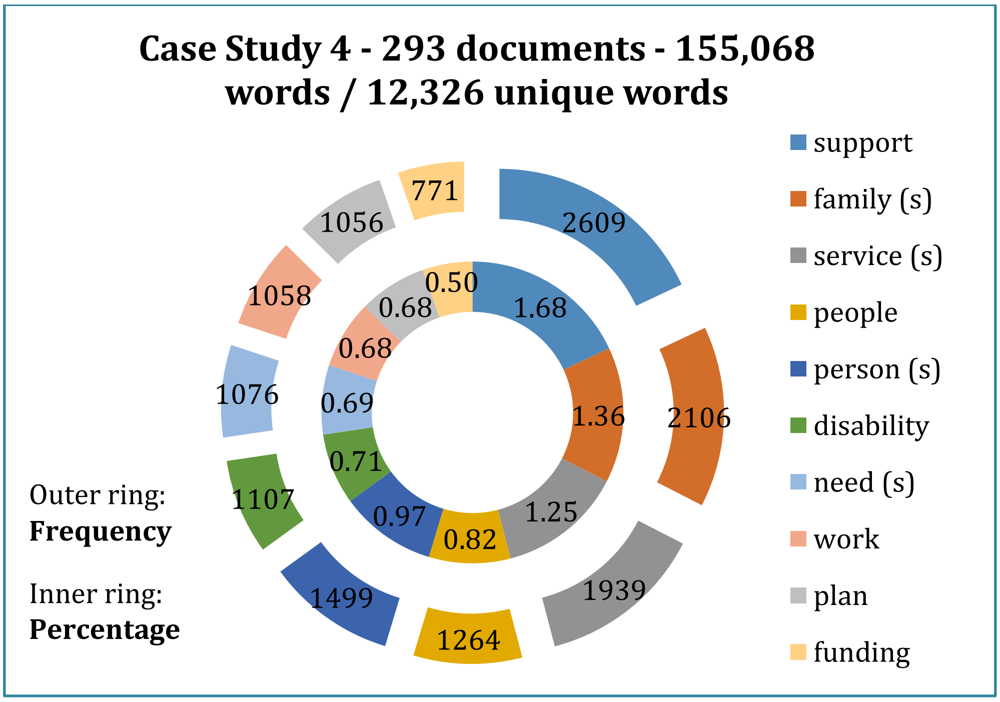
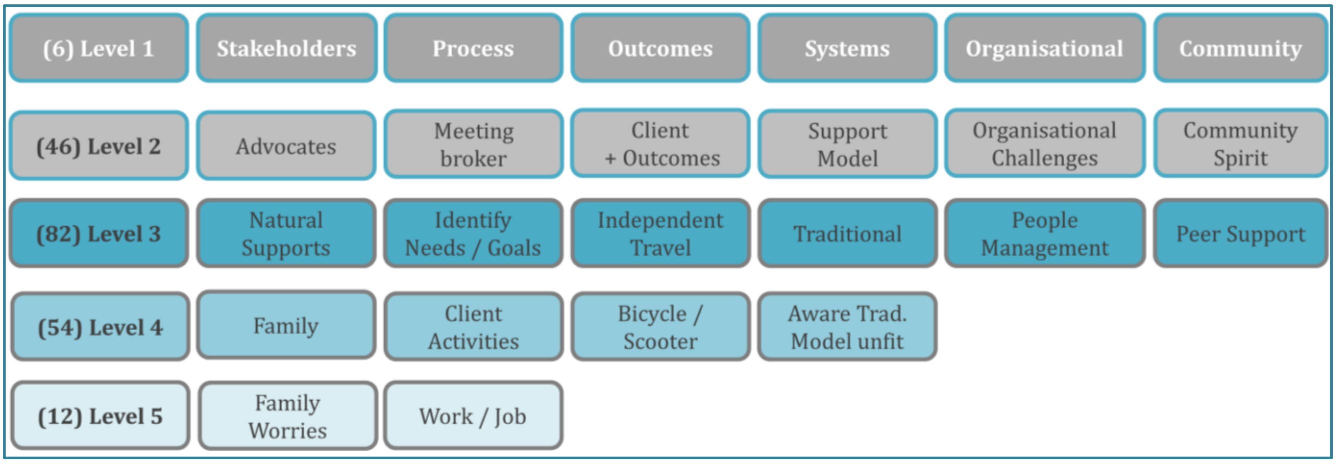


Figure 2.10 - Content analysis for case study 4

2.4.6.2 In-depth interviews

Thematic analysis was used to identify recurring themes, supported by the use of MAXQDA qualitative data analysis software. The interpretive coding (Mason, 2002) reflected the ontological and epistemological perspective of critical realism. Thus, the aim was to explain social phenomena and, in particular, to identify the mechanisms underpinning outcomes (Gilson, 2012). A line by line coding initially generated 200 codes and 3,224 coded segments of text. All transcripts were then re-read, assigning multiple codes to each text segment resulting in 5,540 coded segments of text (see Appendix 1.15). A number of original codes were merged or recoded on the second iteration, while some categories were expanded with more detailed codes. This process led to the identification of 6 superordinate themes including: ‘stakeholders’, ‘process’, ‘outcomes’, ‘systems’, ‘organisational’ and ‘community’. A number of sub-themes were next identified and categorised at up to 5 levels of detail (from macro level 1 to micro level 5). An example of the coding structure is provided below (Figure 2.11). The analysis - visualising and prioritising co-occurring themes and sub-themes – was aided by the use of: 1) code weights (i.e.

in how many interviews a code arose; 2) colour coding; and 3) MaxMaps - the visual tools available within MAXQDA.



(6) Level 1	Stakeholders	Process	Outcomes	Systems	Organisational	Community
(46) Level 2	Advocates	Meeting broker	Client + Outcomes	Support Model	Organisational Challenges	Community Spirit
(82) Level 3	Natural Supports	Identify Needs / Goals	Independent Travel	Traditional	People Management	Peer Support
(54) Level 4	Family	Client Activities	Bicycle / Scooter	Aware Trad. Model unfit		
(12) Level 5	Family Worries	Work / Job				

Figure 2.11 – Example of coding structure (including number of codes per level)

2.4.6.3 Participatory workshop

The data produced as part of the group work conducted during the participatory workshop (i.e. and as recorded on flipcharts), were collated, analysed and written up into a brief report (Appendix 1.16) which was subsequently shared (upon request) with the four organisations for distribution among workshop participants. Overall, the preliminary findings were very well received, with the rigorous methods and key messages endorsed by those in attendance. Some of the comments about the overall approach and the general discussion are provided below (Box 2.2).

Box 2.2 – Selected comments about the participatory workshop

"The presentation is right in touch with everything that's going on. It reflects all the stuff that we've been talking about over the last two to three years" – Staff member (CS1).

"I suppose just to say, very impressive this year's analysis. It obviously took hours and hours and hours and your familiarity with the material is very evident. Like, it seemed like you were reading quotes without really looking at them." - Staff member (CS4)

"Thank you so much for doing the research. It gives me hope that things will change. That you know, the HSE will buy into it." - Parent (CS3)

2.5 STUDY THREE

Study Three involved a systematic review which was registered with the Campbell Collaboration and undertaken in collaboration with a number of expert authors including the principal supervisor. The objectives of the review were to: (1) examine the effectiveness of individualised funding interventions for adults with a lifelong 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 individualised funding, with a particular focus on the stage of 'initial implementation' as described by Fixsen and colleagues (2009).

The process of registering a review with the Campbell Collaboration involves the completion and submission of the following:

1. A 'Title Registration Form' (TRF), which must be approved, by the editorial board of the review group/subgroup (in this case Carlton J. Fong & Sandra Wilson - Education Coordinating Group Editors and John Westbrook - Disability Subgroup Coordinator), before proceeding (Fleming, Furlong, McGilloway, Keogh, & Hernon, 2015)(Freely available from The Campbell Library[8]);

2. A detailed 'Protocol' which is peer reviewed and if accepted, published in the Campbell Collaboration library (Fleming, Furlong, et al., 2016)(Freely available from The Campbell Library[8]);

3. The final systematic review report for final peer review and publication in the Campbell Library (Study Three - Chapter Five).

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[8] https://www.campbellcollaboration.org/library/personal-budgeting-outcomes-people-with-disability.html

In line with the above, the TRF and protocol were published in the Campbell Collaboration library after an extensive peer review process (Fleming, Furlong, et al., 2015; Fleming, Furlong, et al., 2016). The protocol was reviewed by two methodologists, an information retrieval specialist and a content reviewer. In total, 111 comments were returned and addressed in the final published version. The final TRF was submitted on November 14th 2014 followed by publication of the final protocol on 2nd May 2016.

2.6 Other cross-cutting methodological issues

2.6.1 Ethical considerations

There were no ethical considerations pertaining to Studies One or Three. Study Two received ethical approval from the Maynooth University Social Research Ethics Subcommittee in 2014 (SRESC-2014-059 - Appendix 1.17). Some of the key points are highlighted below.

2.6.1.1 Sharing sensitive material

The internal documents, shared as part of the documentary analysis, potentially contained sensitive material, and therefore a secure data sharing process was utilised. Initially, the nominated point of contact was emailed to arrange the sharing of initiative documents and, with the participant consent, the names of potential participants who were happy to hear more about the research. This facilitated the personalisation of invitation letters. In order to share this information securely, the liaison person was sent an 8GB SanDisk Cruzer Edge USB flash drive with SecureAccess™ software which password-protected a private folder (vault) with 128-bit AES encryption. The flash drive was sent by post with instructions on how to access and load files into the encrypted vault. The password (set by the lead researcher) was sent separately by email. Once the relevant materials were uploaded, the encrypted flash drive was returned to the researcher in a stamped addressed envelope.

2.6.1.2 Managing vulnerability of participants

All of the initiative participants had an intellectual, developmental and/or a physical disability or mental health problem. The type and level of disability varied across the sample. Discussions took place with the participants' parent or advocate when necessary, in order to assess level of comprehension. The information sheet - in line with NDA recommendations - was devised to be as accessible, appropriate and as detailed as possible. The person with a disability was given the option to have an interpreter or advocate present in the room, if necessary or desired. In these cases, the advocate was invited to assist with the interview. The researcher ensured that all of this information was provided (and explained, where necessary) by the gatekeeper, and necessary arrangements made in advance of the interview.

2.6.1.3 Use of proxy respondents / advocates

Proxy respondents were not required; however advocates (of the participant's choosing) were often present to assist if required. The researcher endeavoured to ensure that the advocate was chosen freely and that they knew the participant and their views and preferences well. This was achieved by asking gatekeepers, in advance, about the participant's preferred advocate, checking their history with that individual and the length of time the advocate had worked/lived with the participant. The researcher also accommodated the availability of both the participant and their advocate. Prior to the interview, the individual with a disability was asked to confirm that they were happy with the advocate being present during the interview. When an advocate proffered an answer, or elaborated on a point, the individual with a disability was asked to confirm if they agreed with the response (if they had not already done so).

The researcher arranged an informal ice breaker, such as a beverage and informal chat, before beginning the formal procedures of consent, in order to put the participant at ease, and to allow the researcher time to assess and respond to the participant's potential speech difficulties. This was facilitated by the family member, advocate or organisational staff.

2.6.1.4 Recruitment and informed consent

The processes of invitation and consent were summarised earlier in section 2.4.4. However, further detail is provided here for organisations, staff members, initiative participants and their advocates respectively.

Organisations

After informal meetings had taken place with the organisation CEO or initiative lead, a follow-up 'Invitation to Participate' letter was sent to them. The CEO / initiative lead was asked to complete and sign an initial consent form and return by post to the lead researcher (Appendix 1.1 and 1.2).

Individual staff members

After initial consent was obtained from the organisations, they then acted as gatekeeper, negotiating access to the sample of staff members and initiative participants. Staff members were contacted separately either by email or post (if email address was unavailable), inviting them to participate. Staff opted to participate by completing a Participation Form and returning by email or post (Appendix 1.7 to 1.9).

Initiative participants

Initiative participants were contacted with a cover letter and information sheet (Appendix 1.5 and 1.6), with the gatekeeper completing the postal address or hand delivering the invitation pack (for data protection purposes). They were asked to complete or to have an advocate complete a participation form (Appendix 1.9) and to return it by email or post. In other cases the gatekeeper facilitated suitable meeting times and locations. Prior to each interview (staff, initiative participant or advocate), the researcher revisited the information sheet, explaining each element and soliciting questions from the participants. Written informed consent was then obtained from each participant. A written copy was provided to participants for their own records.

It should be noted that although some participants had an intellectual disability, they all had a level of cognitive capacity to allow them to actively engage with the individualised funding initiative, which can be quite demanding. Therefore, participants generally had the cognitive ability to understand the nature of the research and the information sheet. However, to ensure that the information provided was clearly presented and understood, the researcher read through the information and consent forms before the interview commenced, stopping after each point and asking if the research participant understood what it means and if they had any questions. Verbal affirmation was always possible and visual aids were not necessary.

Advocates

If an advocate had not been present during the interview, initiative participants were asked to nominate an advocate to participate in a follow-up interview. These advocates were provided with an information sheet and consent form, having (in most cases) been present on the day of the interview with the initiative participant. Advocates were asked about their experience of the individualised funding initiative, its successes and challenges and the impact on their lives. They were also asked about the extent to which they felt the individualised funding had impacted the initiative participant, but they were reminded that this was from their own perspective and to try to avoid speaking on behalf of the person with a disability.

2.6.1.5 Data collection

As part of the data collection process, interviewees were reminded that participation was completely voluntary and that they could withdraw from the study at any point and withdraw their data up to the point where data were analysed. They were asked if the conversation could be recorded, with assurances that recordings would only be accessed by the researcher, or by a trusted colleague in order to help with transcription. The steps taken to ensure anonymity were clearly explained, including the planned removal of any personally identifiable information from the transcripts, such as names, addresses and locally identifiable information. Participants were also told that: recorded or transcribed data would remain strictly confidential and would be stored securely on an encrypted laptop or locked in a cabinet in Maynooth University; that the recordings and documents with identifiable information would be destroyed/overwritten by the researcher within five years; and that consent forms would be stored separately from transcriptions or any other hard copies of material.

The interviews with initiative participants lasted 66 minutes on average and in order to make the experience a positive one, thereby avoiding tiredness, stress and research fatigue, sufficient time was factored in for breaks (although these were usually not needed). Furthermore, in order that the researcher was 'disability aware' (e.g. using appropriate language), he immersed himself in the disability studies literature and visited a number of community projects (funded by Genio) prior to the study. The documentary analysis was also helpful in this regard.

Power relationship / perceived conflict of interest

The lead researcher's SPHeRE scholarship was funded by Genio, which also funded the pilot initiatives. This association may have led to concerns amongst the participants that any neutral or negative reports may have had an adverse effect on their services or on the organisation. However, the researcher explained clearly that he was independent of Genio and was conducting objective research as part of a PhD in Maynooth University.

Furthermore, the researcher was sensitive, at all times, to any visible signs of stress or tiredness and responded by asking if the participant would like a break, reminding the participant that they did not have to discuss the topic if they did not wish to do so. The researcher also ensured that the participant understood their conversation and that all information provided was confidential, that it was to be accessed only by the researcher and that any reported information would be anonymised.

2.6.1.6 Minimising risks/harm

The researcher was sensitive to the well-being of participants at all times and endeavoured to minimise any psychological harm by taking steps to protect the dignity and welfare of participants (Evans, 2007, p.14) and to ensure minimal risk such that any "harm or discomfort participants may experience in the research is [was] not greater than what they might experience in their daily lives or during routine physical or psychological tests" (Zechmeister, Zechmeister, & Shaughnessy, 2000, p.59).

Participants were sometimes physically unable to greet people in the usual manner, such as shaking hands and it was possible that this may cause stress or embarrassment for them, particularly when meeting someone unfamiliar. Therefore, the researcher discussed each individual with the gatekeeper before meeting them in person. There was also a risk that the researcher would have some difficulty in understanding participants at first, due to any speech difficulties. Again, the researcher discussed this with the gatekeeper prior to meeting the participant in person. The researcher assessed the situation upon arrival (during an informal ice-breaker) and was very open and upfront with the participant in order to explain that he may need to ask the person to repeat what they are saying, apologise for the inconvenience and attempt to reassure the participant in a non-judgemental manner.

The researcher attempted to build trust and rapport with participants whilst being completely open about the purpose of the study and realistic outcomes. Furthermore, at the time of interviews, the researcher had 10 years' research experience, including 'real world' qualitative interviews, a M.Sc. in applied social research and had recently participated in a taught module in data collection (including interviewing skills) as part of a structured PhD programme. Thus, he had the skills required to recognise and manage any participant distress.

The interviews were carefully concluded, ensuring the participant did not have any worries or concerns about the information shared. Their emotional state was assessed by asking how they are feeling about the interview process and whether they have had any unexpected emotions. They were directed to the information sheet where a number of sources of support with contact details were provided, if needed.

Whilst there was a risk that unforeseen emotional distress would arise during the interview (e.g. when recalling previous life experiences), every effort was made to debrief the participant appropriately, ending the interview on a positive note and referring them to the sources of support indicated in the information sheet. The participant was also informed that they could request a copy of the anonymised interview transcript if so desired.

Interview participants who chose not to participate or who were not available for the participatory workshop were given an opportunity to contact the researcher to provide feedback or ask questions on a one-to-one basis if so desired. This was simply a debriefing measure to ensure there were no outstanding issues relating to participation in the research.

2.6.1.7 Participatory workshop

As outlined earlier, all participants were invited to the participatory workshop, where they were, once again, thanked for their contribution and were given the opportunity to participate further. Those who had participated in the in-depth interviews were reminded that they might recognise some of their own comments within the presentation, but that the comments had been anonymised, and therefore the person did not have to identify themselves as the data source. Equally, for the purpose of empowerment and true to participatory methods, individuals were also welcome to identify themselves as the source, if so preferred.

At the outset, it was explained that all participant feedback would be recorded, analysed and potentially reported as part of the study, but that all names, sensitive information or personally identifiable information would be changed to protect the identity of participants. Participants were asked to treat the information shared within the workshop as confidential and were assured that the researcher would also treat information confidentially, in line with ethical principles and obligations. Participants were also asked, when using examples of individual experience, to fictionalise their feedback. It was explained that active participation in the feedback would be interpreted as implied consent to use the data. It was also explained that those who did not wish to actively participate could, alternatively, sit in on the groups and simply adopt a listening role (Appendix 1.18). Everybody actively participated and although anonymity was offered, participants consented to the use of photography during the workshop.

2.6.2 Researcher Reflexivity

Individuals are innately influenced by their own personal life experiences, sociodemographic backgrounds and educational / work opportunities. With this in mind, researchers, in particular, need to be aware of their own biases, particularly when designing research projects, conducting analysis, interpreting findings and reporting results. This is even more applicable to qualitative research which formed an important part of this mixed methods study. Conventional ideals would favour objectivity and distance, but by facilitating insights into personal and social experiences, reflexivity should situate the research within these potential biases, enhancing understanding of the topic under investigation (Finlay & Gough, 2003). At an early stage in the research reported here, these biases were therefore considered and captured in order to (explicitly) make the researcher more aware of his potential biases, thereby prompting him to make objective decisions throughout the research process. These reflections and biases are outlined below.

Disability is a complex subject that has been extensively studied and written about and yet progress in terms of alleviating social, political and economic oppression, has been generally slow. Examples of some of the key themes explored in the literature, to date, include: social deviance; personal tragedy; labelling; exclusion; employment limitations; gender issues; personal identity; cultural and media representations; sexual deviance; anti-discrimination legislation; social movement; and internationalisation (Barnes & Mercer, 2003). A striking cross-cutting element here is the consistent challenges faced by all oppressed social groups, regardless of the origin of the oppression. Many of these resonated with the researcher and it was these which first attracted him to this study - having grown up as a gay man in a small rural town in Ireland during the 1980s and 1990s.

The parallels between gay people and people with a disability have been previously described. For example, Corbett (1994) explored the relationship between disability politics and gay pride, highlighting that both are about fighting oppression and challenging inequalities of opportunity and civil rights. For example, the author focuses on the power of social movements; the effect that collective power can have on social prejudice, hostility and discrimination; and the empowerment linked to taking ownership of oppressive labelling and 'upcycling' these crippling labels to the benefit of the oppressed (Corbett, 1994). Oliver (2009) draws comparisons not only to heterosexism but also classism, racism, ageism and patriarchy, and like others he highlights the added complexities of 'simultaneous oppression' i.e. falling under two or more of these oppressed groups, such as a black, lesbian woman who has a disability:

> *"I got fed up to the back teeth of being told by white disabled people that as black disabled people we shouldn't be concerned with the issues of race and disability; that we should be concerned only with issues of disability because that was the fight; that was the most important element in our character." (J. Campbell & Oliver, 1996, p. 132)*

Such simultaneous oppression creates an internal conflict within the oppressed group, such that straight people with a disability may not wish to become involved in equality campaigns relating to the minority of gay people with a disability within the community (Michael Oliver, 2009).

During the early stages of the research project, when listening to an advocate for people with a disability speak about her childhood and her struggle to accept her blindness the researcher was stuck by the similarities that exist for gay people coming to terms with their sexuality. In the case of the woman above, this was not a denial in the conventional sense in that she had accepted, to a large degree, that she was blind, but it was the denial that she had a disability or had anything in common with other people with a disability, a concept explored in detail by Oliver (2009). The woman's experiences led to an eventual 'coming out' to her mother, who had accepted the blindness years earlier and who was unaware of her daughter's inner turmoil:

> *"When lesbian and gay men come out, they declare to the world and themselves that they embrace their sexuality and all the joy and pain and ability to love that this brings. They begin to reject the guilt, the shame, the self-hatred and the abuse and to become at peace with themselves. Surprising as it may seem, this experience can be almost exactly the same when disabled people come out and declare they are disabled." (Gillespie-Sell and Ruebain, 1992 p. 213 as cited inJ. Campbell & Oliver, 1996)*

There are many social movements which struggle with such oppression, but the current research was motivated by a strong sense of social injustice and in a rapidly changing social context in Ireland which became the first country in the world (by popular vote) to approve marriage equality for gay people. In fact, the researcher played an integral role in this campaign, coordinating door-to-door canvassing efforts for the largest voting constituency in the country (Healy, Sheehan, & Whelan, 2015, p. 184). Arguably, the disability movement are advancing their concerns at a much slower pace. Indeed, disability campaigners have used the marriage equality referendum in Ireland to highlight issues of inequality within the disability sector, and specifically the Irish government's failure to ratify the UN Convention on the Rights of Persons with Disabilities, 10 years after they had committed to do so (Clonan, 2017; Linehan, 2017). This raises questions as to why legislation and policy are not changing more rapidly to accommodate the needs of people living with a disability. As a young man, the lead researcher was empowered by education and subsequent employment to take control of his life. Therefore, it seemed fitting that he use these skills in an attempt to advance policy and practice for fellow citizens, in a sector continuing to struggle with social injustice and limitations in terms of personal choice, control and self-determination.

Having taken all of the above into careful consideration, the researcher was aware of a potential personal bias in terms of advancing social justice. However, every effort was made to ensure an objective, systematic and evidence-based approach to all phases of the research. Indeed, arguably, the peer review process inherently monitors such biases and promotes greater objectivity with regard to the reporting of results. Ongoing dialogue with the supervisory team also took place throughout the research process to monitor and discuss potential biases. Furthermore, a number of other mechanisms were put in place to ensure that the researcher conducted the study as intended, followed strict ethical guidelines and utilised the most appropriate methods for the research in question. These included the development of a study protocol (as required by the SPHeRE programme); an annual review process undertaken both by Maynooth University Department of Psychology and the SPHeRE programme; and a critical review by Genio's International Research Advisory Board.

2.7 CONCLUSION

In summary, this chapter outlined the main epistemological, methodological and ethical considerations relevant to the conduct of each of the three studies undertaken as part of this research. The published and submitted work pertaining to each of these studies is presented in the next three chapters.

CHAPTER THREE: STUDY ONE

DAY SERVICE PROVISION FOR PEOPLE WITH INTELLECTUAL DISABILITIES: A CASE STUDY MAPPING 15-YEAR TRENDS IN IRELAND

This is the accepted version of the following publication: Fleming, P.[1], McGilloway, S.[1] & Barry, S.[2] 2016. Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland. *Journal of Applied Research in Intellectual Disabilities*, which has been published, on 26/02/2016, in final form at http://onlinelibrary.wiley.com/doi/10.1111/jar.12249/abstract;jsessionid=BD2A53470B73A0E69D4E1DDA3B77C70C.f03t03 This article may be used for non-commercial purposes in accordance with the Wiley Self-Archiving Policy [http://olabout.wiley.com/WileyCDA/Section/id-828039.html].

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ABSTRACT

Background

Day-services for people with intellectual disabilities are experiencing a global paradigm shift towards innovative person-centred models of care. This study maps changing trends in day-service utilisation to highlight how policy, emergent patterns and demographic trends influence service delivery.

Methods

National intellectual disability data (1998-2013) were analysed using WINPEPI software and mapped using QGIS Geographic Information System.

Results

Statistically significant changes indicated: fewer people availing of day-services as a proportion of the general population; more males; fewer people aged <35; a doubling in person-centred plans; and an emerging urban/rural divide. Day-services did not change substantially and often did not reflect demand.

Conclusions

Emergent trends can inform future direction of disability services. Government funds should support individualised models, more adaptive to changing trends. National databases need flexibility to respond to policy and user demands. Future research should focus on day-service utilisation of younger people and the impact of rurality on service availability, utilisation, quality and migration.

Keywords:

Intellectual disability, day-services, individualised support, personal budget, person-centred plan, implementation

4.1 INTRODUCTION

The future of day support services for persons with intellectual disabilities is of considerable international relevance, particularly for high income countries which tend to invest heavily in such services/supports, but often with questionable outcomes for service users (HSE, 2012b; Whittaker & McIntosh, 2000). Despite recent (progressive) policy developments (Department of Health, 2012), Ireland is a prime example of a high income country which is lagging behind many of its European neighbours. For instance, it has yet to ratify the UN Convention on Human Rights of Individuals with Disabilities which strives for true social inclusion for people with disabilities, including equal access to information, transport, education, employment and income support (Lee & Raley, 2015).

The European Association of Service Providers for Persons with Disabilities (EASPD)[9] identified six underperforming countries (Austria, France, Finland, Ireland, Hungary, Bulgaria and Romania) which were in need of capacity-building training (Ward, 2015). Amongst these, the process of de-institutionalisation in Ireland had stalled due to cuts in public expenditure, specifically a 66% reduction in the 'community employment scheme' - an essential source of funding for personal assistants required to facilitate independent living. This reportedly resulted in instances of re-institutionalisation, an austerity-related trend also seen in Bulgaria where spending allocated to institutional services far outweighed community-based services; likewise, in Portugal, the lack of new investment has seen an increasing number of people using more institutionalised forms of care (Hauben, Coucheir, Spooren, McAnaney, & Delfosse, 2012). Other areas identified as in need of essential policy change in improving the wellbeing of people with disabilities include: employment; health; independent living; and youth guarantee (Bignal, 2013).

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[9] EASPD is a European not-for-profit organisation representing over 10,000 social service provider organisations across Europe and disability. The main objective of EASPD is to promote equal opportunities for people with disabilities through effective and high-quality service systems.

The objectives of the current study, which was undertaken as the first stage of a larger multi-component evaluation of individualised funding, were to: (1) map any changing trends in day service provision in Ireland; (2) highlight where national policy changes, driven by international best practice, may be influencing service delivery; and (3) highlight potential future service needs and lessons for similar high income, underperforming countries in Europe and elsewhere, based on emergent patterns and changing demographic trends.

3.1.1 Historical context

From the late 19th century, the disability sector landscape in Ireland was dominated by large religious-run institutions. The subsequent Health Acts of 1953 and 1970 empowered the Department of Health to offer financial support to family and advocate-led organisations which eventually became the principal mechanism for providing activities, vocational training and sheltered work for people with disabilities. However, these developments were largely unsystematic and often unfit for purpose, with people remaining in child-orientated facilities well into adulthood. A segregated culture of 'specialised' services became embedded in service provision during the 1960s, with a range of specialised professions emerging to provide therapy and services to people with intellectual disabilities (HSE, 2011b, 2012b).

In 1984, a landmark Green Paper on Services for Disabled People was published - seen by many as the start of more inclusive policies in Ireland to promote community integration of housing and services. The European Social Fund (ESF) (1970 – 1994), and subsequently the European Regional Development Fund, provided funding and specialist infrastructural support for vocational skills training (HSE, 2012b). In 1993, the UN Standard Rules on the Equalisation of Opportunity for People with Disability influenced the development of the 'Commission on the Status of People with Disabilities' in Ireland, now the 'National Disability Authority', and the production of 'A strategy for equality' (Commission on the Status of People with Disabilities, 1996). A number of policy documents based on international best practice have since been developed (Department of Health, 2012; HSE, 2011b, 2012b). For example, the 'Value for Money and Policy Review of Disability Services in Ireland' (2012) – which is currently used as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of 'supports' rather than 'services' in supporting the transition from a largely institutionalised to a personalised model. To achieve this, person-centred plans, individualised supports and personal budgets were recommended to bring Ireland in line with the global paradigm shift in day services for people with intellectual disabilities.

This historical evolution led to a reliance on voluntary organisations to lead pioneering change within the sector. Semi-autonomous non-governmental-organisations (NGOs), funded largely by the Government, continue to deliver services within geographical designated areas, accounting for around 90% of services delivered to people with intellectual disabilities (HSE, 2012b). Furthermore, the registration and regulation of services is only beginning to happen. Whilst some individualised supports do exist, people are still limited to a range of centre-based group activities with limited individual choice. In 2013, 99.8% of people registered on the National Intellectual Disability Database availed of at least one day programme, representing the highest number since records began in 1996 (Kelly & O'Donohoe, 2014). Of these, 29% were also in receipt of full-time residential care services. While demand for day services continues to grow, expenditure on disability services steadily declined year-on-year after peaking at €1.68 billion (net) in 2009 and falling to €1.45 billion in 2011 and €1.31 billion in the 2015 budget (Department of Health, 2012; Inclusion Ireland, 2014).

Given the extensive national and international developments in disability service provision, this study sought to explore the changing trends in demand and uptake of day services for people with intellectual disabilities in Ireland, whilst also providing insights into how service providers have responded to the changing policy landscape.

3.2 METHODS

The National Intellectual Disability Database (NIDD) collates a minimum set of information, for all people in Ireland who receive or are in need of intellectual disability services, inclusive of day, residential and multidisciplinary services. Individual data forms are used to gather three basic pieces of information: demographic details; current service provision; and future service requirements. Diagnostic or medical information is not gathered as the database is not intended as an epidemiological tool. Snapshot data are gathered at a specific point in time and are updated annually. The national database employs an ongoing validation system whereby gaps or inconsistencies in the data are identified and guidelines and protocols put in place to address these, thereby ensuring greater standardisation (Kelly et al., 2009). An audit of the database in 2007, the focus of which was residential services rather than day services, showed an overall accuracy of 72.2%, with 19.3% of data considered to be inaccurate, and 8.5% of the sought audit data not returned (Dodd et al., 2010). Data relating to the future demand for services was found to be the most inaccurate (50.4%) (due to confusion around contingency and future needs) so it is possible that a similar level of inaccuracy may apply to day services.

For purposes of this study, a standard data request form was submitted to the NIDD which included a detailed rationale and declaration of confidentiality. Due to national data protection regulations, individual level statistics were unavailable. Therefore, aggregate secondary data relating to current day service utilisation and future service needs was requested for adults aged 18 years and over, broken down by county of residence. Data were requested for six specific years between 1998 and 2013, covering a 15 year period at three yearly intervals. The 2013 data were the more recently available at the time of the study. Demographic summary statistics were also provided for each year based on: sex; age group; degree of disability; and receipt of a 'person-centred-plan'. The data request was reviewed and approved by a national committee. For comparative purposes, general population statistics were sourced from the Central Statistics Office (CSO), Ireland's national statistical office.

It should be noted that the NIDD supplied data for the main day service that was used in addition to the second and third day services used. For the purposes of this study, only primary day services were compared since every individual on the dataset had availed of a primary day service, whereas only 5%-18% of people had availed of a second day service between 1998 and

2013, with even fewer availing of a third. In addition to the breakdown by county of residence, data were broken down by local health office, but due to the shifting parameters of local health authorities over the 15-year period, it was deemed more appropriate to map trends based on the unchanging geographical county borders.

The most popular day services were examined first in order to map general trends (i.e. those with 500 people or more attending or wishing to attend). The aggregation of data restricted the complexity and depth of statistical analysis. Upton's chi-square was used to test for statistically significant differences when comparing proportions of two independent samples, as recommended by Campbell (2007); the analysis was conducted using WINPEPI, a computer programme specifically developed for epidemiologists conducting health research (Abramson, 2011). The data were collated and mapped using QGIS Geographic Information System (QGIS, 2015) and various trend visualisation tools in Microsoft Excel (2010).

It should be noted that when comparing the NIDD and general population data, the census year did not always directly correlate with the data provided by the NIDD; for example, census data are presented from 1996, while NIDD data for the study commenced in 1998. This is clearly indicated throughout the graphs.

3.3 RESULTS

3.3.1 Demographic and background information

The total number of adults (18+) with an intellectual disability registered on the NIDD in 1998 was 14,897, increasing to 18,275 in 2013. Generally, more men than women availed of day services with the gap widening over time, increasing from 5.3% (n=785) in 1998 to 8.7% (n=1,585) in 2013 ($p < 0.001$). In contrast, the census data for a similar period showed significantly more women than men in the general population (1996 – 51.1% vs. 48.9%; 2011 - 51.0% vs. 49.0% $p < 0.001$). It might also be of interest to note here, that the overall population in Ireland increased during the 15 year period (1996-2011) by almost 1 million (21%), largely due to mass immigration (CSO, 2012b).

NIDD summary data were provided in five year age groups. These were further collapsed into five categories and CSO data were extracted within the same parameters for direct comparison. When presented by age group, the population growth pattern within the NIDD was consistent with the older general population during a similar time period, i.e. those aged 50 years and older (Figure 3.1). Whilst the general population showed a steady growth in the 35-49 age group, the NIDD data showed a levelling off and slight drop from 2010 to 2013. Even more marked, was the difference for the 18-34 category; the census showed a steady growth up to 2006 where it then began to decline slightly, whereas the NIDD population showed a steady decline over a similar time period, levelling off between 2010 and 2013.

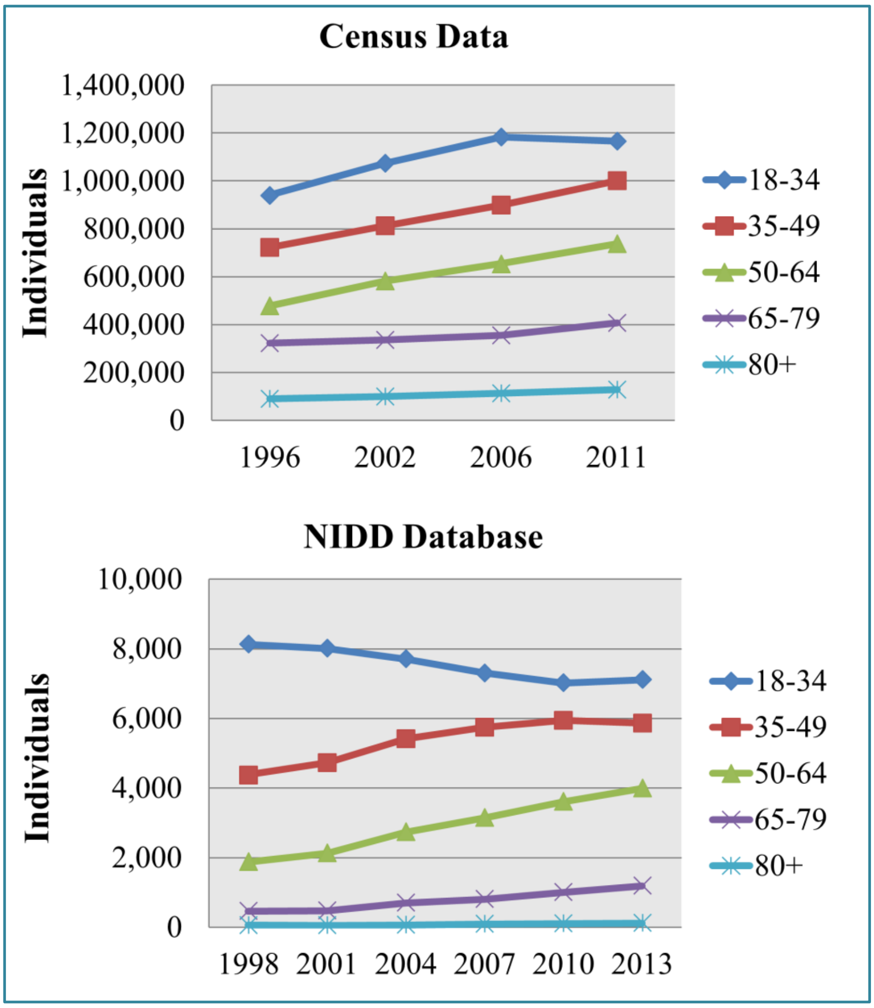


Figure 3.1 – Changes in Age Groups

The NIDD categorises intellectual disability using the International Statistical Classification of Diseases, 10th Revision, (ICD-10) criteria which describe the degree of disability as ‘mild’, ‘moderate’, ‘severe’ or ‘profound’ (Kelly et al., 2009). Comparable data are available from 2001 to 2013 when all three categories showed an increase, with the ‘moderate’ category accounting for 62.2% of the growth (increasing from 6,495 to 8,296). Over 45% of people on the NIDD had a moderate intellectual disability in 2013, whilst the smallest proportion of people had a severe/profound disability (21.5%). These trends were seen, by and large, throughout the country.

3.3.2 Use of day services

Counties containing the largest urban centres (in the east, south and west of the country) had the largest proportion of people using day services in 2013 including: Dublin (23%, n = 4,200 or a 235:1 ratio with the general population); Cork (11.5%, n = 2,092 / 187:1); Galway, (5.8%, n = 1,066 / 178:1); and Limerick, (5.2%, n = 945 / 154:1) (Figure 3.2). These were followed closely by the suburban county of Kildare with 901 individuals (4.9% / 167:1). The lowest numbers of people availing of day services were in Longford (1.0%, n =182 / 156:1) and Leitrim in the midlands and north-west of the country respectively (0.53%, n = 96 / 247:1) (Figure 3.2).

Interestingly, the ratio for the least populated county in Ireland (Leitrim), exceeds the most highly populated county of Dublin, suggesting that there are very few people with intellectual disabilities in this area availing of day services when compared to the general population. The neighbouring county (Sligo) had the lowest ratio in the country with only 95 people in the general population for every one person availing of intellectual disability day services. This pattern suggests a possible migration of people in need of services to larger urban centres where services are available (in this case from Leitrim to Sligo). This pattern was also seen in other rural counties (e.g. Meath, a neighbouring county of Dublin, which had the largest ratio of 256:1, suggesting a similar migration towards the nearest urban centre).

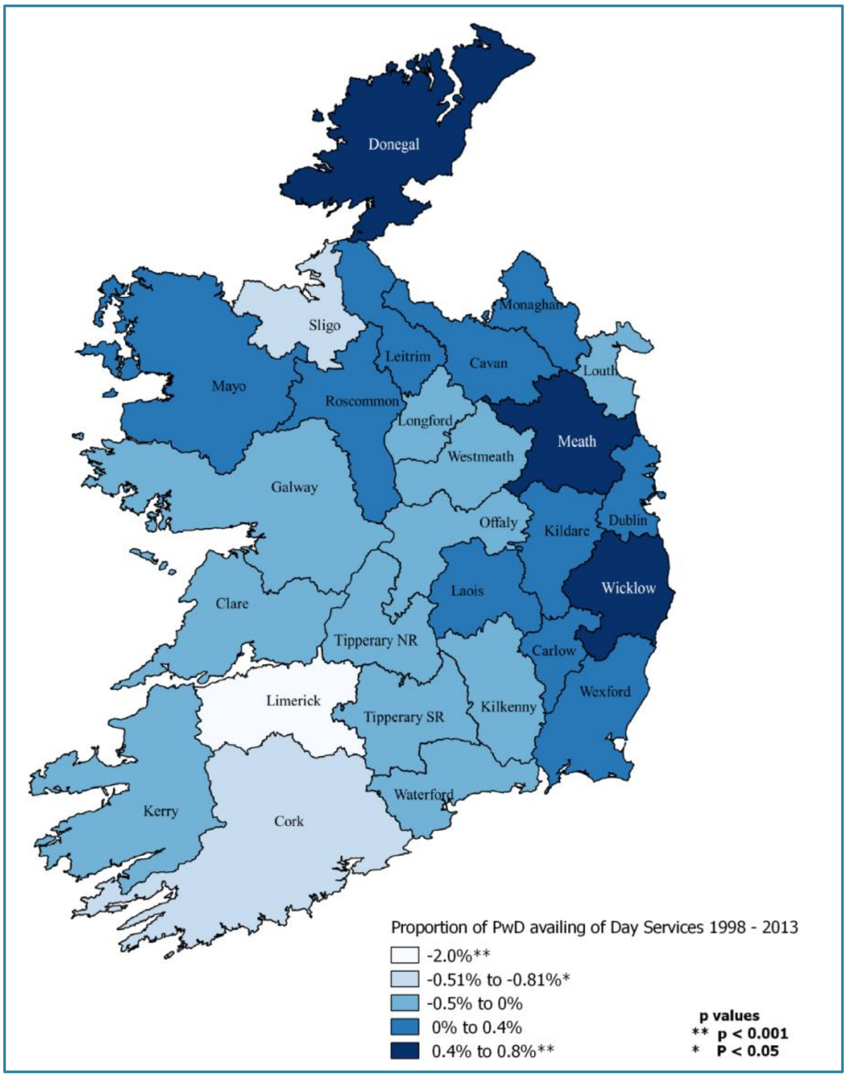


Figure 3.2 – Changing Trends in Uptake of Day Services

While the number of adults with intellectual disabilities availing of day services increased by over 20% from 14,861 to 18,249, a proportional decrease occurred when compared to the general adult population between 1998 and 2013 (0.58% to 0.53% ($p < 0.001$)). The ratio shifted from 172:1 in 1998 to 188:1 in 2013. At a county level, there was almost a 50:50 split between increases and decreases. Three groupings of counties experienced a statistically significant change in the proportion of people with an intellectual disability availing of day services when compared to all people with an intellectual disability on the national database. County Limerick experienced the largest change in the proportion of people availing of day services with a drop of -2.03% ($p < 0.001$). The southern and western regions of Cork and Sligo also experienced a significant decrease (-0.81%; -0.51% $p < 0.05$). Three counties experienced a significant increase: Donegal, 0.74%; Meath, 0.79%; and Wicklow, 0.80% ($p < 0.001$). No other statistically significant changes were observed (Figure 3.2).

3.3.3 Type of day service

In all, 31 distinct types of day services were recorded, 23 (74%) of which have been in place since 1998; the remaining were added to the data collection form over the 15 year period in response to changing demands. The most popular, according to uptake figures, were 'Sheltered work centres' and 'Activation centres' (Table 3.1) (62% in 1998; 55% in 2013). In 1998, these two types of provision accounted for 4,724 (32%) and 4,491 (30%) respectively of all services. Over the 15 year period, 'Sheltered work centres' declined, almost in parallel, by 16.5%, while 'Activation centres' increased by 10%, to account for 40.2% (Figure 3.3(a) – top right quadrant). Sheltered work centres often consist of contract work for which trainees are paid a minimal wage with an accompanying risk of exploitation by service providers.

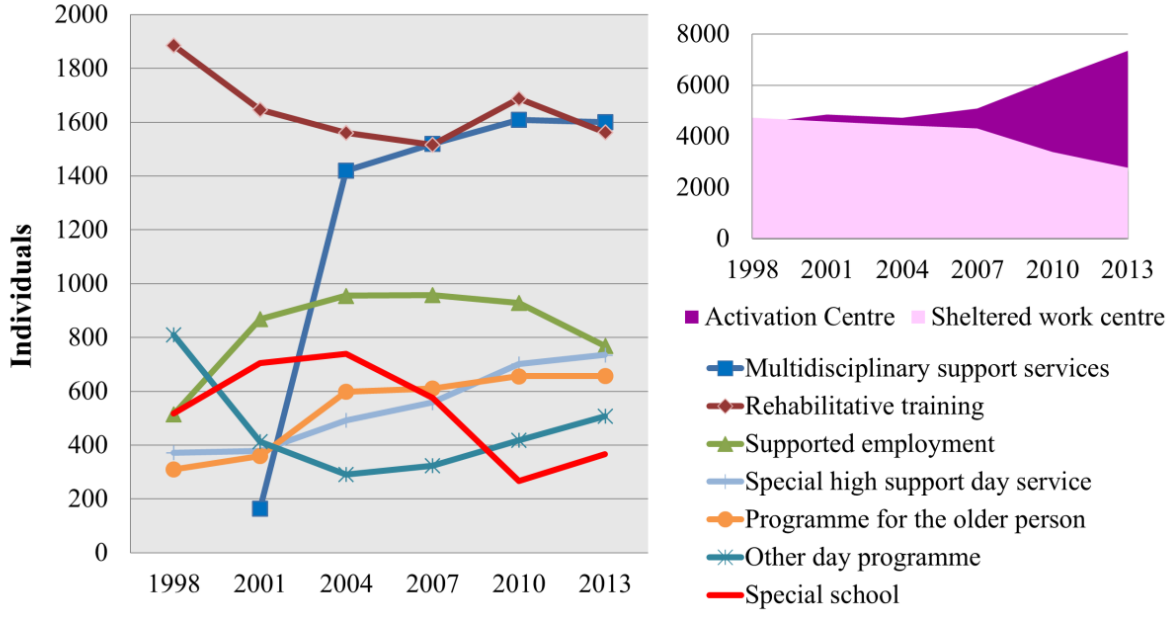
Table 3.1 – Description of Day Services

Sheltered work centres are designed for persons who due to health, physical stamina, or level of intellectual disability are unable to take up open, supported, or sheltered employment. It may include long-term training schemes. The individual does not receive pay or pay PRSI, but may receive nominal payment for work done. The person is allowed to work at his or her own pace, and productivity may be low. Sheltered work may be conducive to improving the person's social, emotional and developmental abilities and may form only part of their day services.
Rehabilitative training focuses on the development of an individual's personal core competencies, life skills, social skills, and basic work skills to a level consistent with that individual's capacities
Activation Centres are day centres for adults who need ongoing care, training, and development in a wide range of skills. Because of the nature of their disabilities, many of these people may not be capable of participating in open or sheltered employment or in special vocational training programmes

Table 3.1 continued…

Multi-disciplinary services are provided by a team of professionals who work together to provide an integrated service to a person with intellectual disability. The team will usually consist of a social worker, physiotherapist, speech and language therapist, nurse, psychologist and outreach teacher (who supports the classroom teacher and provides a link between the service provider and the family). Other health care professionals may be involved in the team as and when required.
Special high support day service is a specially designed day programme for persons who require a higher than usual staff ratio to address specific needs such as challenging behaviour, dual diagnosis or multiple disability. Where the staff ratio is greater than one to one, the service would be more appropriately described as an intensive service.
Programme for the older person is a specialised programme designed to meet the needs of individuals who present with definitive signs of ageing, for example, dementia, Alzheimer's Disease.
Supported employment is employment in the same work environment as the general population. The support may be of a financial nature, and/or through the provision of a support person (co-worker or health agency staff member).
Special School is education provided for children with an intellectual disability by the Department of Education and Science in a special school which is run solely for children with intellectual disability.

An additional seven day services attracted 500 or more people at some point over the 15 year period (Figure 3.3(a)). Of these, 'rehabilitative training' was the most popular in 1998 (12.7%, n = 1,886), although this showed a steady decline over a decade before peaking again in 2010, followed by another decline to 8.6 % (n = 1,562) in 2013. Such rehabilitative training comprises mostly time-limited programmes aimed at school leavers and funded by European Social Fund monies. This service appears to have been largely replaced by 'Multidisciplinary support services' (which is categorised as a day service within the NIDD) which rose from 1.1% (n =163) in 2001 to 8.8% (n = 1,601) in 2013. 'Special high support day services' and 'Programme for the older person' (Table 3.1) also increased steadily over the 15 year period, peaking at 4.0% (n = 735) and 3.6% (n = 657) respectively. An overall reduction in uptake was experienced in ‘Other day programme’ (5.4% to 2.8%); and ‘Special school’ (3.5% to 2.0%). ‘Supported employment’ experienced a general increase (3.5% to 4.2%) but the pattern fluctuated (Figure 3.3(a)).



3.3(a) – Uptake of day services

3.3(b) – Demand for services in future

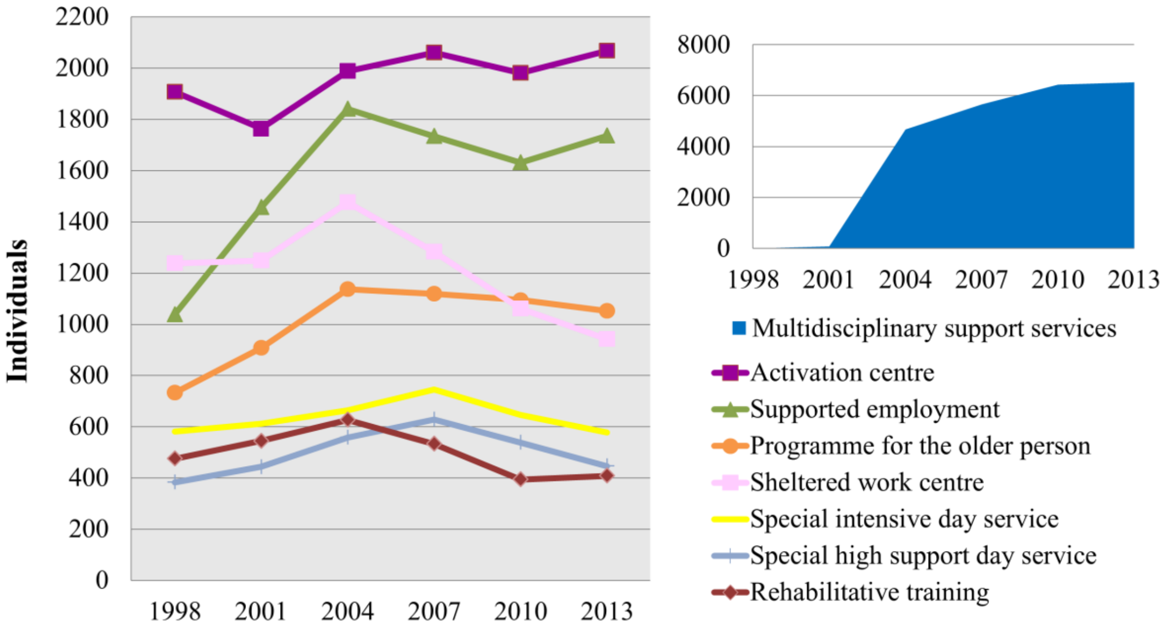


Figure 3.3 - Change in Uptake / Demand in Day Services over 15 year period

A number of services experienced similar trends (when comparing uptake in relation to demand, Figure 3.3). However, these did not necessarily mean that needs were being met. For example, ‘Multidisciplinary support services’ showed a similar upward trend while actual numbers were considerably different, with uptake well below demand. ‘Rehabilitative training’ also experienced a similar downward trend, dropping by 4% for uptake and demand. However, almost one in ten people (8.6%, n=1562) were availing of the service in 2013 (Figure 3.3(a)) whereas fewer than three per cent (2.7%, n=409)) were demanding the service in 2013 (Figure 3.3(b)). Furthermore, uptake and demand were sometimes on opposite trajectories. ‘Special high support day services’, for example, demonstrated a similar upward trend until 2007 when demand started to decline, falling from 4.2% (n = 628) to 2.9% (n = 447). Uptake on the other hand continued to increase.

3.3.4 Personal Care Plan

Personal care plan (PCP) data were available from 2004 onwards. During the next decade, those in receipt of a PCP more than doubled, increasing by over 40% from 37.1% (n=6,237) to 78.7% (n=14,374). Figure 3.4 demonstrates how each county in Ireland was performing in terms of provision of PCPs in 2004 and again in 2013, with the change highlighted over the ten year period. The more rural counties (e.g. Cavan, Offaly, Longford, Meath, Mayo, Kerry and Leitrim) were below the 25th percentile of people in receipt of a PCP in 2004. Of these, Leitrim and Longford (moving north-west of the country) remained below the 25th percentile in 2013, while Meath reached the 75th percentile in 2013, with Cavan approaching same. By contrast, three counties (Kilkenny, Dublin and Louth) dropped below the 75th percentile between 2004 and 2013. Only two counties remained within the 75th percentile for both periods (Monaghan and Wicklow).

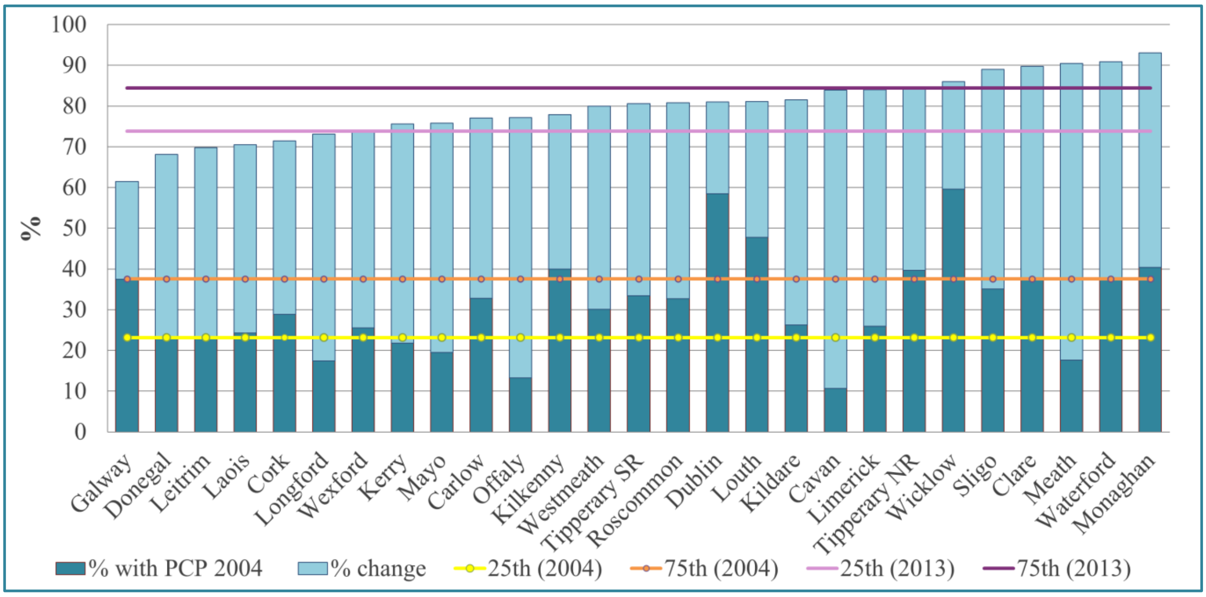


Figure 3.4 – Percentage of people with Person-centred Plan in 2013

3.4 DISCUSSION

This study was undertaken to map the changing trends - during a 15-year period - of day services for people with intellectual disabilities in Ireland in order to: gain insights into the service response to policy recommendations, particularly around personalised supports (facilitated partly by individualised funding); and to determine (insofar as possible) future service needs based on emerging demographic trends.

By and large, day service trends in Ireland suggest little change to the limited menu of services that dictate the lifestyles of people with disabilities, nor do they suggest a move away from centre-based activities. When examining the two most popular day services – use of the more traditional sheltered workshops declined over time in contrast to an increase in the use of activation centres. The lack of clear definitions around 'activation programmes' and the co-facilitation of both activities within the same service, often in the same premises, would suggest that this change was perhaps a re-branding exercise, whereby service providers were seen to make changes in line with policy goals, but with little changing in reality; indeed, evidence suggests that a similar situation has materialised in Australia (Chapman & Soldatic, 2010).

Regardless of the labels used, group-orientated activities within centres continue, which many would argue is exploitative, closed, paternalistic and preventive of proper community integration (Kirby 1986; Murphy and Rogan 1995; Parent et al. 1989; Neufeldt 1990; Schuster 1990 as cited in Lemon & Lemon, 2003). Others claim, by contrast, that rather than simply being physically integrated within the general community, service provision should be concerned with connectedness and that such connectedness is actually more achievable within a community of people with an intellectual disability (Cummins & Lau, 2003). Nonetheless, this study suggests that, whilst a limited number of new services were introduced during the latter part of the 15-year period, the demand for services was generally not met by service providers; in addition, the places provided and the subsequent uptake, were inconsistent with the pattern of demand for supports such as 'special high support day services', 'supported employment', and 'rehabilitative training'.

On a more positive note, the changes that have occurred in Ireland since the 1950s reflect, to some extent, the general paradigm-shift experienced internationally in the delivery of intellectual disability services (Bigby & Frawley, 2010). Taylor and Taylor (2013) describe this shift as an evolution from formal and professionally- led treatment interventions toward an emphasis on the individual and individualised support. For Ireland, person-centred planning remains the most innovative approach for achieving current policy goals related to individualisation of services (HSE, 2012b). This is reflected in the considerable increase in those with a person-centred plan during the 15-year period, indicating progress. Claes et al (2010), in their systematic review of person-centred planning, report a moderately positive impact on personal outcomes, whilst also acknowledging implementation weaknesses, specifically the lack of external systematic support, such as prospective employers, limitation in residential opportunities, overcrowding in available services, and the limited natural supports within the community. These kinds of challenges in translating policy into action are consistent with the UK experience of disability services and of the wider health and social care services (Dowling et al., 2006). They also reflect the Irish experience where views on effectiveness have been mixed, whilst almost 3,000 of those who use day services have no such individualised plans in place (HSE, 2012b).

It is difficult to make international comparisons in relation to degree of disability due to varying definitions and categorisations (McDermott & Turk, 2011; Mont, 2007). However, the proportion of people with moderate disabilities in Ireland is considerably higher than that seen in other countries such as Canada and Western Australia where around 25% of people have a moderate disability (Bittles et al., 2002; Statistics Canada, 2004). In terms of age, the youngest cohort of people in the current study appears to be deviating from the expected population trends. While it is unlikely that the proportion of people being diagnosed with an intellectual disability has decreased significantly, this would suggest that fewer young people are availing of day services. A recent systematic review by Foley, Dyke, Girdler, Bourke and Leonard (2012) concluded that changes to policy and legislation have had very little effect on improving the experiences of school leavers with intellectual disabilities. The same is true for transition programmes and the development of resources despite a number of recommendations to the contrary (Hay & Winn, 2009). However, Foley et al (2012) acknowledge that there are major gaps and weaknesses in the literature; people with disabilities themselves have rarely been involved in the research and when they have, the focus has been on those with mild intellectual disabilities. Research identified in this review highlights a need for service providers to understand the belief systems of families which, in turn, is key to the development and implementation of effective services across the world (King, Currie, Smith, Servais, & McDougall, 2008; Schneider, Wedgewood, Llewellyn, & McConnell, 2006).

Perhaps the overall trends in Ireland suggest that people are ‘voting with their feet’, by avoiding services that may not meet their needs, as seen with residential settings in the past (Kinsella, 1993). Alternatively, perhaps this cohort of people, the first to have attended mainstream second level education, have already attained the life skills being offered in traditional programmes. For example, some evidence suggests that a person’s capacity to manage activities of daily living is the best predictor of future capacity for work or alternatively, the need for transition-to-work programmes (Eagar et al., 2006).

The changing geographical patterns in the uptake of day services are also notable. Although the ratios observed suggest a possible urban migration of people wishing to avail of day services, the 15 year trends suggest otherwise. Aside from the capital, Dublin, which did not experience a significant change in the proportion of people availing of day services - an urban/rural divide is evident. For example, the county of Limerick (with the third largest city in Ireland) experienced the biggest decrease nationally. This was followed by county Cork, with the second largest city. Sligo, the largest town in the western province, also experienced a significant decrease (CSO, 2012a). Conversely, Donegal, which is one of the most geographically isolated and poorest counties in Ireland, had one of the highest increases in the proportion of people availing of day services. This was followed by two more rural, although considerably less isolated, counties of Meath and Wicklow in the east of the country. This trend is unusual considering that 62% of Ireland is now urbanised; in fact, the urban population has increased by 10.6% when compared to a rural growth of 4.6% between 2006 and 2011 (CSO, 2012b). International evidence is mixed on the impact of such urban/rural divides. For example, Gething (1997) argues that people with disabilities living in rural areas are doubly disadvantaged across a wide spectrum of areas; conversely, Nicholson and Cooper (2013) report better opportunities and less deprivation for rural dwellers when compared to urbanites. In the case of Ireland, these patterns of increased use in rural areas may point toward the lack of alternative (and more innovative) forms of service provision in more isolated areas, but a need for further research is indicated.

Finally, the findings show that a disproportionate and growing amount of men avail of day services when compared to the expected general population. A similar trend is being experienced in the United States where, according to statistics from the Employment and Disability Institute (2015), the proportion of women with cognitive disabilities exceeded men significantly in 2008 (2.42% female vs. 2.40% male ($p < 0.001$)) but in 2012, the trend was reversed in favour of men (2.44% female vs. 2.49% male ($p < 0.001$)). Higher rates of intellectual disabilities amongst men have also been seen in population-based figures from Western Australia (Bittles et al., 2002) and for people with learning and developmental disabilities in Canada (Statistics Canada, 2004). Interestingly however, previous studies in Ireland have shown no differences in lifespan between men and women with an intellectual disability, while Australian and Finnish studies suggest a lower life expectancy for men with intellectual disabilities (Bittles et al., 2002; Lavin, McGuire, & Hogan, 2006; Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000). Furthermore, life expectancy in one study diminished as degree of disability increased, while people with mild intellectual disabilities experienced similar life expectancies as the general population (Patja et al., 2000).

3.4.1 Study limitations

A potential limitation of this study relates to registration on the NIDD, which is voluntary whilst data are only captured for people who avail of specialised services. Therefore, the database may not capture *all* people with intellectual disabilities living in Ireland. This may be particularly true for those with a mild intellectual disability, since they tend to use more mainstream services and activities. Nonetheless, the database contains the most accurate data available for people with an intellectual disability in Ireland. Furthermore, coverage and comprehensiveness are considered very good since service providers themselves return the information (Kelly et al., 2009).

Another potential limitation relates to the fact that over half of data pertaining to ‘future demand for residential services’ was found to be inaccurate on the national database (Dodd et al., 2010). Although Dodd et al did not focus on day services in their audit, the authors of this study acknowledge the potential for similar inaccuracies regarding ‘future demand for day services’ data. Furthermore, the database only records needs in terms of existing service options. For these reasons, Dodd et al (2010) argue that the NIDD is no longer useful in providing information for the kind of planning and development of intellectual disabilities that would place the sector ahead of other care groups in terms of competing for limited resources. These authors further contend that low user involvement in the completion of NIDD data forms is not person-centred, nor does it reflect the ethos of policy recommendations for individualised service delivery. The findings of this study would support this view.

3.5 CONCLUSION

As individualisation continues to be at the forefront of innovative change in disability services, a number of key lessons may be identified from the current study. National databases, such as the NIDD, must conduct regular reviews and updating of data capture forms to ensure that their remit is broad enough to include new and innovative models of service delivery. Any emerging urban/rural divides need to be monitored closely and further large-scale studies are required to clarify the experiences of rural dwellers in this respect. Service developments in Ireland and in other developed countries must also be responsive to these kinds of trends within their individual jurisdictions and not become overly focused on urban centres. It is also important that future services incorporate appropriate gender-focused activities because, in the case of the current study, the proportion of men availing of services continue to grow; it is important, therefore, that, for example, 'Arts and Crafts' - historically the most popular activity in the UK - is meeting their needs (Felce et al., 1999). This may be facilitated by ensuring that individualised developments are led by the 'voices' of individuals with a disability and their natural supports. However, this must move beyond the simple provision of personal-care-plans, to ensure that the resources and skills are in place to realise them.

A lack of skills has been reported elsewhere as one of the challenges associated with self-directed support, which is compounded by a low rate of training beyond a general skillset (Bogenschutz, Hewitt, Hall-Lande, & LaLiberte, 2010). In Ireland, a non-profit funding organisation called Genio (whose mission is to develop, test, and scale, cost-effective ways of supporting people who are disadvantaged to live full lives in their communities), has already provided 'Endeavour for Excellence' training, based on the 'Social Role Valorisation' model. This programme was delivered to front-line personnel from approximately 50 service providing organisations over an 8-month period (Genio, 2016). Similar educational programmes could be incorporated into essential staff training both in Ireland and elsewhere.

Finally more in-depth research should be conducted on younger people with intellectual disabilities (e.g. 18–25 year-olds), to determine what services are being used by those who are no longer *formally* reporting service utilisation. Perhaps they are involved in innovative activities such as the personal budgeting initiatives that are currently being evaluated (Fleming, McGilloway, & Barry, 2015a) and which are omitted from the national database; more worryingly, this cohort may not be in receipt of any support and are therefore, invisible within the current service delivery system.

The findings of this study suggest that government funding, both in Ireland and other countries with similar patterns of service limitations (e.g. Austria, Finland, France, Romania and Bulgaria), should aim to promote individualised supports by redistributing funds from traditional, congregated service delivery to individualised models. Personalised budgeting has been at the forefront of change in this regard throughout Canada, the US, Australia and Britain, yet there is no mention of such initiatives on the Irish NIDD, despite specific policy recommendations to the contrary. The findings of our larger evaluation of individualised funding pilot schemes in Ireland should help to address some of the key issues (also commonly reported in other countries) related to resource allocation, operational processes, administration, governance, quality assurance, management and organisation. However, these should not hamper progress for the majority of people with intellectual disabilities; for instance, the smallest proportion of people in Ireland have a severe or profound disability - the group most likely to face challenges with self-directed support (Harkes, Brown, & Horsburgh, 2014). In addition, the learning from the on-the-ground implementation of such new services and initiatives should help to inform future policy goals in order to take account of the 'lived experience' and everyday lives of people with disabilities (Graham, 2010). Without widespread implementation, however, these learnings are not possible.

CHAPTER FOUR: STUDY TWO

THE SUCCESSES AND CHALLENGES OF IMPLEMENTING INDIVIDUALISED FUNDING AND SUPPORTS FOR DISABLED PEOPLE: AN IRISH PERSPECTIVE

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ABSTRACT

‘Individualised funding’ which is rooted in the Independent Living Movement, has formed part of a global paradigm shift in support services for disabled people. Against the backdrop of international experience, a political system aligned with the UK and emergent critics of individualised funding, this paper presents findings from an evaluation of four pilot programmes in Ireland. Exemplified by independent-skills development and community integration, these initiatives have been welcomed as a progressive development beyond traditional service provision, with perceived improvements across a range of organisational, personal, health and social care domains. This paper explores the importance of ‘natural supports’ and how overly-protective behaviour may unintentionally act as a barrier to full implementation. The findings also indicate that unnecessarily complex systems can lead to individual burn-out. Furthermore, a national resource allocation system working in partnership with existing social care professionals and the wider community is recommended, as is learning from overly-simplified, group-based ideologies.

Keywords

Disability, individualised funding, self-directed support, circle of support, implementation, resource allocation system

4.1 INTRODUCTION

The development of individualised funding, person-centred plans and self-directed supports has been at the leading edge of a global paradigm shift within the disability sector. These all aim to place the disabled individual at the centre of the decision making process, recognising their strengths, preferences and aspirations. Thus, they are designed to empower individuals to shape public services including their social care and support, by allowing them to identify their needs, and to make choices about how and when they are supported (Carr, 2010).

Individualised funding is an umbrella term for a wide range of international descriptors that, based on country specific cultural and political contexts, have emerged to describe various processes of personalised funding and the attendant supports required, for disabled individuals (or their network of support). Various initiatives can be found, for example, in Canada, the US, the UK, Australia, Germany, the Netherlands, Finland and Sweden (Carr & Robbins, 2009; Clevnert & Johansson, 2007; Eriksson, 2014; Laragy, Fisher, Purcal, & Jenkinson, 2015; J. Lord & Hutchison, 2003; Moseley, Gettings, & Cooper, 2005; Wiener, Tilly, & Evans Cuellar, 2003). There are several types of individualised funding, the most common of which, in the UK and Ireland, involve a direct payment or a brokerage service. A direct payment, as its name suggests, involves funds being given directly to the disabled person, who then self-manages this money to meet their individual needs and life circumstances. 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). A brokerage model or 'managed' personal budget, on the other hand, provides for a similar amount of freedom for the disabled person 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 'Cash and Counselling' model is another example, found predominantly in the US, which allows the user the flexibility to choose between a self-managed account and a professionally managed/assisted account, thereby representing a combination of the direct payment and brokerage models (NRCPDS, 2014). In Western Australia a similar model called 'shared management' has also been developed and found to be well received by end users (Western Australia's Individualised Services, 2012). As the concept continues to grow throughout Europe, and indeed globally, the list of terms continue to proliferate accordingly (Fleming, 2016b).

Person-centred planning is generally utilised in individualised funding models and refers to a range of approaches used to individualise and organise supports for disabled people. It aims to enable individuals to lead the planning and development of collaborative supports that focus on community integration and participation while simultaneously building positive relationships, respect and skills (Claes et al., 2010; Dowling et al., 2006). Person-centred approaches were first highlighted in the work of Carl Rogers (1958), but their importance grew during the de-institutionalisation of disabled people in Canada and the US from the 1970s onwards (Dowling et al., 2006).

Individualised funding was developed to build the capacity of individuals, their families and communities and was made possible by a global shift towards self-determination and community involvement (J. Lord & Hutchison, 2003). This shift was rooted in the Independent Living Movement and the associated Independent Living Fund, whereby disabled people began to self-direct their support by hiring a personal assistant, thereby gaining more control over their lives and services (Fleming, Furlong, et al., 2016). While the first independent living movements were based in the US and Canada, the concept of an Independent Living Fund originated in the UK during the 1980s. However, during this time, only the more progressive authorities were providing the funding mechanisms for people to self-direct their lives. The campaign for legislative change to facilitate individualised funding, by UK-based authorities, was started in 1989 by the BCODP[10] Independent Living committee, which was formed in response to the broader European Network on Independent Living (ENIL). The direct payments Act 1996

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[10] British Council of Organisations of Disabled People

was subsequently implemented in 1997 as a continuation of the ground-breaking National Health Service and Community Care Act 1990 which emphasised individual need and the importance of disabled people living in their own homes (Evans, 2003).

Following this emergent global trend, a national consultation in the UK (Whittaker & McIntosh, 2000) concluded that, despite progress in de-institutionalisation and the large-scale movement of disabled people into the community, the vast majority still spent their time in congregated settings where their lifestyles were dictated by a menu of limited 'special' services. Subsequently, individualised funding was widely adopted throughout the UK, beyond those involved with the Independent Living Movement, with many positive outcomes reported (Duffy, 2012b; Glendinning et al., 2008; Rabiee et al., 2009). The UN Convention on the Right of Persons with Disabilities subsequently recognised individualised funding as one way to achieve self-determination, whilst many also acknowledged that it was only one way to achieve such goals (United Nations, 2006).

Not unexpectedly, there have also been some criticisms of individualised funding throughout the UK social care sector. For example, Peter Beresford, a leading social work academic, raised concerns from the outset about the lack of input from service users into the shaping of such initiatives and the dearth of evidence-based management plans for the transition from outdated 'one-size-fits-all' services toward the government's national implementation of individualised funding (Beresford, 2008). Indeed, Beresford continued to convey the suspicions of key stakeholders ('service users, practitioners and carers) that individualised funding would not close the gap between policy-based aspirations and the lived experience of those requiring supports (Beresford, 2009). Furthermore, he and a number of others (Pedlar & Hutchinson, 2000; Clare Ungerson, 1997) have argued that individualised funding is turning service users into consumers, thereby commodifying care and, in turn, directing large profits to service providers at the expense of quality for the end user (Beresford, 2014).

Others still have argued that perhaps UK evaluations are flawed in that they are geared toward a neo-liberal ideology based on consumerist notions of choice; indeed, a number of authors have suggested that focusing on the funding mechanism over-simplifies the factors that influence user control (Askheim, 2005; Slasberg & Beresford, 2015). Instead they argue that the key lessons drawn should have focused on the successes related to needs-based planning, carried out in a person-centred way - arguably the real triumph of individualised funding in the UK (Slasberg & Beresford, 2015).

Regardless of such criticism and related challenges facing the UK, Ireland seems set to follow suit due to growing public demand for individualised funding, based on policy recommendations and attendant government commitments (Department of the Taoiseach, 2011, 2016). Historically, Ireland is similar to the UK in terms of disability policy and practice, albeit generally lagging behind in terms of implementation. Large religious-run institutions dominated the landscape from the late 19th century. The Health Acts of 1953 and 1970 empowered the Department of Health to offer financial support to family and advocate-led organisations which eventually became the principal mechanism for providing activities, vocational training and sheltered work for disabled people. A segregated culture of 'specialised' services became embedded in service provision during the 1960s, with a range of specialised professions emerging to provide therapy and services to people with an intellectual impairment. A landmark Green Paper on Services for Disabled People (Department of Health & Social Welfare, 1984) was seen by many as the start of more progressive and inclusive policies in Ireland based on international best practice and promoting community integration of housing and services. The European Social Fund and consequently the European Regional Development Fund (1970 - present), enabled specialist infrastructures to be put in place in Ireland to provide vocational skills training. The UN Standard Rules on the Equalisation of Opportunity for the People with Disability (1993) critically influenced the development of the 'Commission on the Status of People with Disabilities' in the latter part of the same year - now the 'National Disability Authority' (NDA) (Fleming, McGilloway, & Barry, 2016a).

The NDA is an independent state body providing expert advice to the Irish government on disability policy and practice. It has commissioned and supported a number of key evidence-based policy documents, which have seen the disability sector in Ireland align itself more closely with international best practice, including the deinstitutionalisation of people with a wide range of disabling impairments (Fleming, McGilloway, et al., 2016a). This transition is, however, still ongoing with 3,200 people (7.3% of those registered with the national disability database) remaining in congregated settings in 2013 (HSE, 2014a), with many promoting individualised funding as a mechanism to accelerate the process. Advocacy groups in Ireland, on behalf of disabled people and their support networks, are demanding that the newly formed government (2016) live up to past and current commitments to implement policy-based recommendations for individualised funding. Indeed the current Minister of State for Disability has publically committed to the implementation of individualised budgets, with plans to assemble a taskforce to oversee implementation (Inclusion Ireland, 2016). Furthermore, the Value for Money and Policy Review of Disability Services in Ireland (2012) – which is currently used, by the aforementioned advocates and others, as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of ‘supports’ rather than ‘services’ to reflect the transition from an institutionalised to a personalised model. Notably, the report cautioned against a ‘drift’ towards individualised supports, and specifically recommended the piloting and testing of individualised funding prior to any full transition.

To this end, the NDA, whose research informed current policy recommendations, has also commissioned a body of research to explore and test the feasibility of four different resource allocation tools with the view to recommending the most appropriate system to facilitate national implementation in Ireland (NDA, 2015). To complement that body of work, this current study was undertaken as part of a larger multi-component international evaluation of individualised funding (Fleming, Furlong, et al., 2016; Fleming, McGilloway, et al., 2016a).

The objectives of the study were to assess if individualised funding was: (1) perceived to be effective at improving health and social care outcomes in Ireland; (2) acceptable and feasible within the Irish context; and (3) an appropriate mechanism for supporting disabled people to gain independence and self-determined lives, fully integrated within the community. Four individualised funding pilot initiatives, grant funded by an Irish NGO called Genio[11], were evaluated as part of this study. These pilots consisted of three brokerage and one direct payment model(s) and were based on international best practice and policy (Table 4.1).

4.2 METHODS

4.2.1 Participants and settings

A total of 24 interviews were conducted with 35 individual participants and in some cases, project participants and advocates were interviewed together (Table 4.1). Eight secondary data files pertaining to 9 individuals were also analysed. The largest proportion (45%) of individuals involved had some form of intellectual, physical or mental health impairment.

Through a process of purposive sampling, four organisations (cases) were invited, and subsequently consented, to participate in the research. Recruitment was facilitated by a staff member within each organisation who acted as gatekeeper, distributing an information pack (containing written invitations, information sheets, consent forms and participation forms) to prospective project participants and their advocates. Project participants were given the option to have an advocate present with them during the interview which took place either in their home or the offices of the host organisation.

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[11] A non-profit funding organisation whose mission is to develop, test, and scale, cost-effective ways of supporting people who are disadvantaged to live full lives in their communities. Currently Genio works to improve the lives of disabled people, people with mental health difficulties and dementia.

Table 4.1 - Profile of study sample

Study involved 44 individuals	Staff (12)		Project Participants (20)		Advocates (12)	
	Male	Female	Male	Female	Male	Female
Case Study 1 (CS1)	2	1	3	2	2	4
Case Study 2 (CS2)	1	1	4	3	0	2
Case Study 3 (CS3)	1	3	3	1	0	2
Case Study 4 (CS4)	1	2	1	3	0	2
Total n (%)	**5 (11%)**	**7 (16%)**	**11 (25%)**	**9 (20%)**	**2 (5%)**	**10 (23%)**

[CS1] Brokerage service supporting 11 individuals with a physical or intellectual impairment*
[CS2] Direct Payment service supporting 20 individuals with a physical or sensory impairment*
[CS3] Brokerage service supporting 5 individuals with an intellectual or mental health impairment*
[CS4] Brokerage service supporting 9 individuals an intellectual or developmental impairment*
*Services were not limited to these impairments but reflected majority of participating individuals

4.3 METHOD

The four individualised funding initiatives that were the focus of this study were at a very early stage of development and, as a result, only a small number of disabled people were involved in each of the initiatives. Additionally, little was known about the structures, processes, funding mechanisms, or successes and challenges underpinning the various initiatives. Therefore, an exploratory mixed methods approach was used and applied within a 'critical realism' framework (Gilson, 2012), including documentary analysis, in-depth interviews, secondary data analysis and a participatory workshop. A broader implementation science framework was also used to explore the various stages of the implementation process, namely: Exploration and Adoption; Programme Installation; Initial Implementation; Full operation; Innovation; and Sustainability (D. Fixsen et al., 2005). The study received ethical approval from the Social Research Ethics Subcommittee at Maynooth University.

A documentary analysis was initially carried out using a series of documents identified by the organisations as integral to the development and implementation of the projects. These included, amongst others: minutes of meetings; administrative forms; correspondence; annual reports; strategic documents and action plans; policies; contracts and agreements; person-centred plans and weekly schedules; presentations and other informational materials. These documents provided the researcher with important insights into key concepts to explore, such as sustainability, conflict of interest, and organisational change. This process also helped to inform, in part, the development of the interview schedules, separate versions of which were devised for staff and project participants. Interview schedules were adapted to explore emergent themes, an approach which worked well with the overall framework of critical realism.

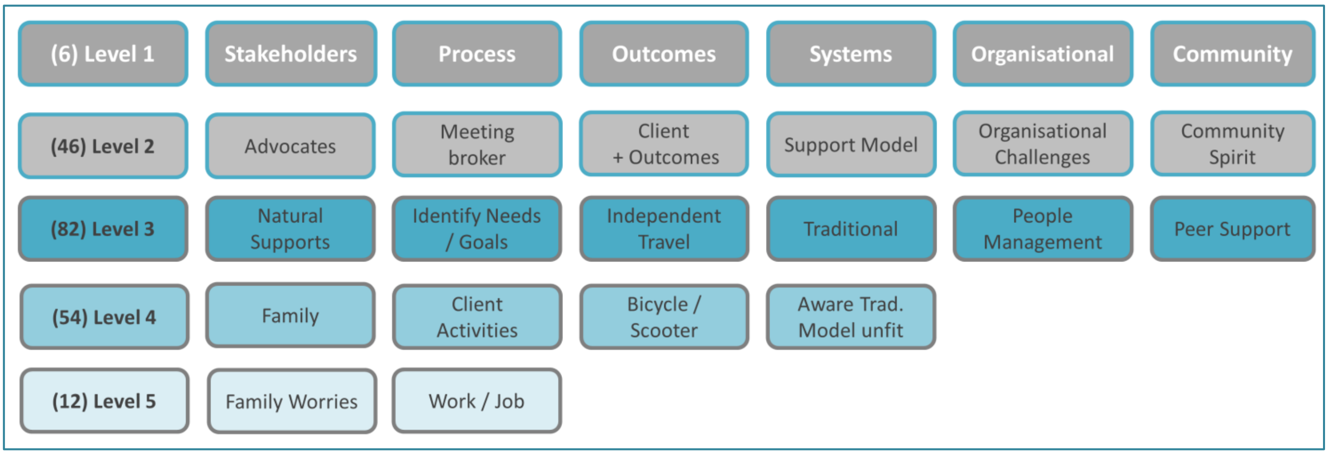
Interviews were audio recorded, with consent, using a digital dictaphone and lasted approximately one hour, on average. In addition to face-to-face interviews, secondary data were used for a small number of participants who were unavailable for interview; these data comprised publicly available online video files in which these individuals were discussing their experience of the individualised funding initiative. The content was prepared in advance and each video was of approximately 8 minutes' duration. While additional participants and staff members were available to be interviewed in most organisations, data collection ceased once saturation point was reached and no new themes were emerging. Primary and secondary data were transcribed verbatim and anonymised.

4.3.1 Analysis

A thematic analysis was used to identify recurring themes and was facilitated by the use of MAXQDA qualitative data analysis software. The interpretive coding (Mason, 2002) related to the ontological and epistemological perspective of Critical Realism. Thus, the aim was to generate theories that explain social phenomena and, in particular, to identify the mechanisms underpinning outcomes (Gilson, 2012). On completion of the analysis, the validity and acceptability of the findings was tested by soliciting feedback from key stakeholders as part of a participatory workshop involving disabled people, family members, advocates and staff members from the four individualised-funding initiatives. Such participatory approaches are recommended for population based research and in particular to improve the ethics of disability related research (Good, 2009).

4.4 FINDINGS

A total of six superordinate themes were identified, within which all other themes were subcategorised, with up to 5 levels of detail (from macro (Level 1) to micro (Level 5)) (Figure 4.1). A selection of the key themes and sub-themes is described here.



(6) Level 1	Stakeholders	Process	Outcomes	Systems	Organisational	Community
(46) Level 2	Advocates	Meeting broker	Client + Outcomes	Support Model	Organisational Challenges	Community Spirit
(82) Level 3	Natural Supports	Identify Needs / Goals	Independent Travel	Traditional	People Management	Peer Support
(54) Level 4	Family	Client Activities	Bicycle / Scooter	Aware Trad. Model unfit		
(12) Level 5	Family Worries	Work / Job				

Figure 4.1 - Example of coding structure (including number of codes per level)

In terms of stakeholders and outcomes (Figure 4.1), the findings clearly endorsed individualised funding as a means of securing improvements on a wide range of personal, health and social care domains. Disabled individuals perceived themselves as more successful, confident, adaptive, skilled, empowered, independent, in control and with a greater sense of purpose.

> *"I felt I got more confident than when I ended (traditional day service) you kind of meet the real me"* (Project Participant CS4)

> *"The new responsibilities, the new way of seeing yourself, the new position that you're occupying … and for a role in life, in the community, I think that's massive and it's changing perceptions as well from the outside"* (Project Participant CS2)

These successes were supported by increased opportunities to develop independent life skills, social and community supports and engagement with new opportunities and experiences. A change in the mind-set of paid support and natural supports (family, friends and wider community) enabled individuals to have a voice in the decision making process which allowed them to identify and trial various activities:

> *"…traditionally we've had a porridge society, a porridge menu, so we've fed porridge all our lives to individuals, then we give them an à la carte menu and we say: 'What do you want to do?' and they say: 'I'll have porridge', you know that's not choice… but by finding out from the individual what they actually want to be doing with their life, and funding them accordingly."* (Staff CS1)

The kind of attitudinal changes seen in family members of disabled individuals reflected a move from fear and anxiety related to their impairment toward an appreciation of their abilities, passions and interests. Individuals were, for the first time, afforded opportunities to move freely within the community, also facilitated by the option to purchase assistive technology which was not readily available through the traditional funding model.

> *"..but I say they [the participant's parents] were frightened… I'd say they would be concerned but … as the weeks went on … I'd say they weren't that worried at all. They knew I could handle it."* (Project participant CS1)

In terms of support processes and community (Figure 4.1), the availability of a 'circle of support' for project participants was an important factor in the successful implementation of individualised funding. This consisted of paid supports (e.g. broker, personal assistant, mentor, educators from community based courses) and natural supports (immediate and extended family members, neighbours, friends, colleagues, and community members). An organic/informal process was deemed most appropriate; that is, one that was needs-led, innovative and which harnessed community spirit and peer support as well as using existing (and often free) resources within the community.

> *"I couldn't have achieved these things without my company board and circle of support. These people are motivated, conscientious and willing to assist me in gaining more autonomy in my life."* (Project participant CS2)

Paid supports often played a crucial role in identifying and building this circle of support, particularly when none existed. As such, staff needed a broad set of skills and attributes including: a practical yet amenable and friendly approach; vision; innovation; personal experience of disability; and an active role in the community. In the 'Initial Implementation' of the new model of service delivery, paid supports were more actively involved in supporting individuals and their natural supports because they were better equipped with the tools and hands-on experience of the desk-based and field research which they had conducted in the earlier 'Exploration and Adoption' and 'Programme Installation' phases of the implementation process. This involved resource intensive visits to individualised projects in the UK and US to harness their experiences and to adapt relevant administrative materials. Having developed the process and the roles and responsibilities of paid and natural supports, staff members were then able to focus on the expansion and the sustainability of individualised funding.

One of the key challenges that emerged for the four initiatives was access to funding which was very much hampered by existing systems and organisational impediments.

> *"The biggest single problem, and the biggest single delay has been trying to get the funding, and that comes in under a couple of headings. One is decoupling funding from a block grant[12]…"* (Staff CS4)

Since there is currently no national resource allocation system in place, the pilot projects relied heavily on informal arrangements with disability managers on a person-by-person basis, often relying on pre-existing personal or organisational relationships. Furthermore, this often involved negotiating with another traditional service provider where individuals' funds were tied up, even if the individual was no longer availing of those services. This often led to overly-

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[12] Block funding to service providers whereby previous annual spend for a service provider is used to estimate the required funding for the upcoming year (NDA, 2011)

complex processes and attendant high levels of stress and frustration for individuals and families, who found it difficult to engage with the process at times.

> *"…a lot of these families are fragile enough and you can't have that process [being] so difficult that it breaks people…."* (Parent CS4)

Pilot project staff members were, however, successful in negotiating more formalised arrangements with the Health Service Executive[13] and were also able to reflect value for money, both real and conceptual.

> *"…our definition of value for money is going to be financial, but it's also going to incorporate the social, personal value, which is really important…a more holistic view…"* (Staff CS2)

Participants reported a new appreciation for money, money management and the benefits garnered from the flexibility of 'shopping around' or deciding how much and when support is needed, thereby serving as an incentive to motivate them to become more independent and to help make the funds go further to meet additional needs.

> *"…she's given a wee bit more freedom with money because, before this she didn't realise the value of money, she would go in and spend whatever, buy whatever, hand over money and not wait for her money, her pennies [change] back..." (Parent CS1)*

> *"No you have the PA [in traditional service] and that's it.... It can be, either / or [with individualised funding], it can be like - theres 6 hours of PA to help you prepare your meals and then get the [specialised chopping] board to help you do more and as you get more confident then 6 [PA hours] could become 5 ... It also creates a bit of independence for a person. Like knowing that you're not going to get everything you ask for. And you're going to have to take out your finger and do a bit yourself*" (Project participant CS1)

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[13] Health Service Executive (HSE) provides all of Ireland's public health services in hospitals and communities.

The challenge of releasing funds, however, was further compounded by organisational disengagement at a local level where the shift in power to individuals and families was met with some suspicion.

> *"You need the flexibility from the funding streams ... and my big concern for the budget is ... I think it's a cheap way of you know dealing with [individuals], 'There you are, there's your 10 grand, there's your 20 grand, now you're finished with the government for the rest of your life almost'. And that's not good enough either"* (Staff CS3)

A source of greater concern perhaps, at national level, was the perceived view of senior staff from within the Health Service Executive and State ministers who, according to some participants had distanced themselves from discussions related to national roll-out. This had a demotivating and demoralising knock-on effect on project staff.

> *"[The senior health manager said]...it won't be here for another four or five years, and I said: 'Personalised payments? They'll be here long before that', and she says: 'No it wouldn't' ... When you've got somebody in a position like that there coming out with that...you kind of think: 'Why bother?'"* (Staff CS1)

Another complex challenge related to the tendency of family members to be overprotective, largely out of a fear and anxiety for their family member and disillusionment, to some extent, with the health and social care system. In parallel there was a fear of losing the security of long-standing traditional service provision or the potential for social isolation once separated from these congregated settings. This challenge was identified by individuals, staff and also family members themselves and appeared to be rooted in traditional and paternalistic service provision which reportedly reinforced individuals' impairment, rather than enhanced their abilities.

> *"...parental interference and control. So that was a challenge. So right down to, let's say, the individual would have liked to experience independent living, even respite... but the parent wouldn't let go..."* (Staff member CS1)

> *"…you can build up your responsibility that…the child can do nothing without you, … and it gives you an excuse for maybe not doing a lot of things yourself."* (Parent CS1)

Furthermore families felt overburdened with administrative tasks, had a tendency to be suspicious of certain tools or terminology, such as person-centred plans, since they had witnessed such initiatives failing in the past. Unchecked, these potential deterrents could lead to burn-out or disengagement with the new model.

> *"…I've seen it within the PCP process, not here, whereby people have just duplicated what's gone on six months ago, or three months ago, and that's nonsense…"* (Parent CS1)

For project staff, the need to manage family cynicism while moving forward with the new model was also challenging. This required careful planning, time and people management skills and highlights a clear need for training for all support network members, paid and unpaid.

4.5 DISCUSSION

The findings from this study reflect a perceived improvement in a range of personal, health and social care domains. The new system was reported to be acceptable, whilst also representing an improvement on the traditional services to which disabled individuals were previously accustomed. The organisations implementing the initiatives also experienced a number of benefits including: a perceived sense of accomplishment, paving the way for future generations; progress in de-bundling money from the block grant; a sense of freedom from the restrictions imposed by the Health Service Executive; and a more enabling work culture which led to greater commitment and enthusiasm from project staff and participants alike.

Participants also reported a new appreciation for the meaning and value of money - arising from their new experiences, having 'shopped around' to seek out the 'cheapest' option, in an effort to make savings and put cash back into their service fund. These tangible monetary observations ranged from cost neutrality to considerable savings. Similar findings have been reported in Wales (Stainton, Boyce, & Phillips, 2009) and more recently in a New Zealand study, which indicated that individualised funding can lead to significant cost reductions in the delivery of disability services over time (Field, 2015). In addition, there were considerable personal and social benefits. As expected with the implementation of pilot initiatives, some key challenges and lessons emerged, but these were, by and large, overcome by creative and innovative, individually tailored solutions. For example, in one instance, a mobility scooter was funded which, somewhat counterintuitively, falls outside the eligibility criteria within the traditional medicalised model, where a substantially more expensive electric wheelchair is the only option.

Collectively, the findings from the present study highlight several other potential barriers to success including: staff limitations in terms of time and knowledge acquisition; administrative burden for families; uncertainty around money allocation and sustainability; fear of losing traditional support if new models cease; family burn-out due to long history of fighting the system and overly complex processes related to the new model; time and effort required to build a 'circle of support' where none exists; and the potential for individuals to become disengaged with the process, or socially isolated due to lack of skills required to deal with their new life circumstances. With regard to the last of these, some would argue that community connectedness is easier to achieve within settings where people are grouped together based on similar impairments, rather than in the general community which can be difficult and stressful (Cummins & Lau, 2003). The evidence from this study, however, would suggest that the traditional congregated model of service provision has led to a lack of social awareness, skills and attributes - the very cause of stress and difficulties related to community integration.

Likewise, a recent study in Canada indicated many similar reasons for low uptake of its individualised funding scheme including: inadequate information delivery leading to a limited understanding of the new system; peer influences (i.e. following the crowd); a lack of staff training; fear of isolation; frustration with regard to the amount of paperwork involved; families risk-aversion and fear of losing security associated with traditional services; and a perception that the wider community was generally unwelcoming (Bahadshah et al., 2015). The last of these is interesting because it is at variance with the present study which found that the wider community in Ireland was not perceived to be 'unwelcoming', although personal safety fears were associated with unsupervised community interaction.

There is considerable scope to address these kinds of barriers through the continued development of systems in Ireland and similar countries (e.g. Finland) and regions therein (e.g. remote parts of Canada and Australia) which are in the early stages of implementing individualised funding schemes. A key message/lesson emerging from the current study (as in the work by Bahadshah et al (2015)) focuses on the need for information to alleviate fears/confusion and to be delivered in an accessible and transparent way. Information dissemination could start with the basics of how state funding mechanisms work within a country, how much is currently allocated per person, where this funding currently resides and how to access that funding, if at all possible. Our findings indicate that people have very little understanding of how money is allocated and the processes involved in gaining access to such support, whilst there is also a need to promote a greater sense of ownership of that process.

The findings from our study suggest that supporting individuals and their advocates to gain access to all available information will further promote a (necessary) shift in power from service provider to recipient; a resistance to this power shift was identified here as a potential barrier to successful implementation. For many countries, such as Ireland, national systems may not be in place and, therefore, early adopters must often find a temporary solution, usually with the help of an advocate who has pre-existing and trusted relationships with the health service. Once empowered with this information, individuals can then explore the options available to them and plan which model best meets their needs and how best to utilise the allocated funds in a positive and constructive manner.

The need for strong family/natural support was also identified within the current study where a lack of such support was seen to lead to participant drop-out or as a potential deterrent for organisations interested in facilitating individualised funding. Likewise, Curryer (2015) found that family members provided a fundamental source of practical and emotional support as well as a key role in the decision making process. Kyle, Chiapetta and Hannah (2015) further argue that such support is necessary for successful implementation, the lack of which was also seen as a challenge in Finland where, similar to Ireland, a history of institutionalisation has separated families from their disabled relatives (Rajalahti, 2015).

However, the lines between support and adverse interference are often blurred to the extent that some individuals may compromise to meet the wishes of their family (Curryer, 2015). In the current study, family interference, whilst clearly present in some cases, was often paternalistic, unintentional or even unrecognised. The impact of such anxiety-based control from families who feel responsible for the protection of their disabled family member – and especially where individual preferences do not align with family values or norms or involve some level of risk - has not yet been assessed (Curryer, Stancliffe, & Dew, 2015). Marshall (2015) also argues that advocates, paid and unpaid, must accept a degree of risk in favour of the individuals' perspective, albeit within the parameters of personal safety, even if this causes discomfort.

The above findings suggest a need for appropriate training for both paid and natural supports in order to facilitate a culture of equality, where everyone is a valued citizen and where disabled people are not expected to compromise. 'Social role valorisation' is one such model which has been found to increase the status of disabled people, whilst exploring and developing relationships that help these individuals to achieve their desired tasks and outcomes (Duffy, 2015; Peipman & Vermeij-Irvin, 2015). Such training can also overcome some of the other issues identified in this study and also during the early implementation phase in other jurisdictions including Scotland; these include: how and where to access proper support, advice and training; how to ensure flexibility to adapt to individual and changing needs; and how to carry out a person-centred assessment (Ridley & Jones, 2003).

The lack of a standardised national resource allocation system was identified in the current study as a key barrier for those attempting to implement individualised funding initiatives in Ireland. This was seen as impacting all stages of the implementation process including, in particular, sustainability and was compounded by a degree of resistance to organisational change both amongst practitioners and also managers within the national health service. This has also been found to pose a significant challenge for other countries in the early stages of individualised funding implementation (Rajalahti, 2015). Importantly however, countries with several decades of experience with individualised funding, such as Canada, Australia and the UK, have warned against over-emphasising the development of such systems as they can often divert attention away from the kinds of personal and social values that inspired individualised funding in the first place (Kendrick et al., 2015).

Rather than becoming entangled in the debates around the ‘best’ type of needs assessment to inform resource allocation systems (e.g. medicalised model of assessment versus the social model versus self-assessment), our evidence suggests that there is considerable scope to collaborate in partnership with social workers, who have the advantage of knowledge and experience. Assessors could share their skills and teach disabled individuals how to assess their needs, in a systematic and transparent way, whilst taking on board, the types of social and environmental barriers that need to be tackled in addition to other health care needs (Renshaw, 2008).

4.6 CONCLUSION

This study represents a valuable addition to the international literature and was based on a meticulously applied qualitative approach which involved a reasonable sample of disabled people, their advocates and staff at different stages of life and from a wide range of geographical and socio-demographic backgrounds. While not without its limitations (e.g. in terms of the small number and scale of the projects involved), the in-depth nature of the methodology, grounded in a framework of critical realism and guided by an implementation science framework, ensured robust findings.

Despite the political, procedural and cultural challenges and restrictions, the individualised funding model was considered to be feasible in Ireland, with perceived improvements across a range of domains for disabled people, their families, advocates and the organisations with whom they engaged. Whilst the study illuminates factors which facilitated the implementation of the four initiatives, it also highlights potential barriers to success. These provide important lessons not only within an Irish context, but also internationally for other countries that are in the early stages of implementation/change. For example, careful consideration and planning needs to be undertaken in order to guide the complex transition from traditional paternalistic settings to an independent, community-based life. Furthermore, remaining within the ‘easier’, one-size-fits-all, group-based settings is, arguably, no longer acceptable or appropriate.

The experience of countries which are at a more advanced stage with respect to the implementation of individualised funding, (e.g. Canada, the US, Australia, New Zealand and the UK), suggests that the development of robust and efficient systems should not detract from the personal, social and health gains possible from individualised funding. These values must guide all policy and practice decisions involving ongoing consultation with recipients of individualised funding. Additionally, information dissemination needs to be carefully planned and piloted with the target audience in order to address potentially low uptake due to knowledge gaps, confusion and concerns.

Advocates, whether paid or natural, should be offered training opportunities to obtain the theoretical and practical skills to deliver meaningful person-centred support. Service providers and advocates also need to actively control their urge to ‘protect’, thereby empowering individuals to take ownership over their individualised funding and the decisions associated with full active citizenship. Further research is needed to explore the complex and delicate balance between controlling this impulse whilst also identifying and supporting individuals who may be overwhelmed with the challenges associated with suddenly having choice and control, or those who need guidance to navigate their way through this new and often complex process.

CHAPTER FIVE: STUDY THREE

INDIVIDUALISED FUNDING INTERVENTIONS TO IMPROVE HEALTH AND SOCIAL CARE OUTCOMES FOR PEOPLE WITH A DISABILITY: A MIXED-METHODS SYSTEMATIC REVIEW

This is the submitted version of the following report: Fleming, P.[1], McGilloway, S[1]., Hernon, M.[2], Furlong, M.[1], O'Doherty, S. (RIP) [1], Keogh, F.[3], & Stainton, T[4]. (2017 – under review). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review[14], which was submitted to the Campbell Collaboration for review, on 14/09/2017.

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[14] Plain Language Summary was included in original submission to Campbell Collaboration. In addition, formatting has been changed to reflect thesis layout.

EXECUTIVE SUMMARY/ABSTRACT

Background

The World Health Organisation estimates that 15% of the world's population live with a disability and that this number will continue to grow into the future, but with the attendant challenge of increasing unmet need due to poor access to health and social care (WHO, 2013). Historically, the types of supports available to people with a disability were based on medical needs only. More recently, however, the importance of social care needs, such as keeping active and socialising, has been recognised (Malley et al., 2012). There is now an international policy imperative for people with a disability to live autonomous, self-determined lives whereby they are empowered and as independent as possible, choosing their supports and self-directing their lives (Perreault & Vallerand, 2007; Saebu et al., 2013).

One way to achieve self-determination is by means of a personal budget (United Nations, 2006). Personal budgets are just one example of many terms used to describe individualised funding – a mechanism to provide personalised and self-directed supports for people with a disability, which places them at the centre of decision-making around how and when they are supported (Carr, 2010). Individualised funding – which is rooted in the Independent Living Movement (Jon Glasby & Littlechild, 2009) - has evolved to take many forms. These include, for example, direct-payments, whereby funds are 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, 2014a). Alternatively, a microboard, brokerage model, or 'managed' personal budget provide a similar amount of freedom for the person with a disability, but an intermediary service assumes responsibility for administrative tasks, while sometimes also providing support, guidance and information to enable the person to successfully plan, arrange and manage their supports or care plans (Carr, 2010). Other types of models also exist, largely guided by country-specific contexts, such as social benefits systems.

The intervention

For the purposes of this review, the intervention included any form of individualised funding regardless of the name given, provided it met the following criteria: (1) it must be provided by the state as financial support for people with a lifelong 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 'intermediary' 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 individualised fund, in whatever way is feasible; and (5) the individualised fund 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.

Commentators have indicated that strategic and policy decisions appear to be evolving on the basis of locally sourced or anecdotal evidence, due mainly to a lack of high quality experimental studies in the area (Harkes et al., 2014; Webber et al., 2014). While previous literature reviews exist (Carter Anand et al., 2012; Webber et al., 2014), we are not aware of any systematic review that focuses on the effectiveness of individualised funding in relation to people with a disability of any kind. Given the new policy imperative around individualised funding and the growing pool of studies in this area, there is now a need for a systematic review of these models across a spectrum of disabilities, in order to assess their effectiveness in relation to health and social care outcomes.

Objectives

The objectives of this review are to: (1) examine the effectiveness of individualised funding interventions for adults with a lifelong 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 individualised funding, with a particular focus on the stage of 'initial implementation' as described by Fixsen and colleagues (D. Fixsen et al., 2005).

Search methods

In line with the study protocol (Fleming, Furlong, et al., 2016), ten academic databases and nine other grey literature databases/search engines were utilised. The terms used to customise the search string for specific databases were based on the 'population' and 'intervention' of interest. 'Disability' and all possible variations including mental health, disorders and autism was the first keyword. 'Budget' and all variations of same was the second keyword. Database specific conventions were followed to 'explode' or 'truncate' key terms as appropriate. A list of free-text terms which were identified in the literature supplemented the syntax developed. Study design and outcomes were not included as part of the search strategy as it was anticipated that this would potentially lead to the omission of relevant literature. Bibliographies from included and some excluded studies (e.g. literature reviews) were used to guide forward citation searching. Conference proceedings, manual browsing of key journals and other online materials guided hand-searching.

Selection criteria

The population of interest included: adults aged 18 years and over receiving a personal budget, with any form or level of lifelong disability (physical, sensory, intellectual or developmental disability, level of mental health problem, disorder or illness, or dementia), residing in any country and any type of residential setting (own home, group home, residential care setting, nursing home, hospital, institution). Studies in any language were included.

Minors and older people without a lifelong disability (i.e. no disability in 10 years prior to reaching the age of 65) were excluded, as were privately funded individualised funding interventions.

Data collection and analysis

Due to the very large search results (n = 82,274 after duplicates and non-relevant grey literature excluded), an extensive, thorough and transparent 'results refinement process' was developed in order to filter these results. Following this refinement process, a screening of studies, based on the inclusion/exclusion criteria, was undertaken in two stages. The first stage involved title and abstract screening; the second involved full text documents. Three independent researchers were involved at each stage. Risk of bias and quality of research was evaluated using a range of tools (depending on study design) by one reviewer (PF). Further quality screening took place, during full text screening, by two second reviewers (MH & SOD).

A very high level of heterogeneity was observed, mainly based on the use of inconsistent, unstandardised, and often unvalidated outcome measures as well as the selection of control groups. With regard to the latter, some control group participants were randomly assigned, some did not wish to leave traditional services, whilst others were on a waiting list to avail of individualised funding. Furthermore, the study designs were heavily influenced by country-specific, and changing economic and policy landscapes. Therefore, a narrative analysis of quantitative data was considered the approach which would best represent the results. Narrative systematic reviews serve several functions including reporting the effects of interventions and also the factors impacting their implementation (Popay et al., 2006). A meta-synthesis of qualitative data was undertaken to build upon the latter point, based on the experiences of intervention participants, in addition to outlining the key facilitators and challenges associated with implementation, from the perspective of multiple stakeholders. Key themes were identified, which were conceptually folded together across studies.

Results

Of the 82,274 potentially relevant titles originally identified, 7,158 were independently double screened based on ‘title / abstract’ and a subsequent 328 full-text articles were doubled screened. In total, 73 studies met the inclusion criteria and were included in the review, 66 (90%) of which were qualitative in nature.

Quantitative

Seven unique studies contained eligible quantitative data (including three mixed methods) and were included in the review, representing nineteen titles in total. One of the studies was an unpublished report (available online), while the remaining six were reported in both unpublished reports and published peer-reviewed journal articles. All studies were English language and the majority were based in the United States (n=5). One study was a ‘quasi-experimental controlled longitudinal survey’, three were ‘randomised, controlled cross-sectional surveys’ and three were ‘randomised controlled before and after studies’. A total of 4,834 adults were represented in the narrative synthesis, with a collective response rate of 73%. The risk of bias was high or unclear for majority of studies, while the quality rating was fair to good. Five studies reported one or both primary outcomes of interest.

Two of the four studies which reported quality of life outcomes showed positive effects for those receiving individualised funding (two showed no difference):

- Site 1 (I: 43.4 / C: 22.9, MD = 20.5 (p < 0.001)); Site 2 (I: 63.5 / C: 50.2, MD = 13.3 (p < 0.01)); and Site 3 (I: 37.5 / C: 21.0, MD = 16.5 (p < 0.001)) (Brown et al., 2007);
- (I: M = 10.12, SD = 6.93 / C: M = 13.28, SD = 7.37, MD = -3.16, (p <0.001) (95% CI: -4.65, -1.67)) (Woolham & Benton, 2013).

All five studies reporting client satisfaction showed positive effects for those receiving the intervention:

- (I: 61.4, : 9.7 / C: 52.1, SD = 10.9, MD = 9.3, (P < 0.001), (CI 95%: 4.80 – 13.80)) (Beatty, Richmond, Tepper, & DeJong, 1998);

- satisfaction with:
    - technical quality - (I: 20.90, SD = 3.31 / C: 20.07, SD = 3.82, MD = 0.83, ($p < 0.001$), (CI 95%: 0.41 – 1.25);
    - service impact - (I: 8.09, SD = 1.98 / C: 7.63, SD = 1.96, MD = 0.46, ($p < 0.001$), (CI 95%: 0.23 – 0.69));
    - general satisfaction (I: 9.06 , SD = 1.65 / C: 8.66, SD = 2.07, MD = 0.40, ($p < 0.001$), (CI 95%:0.18 – 0.62)); and
    - interpersonal manner (I: 7.45, SD = 1.80 / C: 6.43, SD = 1.92, MD = 1.02, ($p < 0.001$), (CI 95%: 0.80 – 1.24)) (Benjamin, Matthias, & Franke, 2000);
- satisfaction with:
    - caregiver help –
        - Site 1 (I: 90.4 / C: 64.0, MD = 26.4, ($p < 0.001$));
        - Site 2 (I: 85.4 / C: 70.9, MD = 14.5, ($p < 0.01$)); and
        - Site 3 (I: 84.4 / C: 66.0, MD = 18.4, ($p < 0.001$));
    - and overall care arrangements –
        - Site 1 (I: 71.0 / C: 41.9, MD = 29.2, ($p < 0.001$));
        - Site 2 (I: 68.2 / C: 48.0, MD = 20.2, ($p < 0.01$)); and
        - Site 3 (I: 51.9 / C: 35.0, MD = 16.9, ($p < 0.001$))(Brown et al., 2007);
- (I: M = 3.89, SD = 0.85 / C: M = 2.82, SD = 1.25, MD = 1.07, (CI 95%: 0.63 – 1.51) ($p < 0.001$)) (Caldwell, Heller, & Taylor, 2007);
- and (I: n = 478, C: n = 431, proportion satisfied I: 0.78, C: 0.70, $x^2 = 7.54$, ($p < 0.01$)) (Glendinning et al., 2008).

Secondary outcomes included physical functioning, costs and adverse effects. Only one study reported physical functioning, with no difference detected between intervention and control groups.

Two studies reported cost effectiveness data. One showed no difference between groups, while the other suggested that individualised funding was less cost-effective than traditional supports (in one of two measures). Personal Care / HCBS alone - (Arkansas I: M = 5,435 / C: M = 2,430, MD = 3,005, ($p < 0.001$), Florida I: M = 22,017 / C: M = 18,321, MD = 3,696, ($p < 0.001$), New Jersey I: M = 11,166, C: M = 9,220, MD = 1,946, ($p < 0.001$)) (Brown et al., 2007, Table V.1; Dale & Brown, 2005).

Five studies reported adverse effects with two reporting no difference between intervention and control. One study reported two measures of ‘unmet need’, with one favouring the control group (I: M = 5.07, SD = 1.54, C: M = 5.38, SD = 1.21, MD = -0.31, p < 0.001, (CI 95%: -0.48 - -0.14) (Benjamin et al., 2000), the second showing no difference. For the remaining two studies, those receiving individualised funding reported fewer:

- adverse effects: (I: M = 3.11, SD = 3.30 / C: M = 7, SD = 5.31, MD = -3.89, (p < 0.001), (CI 95%: -5.71 - -2.07)) (Caldwell et al., 2007); and
- unmet needs with daily living activities –
    - Site 1 (I: 25.8 / C: 41.0, MD = -15.2, (p < 0.01));
    - Site 2 (I: 26.7 / C: 33.8, MD = -7.1, (p < o.o5)); and
    - Site 3 (I: 46.1 / C: 54.5, MD = -8.4, (p < 0.05)) (Brown et al., 2007).

The remaining five measures of unmet need, in the last study, varied between study sites - some reporting no difference, whilst others favoured the intervention group.

Other relevant health and social care outcomes were also reported in three of the four quantitative studies. Safety / sense of security was the only outcome on which a significant difference was reported and in favour of the intervention group (I: M = 9.18, SD = 1.57, C: 8.96, SD = 1.65, MD = 0.22, p < 0.05 (CI 95%: 0.03 – 0.41)) (Benjamin et al., 2000).

Qualitative

Implementation facilitators

1) People with a disability and their carers/representatives consistently report many perceived benefits of individualised funding. This strongly suggests that implementation is well received and often advocated for, among people with a disability. Benefits that are particularly valued include: flexibility, improved self-image and self-belief; more value for money; community integration; freedom to choose ‘who supports you; ‘social opportunities’; and needs-led support.

2) There are many mechanisms of success discussed, including the importance of strong, trusting and collaborative relationships. These extend to both paid and unpaid individuals, often forming the person's network of support which, in turn, plays an integral role in facilitating processes such as information sourcing, staff recruitment, network building, and support with administrative and management tasks. Factors that strengthen these relationships include: financial recognition for family and friends, appropriate rates of pay, a shift in power from agencies to the individual or avoidance of paternalistic behaviour.

3) Implementation facilitators from the perspective of staff, include the involvement of local support organisations, and the availability of a network of support for the person with a disability. Timely relevant training for practitioners, coordinators and other frontline staff is also seen as an important facilitator, as are sufficient support and other human resources available to people with a disability, such as intermediary services, community integration and innovative/creative supporters.

Implementation challenges

1) Perceived challenges for participants include agency involvement and lack of trusting working-relationships due to previous negative experiences. Participants often experience long delays in accessing and receiving funds, which are compounded by overly complex, rigid, and bureaucratic assessment, administrative and review processes. A general lack of clarity (e.g. allowable budget use) and inconsistent approaches to delivery as well as unmet information needs are other major concerns, as are difficulties with finding and retaining suitable staff. Various internal factors (e.g. managing personal issues and negative emotions) and external factors (e.g. weak network of support) are mentioned as additional challenges to the process of implementation.

2) A number of barriers, whilst viewed as generally manageable in the short term, were considered potentially problematic in the longer term. These include: inaccurate or inaccessible information sometimes due to an unclear understanding of individualised funding (compounded

by an absence of practitioner training); cumbersome systems that duplicate work and are framed within the directive medical model (i.e. based on a perception that staff inappropriately focus on targets and costs rather than quality of support provided); and a lack of resources/available support, exacerbated by an inaccurate estimation of need and subsequent delay in reviewing /adjusting budgets. This, amongst other things, can lead to conflict and tensions in working relationships, which are also hampered by disabling practices (e.g. exclusion from decision-making). Lastly, financial hardship is commonly cited, with hidden costs or administrative charges widely identified as a source of considerable concern and stress for participants.

3) Other challenges to implementation, from the perspective of, or related to, staff/organisations include: risk aversion rooted in fears associated with perceived vulnerability of people with a disability and potential for abuse or exploitation; fear of misuse or fraud (by people with a disability); and concerns related to the long-term sustainability of individualised funding, the quality of available supports and the impact on the traditional service providers/workforce. Staff also highlight logistical challenges in accommodating a wide range of support needs in an individualised way including, for example, responding to individual expectations and socio-demographic differences.

Authors' conclusions

Due to the considerable and growing interest in individualised funding as a means to improve the lived experience of people with a disability and their wider network of support (paid and unpaid), this review provides a comprehensive synthesis of evidence for future governments, funders, and policy makers. Commentators have previously criticised governments for proceeding with individualised funding initiatives without carefully considering the evidence. This review, therefore, provides an up-to-date repository of such evidence, particularly for countries at the early stages of planning or implementation. Not only does it present the most robust effectiveness data available, but it also specifically highlights implementation successes and challenges.

The evidence suggests that practitioners and funders need to shift their focus from one of scepticism, often grounded in fears, to one of opportunity and enthusiasm. Many of the fears, such as fraud / misuse of funds, job losses, recipients flooding the system, are not based on evidence. Funders and practitioners should be guided by the many examples of good practice outlined in this review, whilst working collaboratively toward, and appreciating the consistently reported benefits of, individualised funding. Greater investment is needed in education and training in order to facilitate stakeholder buy-in and generate a better understanding of individualised funding and the philosophy and ethos and the associated mechanisms required for its successful implementation. Finally, policy makers need to be cognisant of the inevitable set-up and transitionary costs involved such as capital funding for education and training, as well as redevelopment of assessment, review and other governance systems. In order to facilitate this spending, policy need to be put in place to allow the release of funds from block grants, if implementation is to be cost-effective in the longer term.

This review clearly highlights and synthesises the extensive and rich qualitative evidence from studies conducted in many countries - across changing social, political, economic, social care and healthcare landscapes - and over a considerable period of time. It also points to the inherent difficulties associated with collecting quantitative data on complex social interventions of this nature, with a subsequent lack of robust effectiveness data. The complexities around set-up and attendant delays, highlighted in the qualitative data, suggest necessary changes in any future collection of quantitative outcomes. For example, future researchers should consider (resources permitting) conducting studies which incorporate longer follow-ups (minimum 9 months), and ideally at multiple time-points over a longer period of time. Finally, the authors of this review would encourage the adoption of mixed-methods approaches in further systematic reviews when assessing the effectiveness of complex 'real-world' interventions in the field of health and social care.

5.1 BACKGROUND

5.1.1 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 (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 (Patja et al., 2000).

The many different needs of people with a disability, learning difficulty or mental health problems tend to be met through a range of activities, which may be described, collectively, as 'social care'. These 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 all 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. While controlled motivation – when compared to amotivation - 'can lead to improvements, these are limited because individuals feel a 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 that have examined self-determination in a sample of people with a disability found similarly positive outcomes (Perreault & Vallerand, 2007; Saebu et al., 2013).

One way to achieve self-determination is by means of a personal budget (United Nations, 2006). Individualised funding is 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 are similar and are based on self-determination, choice and, very often, person centred planning. Thus, individualised funding aims 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 individualised funding 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 an intermediary 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, 2014a). 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 having been the driving force behind microboards in Canada, for example. A micro board is a small non-profit group of informal supports (family and friends) who assist persons with disabilities to develop individualised housing and support options (Malette, 1996). 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 microboard, brokerage model, or 'managed' personal budget, whilst it provides a similar amount of freedom (as a direct payment) for the person with a disability around choice and control of services utilised, it involves a third-party 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). A 'managed' personal budget tends to focus more on administration and financial management, with the budget held centrally by an organisation. This service is often referred to as a fiscal intermediary (Carter Anand et al., 2012). The tasks of a broker, on the other hand, 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, 2014b). 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 seeks 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 et al., 2015; Fleming, McGilloway, & Barry, 2015c). 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, McGilloway, et al., 2015c; John 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 intermediary models described above (NRCPDS, 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, the 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 (Glendinning & Kemp, 2006; C. 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 individualised funding 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, McGilloway, et al., 2015c). 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 individualised funding (Ellis, 2007). Another challenge for staff relates to risk management. A balancing act is required to facilitate positive risk-taking whilst ensuring that the individualised funding-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 (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 individualised funding. For example, in certain jurisdictions 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 focused 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 transitionary period which can present challenges for individuals and families, 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, McGilloway, et al., 2015c). 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, McGilloway, et al., 2016a). 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 sought to take such confounding factors into consideration, both in the inclusion/exclusion criteria and in the subgroup analysis.

5.1.2 The intervention

For the purposes of this review, the intervention included 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 the following terms: '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 lifelong physical, sensory, intellectual, developmental disability, mental health problem or dementia; (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 / intermediary' 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, 2014b); 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.

Individualised funding 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 increase due to greater self-determination, whilst the same is true for physical functioning which may improve due to better independent life skills (i.e. taking on more responsibilities such as shopping and household chores).

Many of these quality of life outcomes, if improved, could arguably generate cost benefits, although the evidence in this respect is very limited. The small pool of evidence would suggest that individualised funding can be cost effective, ranging from 7% to 16% in the US

(Conroy, Fullerton, Brown, & Garrow, 2002) and 30% to 40% in the UK (Zarb & Nadash, 1994). Conversely, one UK study suggested that individualised funding may not result in cost savings, but does represent value for money (John Glasby & Littlechild, 2002). Stainton, Boyce, and Phillips (2009) support these more conservative findings showing relative cost neutrality for individualised funding when compared to independent service providers; however, individualised funding was more cost effective than traditional in-house service provision. Furthermore the authors reported higher levels of user satisfaction for those availing of individualised funding, thereby highlighting the link between client satisfaction, quality of life and cost benefits.

5.1.3 Why it is important to do the review

The international move towards individualised funding 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 individualised funding, such as increased choice and control, a positive impact on quality of life (QoL), reduced service use and potential for cost effectiveness (Field, 2015; Webber et al., 2014). Thus, it is important to explore 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 individualised funding, it is intended that people with disabilities have more autonomy over their lives 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, individualised funding 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 (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 individualised funding 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 individualised funding. Studies include, but are not limited to: RCTs (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, Pearman, & Waters, 2010); and qualitative studies (Coyle, 2009; Homer & Gilder, 2008; Maglajlic, Brandon, & Given, 2000).

5.1.3.1 Prior Reviews

We are aware of only two reviews, to date, which have specifically examined individualised funding 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) (25 studies), 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 individualised funding. 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 individualised funding 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; 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).

5.1.3.2 Contribution of this Review

We are not aware of any systematic review that focuses on the effectiveness of individualised funding in relation to people with a disability of any kind, including mental health problems. Given the new policy imperative around individualised funding 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 was also included in order to capture these findings in an area that is relatively new. Due to the complex nature of implementing novel 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: (1) assesses the effectiveness of individualised funding interventions; (2) reports subgroup differences in order to explore how effects may differ by various client and intervention parameters; and (3) appraises and synthesises 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/individualised funding models to support greater choice and control by individuals in their daily lives.

5.2 OBJECTIVES

5.2.1 Objectives of the review

The objectives of this review are to: (1) examine the effectiveness of individualised funding interventions for adults with a lifelong 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 individualised funding, with a particular focus on the stage of 'initial implementation' as described by Fixsen and colleagues (D. Fixsen et al., 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 process, 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 encounter / 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 facilitated) 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 individualised funding initiatives for people with a disability or mental health problem?

- What is the economic impact of the intervention from both a service user and public service perspective?

5.3 METHODS

5.3.1 Criteria for considering studies for this review

5.3.1.1 Types of studies

Eligible study designs for questions relating to the effectiveness of the individualised funding intervention included 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 individualised funding 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) were considered in this part of the review. Randomised and non-randomised studies are reported separately. Single-case designs, pre-post studies without a control group, non-matched control groups, or groups matched in a post-hoc way after results were known, were excluded from the review.

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

5.3.1.2 Types of interventions

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

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 (NDA, 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.

Individualised funding interventions were excluded where the budget was provided to families, guardians/ other carers (only), or where the person with a disability did not have an active role in the decision making and planning process and could not exercise control over the use of funds. However, studies were included where an advocate was managing the funds after an individual assessment of need took place and provided that the funds were being used to meet the needs identified during the assessment.

A personal budget provided by the person's family or by another private means was not included, as this review focuses on use of public funds for people with a disability. Furthermore, private sources of funding introduce confounding factors which would lead to uncontrollable bias.

5.3.1.3 Types of participants

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
- Older people (>= 65) who have a disability, but where it was not present for at least ten years of their working-adult life. Such disabilities would generally be age-related, such as frailty or difficulty with completing Activities of Daily Living, and are not the focus of this review
- Privately funded individualised funding interventions

5.3.1.4 Types of outcome measures

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) (M. J. 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).

- **Costs 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 (e.g. 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 Data

- For the qualitative synthesis, outcomes or phenomena of interest involved 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.

5.3.1.5 Duration of follow-up

The intervention should be in place for at least 6 months before follow-up. This does not apply in the case of qualitative studies.

5.3.2 Search methods for identification of 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, while several search retrieval specialists provided recommendations during the peer-reviewing process (of the study protocol). Padraic Fleming, the lead author, conducted the searches once the protocol had been peer-reviewed and approved by Campbell Collaboration. The searches were conducted during the period 19th February and 9th March 2016. At the end of the screening process, key journals were searched using key-terms up to the end of January 2017. Studies in any language and from any country were included, provided the abstract was in English.

Searches were completed, as per protocol with a number of minor additions. In some cases the search string could be copied and pasted directly from the protocol, whilst other databases required the search string to be manually populated. As recommended by Higgins and Green (2011), the search strategy is reported in Appendix 2.1, with any changes to protocol highlighted in bold text. The search strategy is reported (exactly) for each database utilised. This ensures that all searches are reproducible. Furthermore, details of additional grey literature databases are included (highlighted in bold), as recommended by Campbell Collaboration information retrieval specialists.

5.3.2.1 Electronic searches

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

The follow databases / search engines were searched:

1. CINAHL (Cumulative Index of Nursing and Allied Health Literature)
2. EMBASE
3. Medline First Search
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
16. Australian Policy Online
17. VHL Regional Portal – Latin America database
18. NORART (Norwegian and Nordic index to periodical articles)
19. Theses Canada

Search Terms

The terms used to customise the search string for specific databases were based on the 'population' and 'intervention' of interest. 'Disability' and all possible variations including mental health, disorders and autism was the first keyword. Where available, database-specific terms were used, encompassing all types of disability (see extensive list for PsychInfo – Appendix 2.1). Any overarching terms, encompassing all disabilities – when available - were exploded (see Embase search string in Appendix 2.1). 'Budget' and all its variations was the second keyword. The following truncations: 'person*'; 'individ*'; and 'self-direct*' were used to refine the results pertaining to the main keywords, linking them when necessary to the main keywords with, for example, 'near/n' or 'w/n', where possible. All other keywords were connected with 'or'/'and' when searching titles and abstracts. Search terms were also truncated, when appropriate, to allow for variations in word endings and spellings. Truncation conventions were specific to the database searched. A list of free-text terms identified in the literature was used to supplement the syntax developed. The term 'self-determination' ('self-determin*') was added to the free-text terms in addition to the terms outlined in the protocol. 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 were not included as part of the search strategy as it was anticipated that this would potentially lead to the omission of relevant studies. Furthermore, the mixed methods approach on which this review is based, led to broad inclusion criteria for study designs (Appendix 2.2 – methods paper).

All search strings are provided in Appendix 2.1. A sample search string is outlined below:

'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 OR 'self-determin*':ab,ti AND [1985-2015]/py

Grey Literature

An international list of grey literature databases published by the Campbell Collaboration (Hammerstrøm et al., 2009) was consulted in the first instance. A US electronic database, run by The New York Academy of Medicine and dedicated to specifically searching grey literature in public health, was also employed (www.greylit.org). Opengrey.eu was used to search grey literature in Europe. Other international grey literature databases utilised, as recommended by Hammerstrøm et al (2009) included: VHL Regional Portal for Latin American databases; NORART capturing Norwegian and Nordic articles; and Australian Policy Online. Boolean operators are not supported by these databases; therefore keywords, based on the database searches of published work, were searched separately (Appendix 2.1). Similar search strategies were employed for other country / region specific sites.

Timelines and other restrictions were not imposed in order to maximise the results from grey literature. Reference lists from relevant studies and previous systematic reviews were visually scanned to identify any unpublished literature not previously identified. Google Scholar, the popular internet search engine, was also 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 was used to search for relevant theses at doctoral and masters level. Finally, Google search engine was searched to identify any relevant conference proceedings and government documents in addition to relevant NGOs that may have potentially useful research materials unpublished elsewhere. In total, 1000 Google results and almost 6,000 Google Scholar titles were scanned (Appendix 2.1).

5.3.2.2 Cross-referencing of bibliographies

The references of each of the final studies included in the review were scanned to identify any additional potentially relevant studies. Literature reviews and other non-eligible studies were also scanned for relevant titles. This forward citation searching led to the addition of 40 additional the full-text screen. The bibliographies from the two previous reviews were also cross-referenced (Carter Anand et al., 2012; Webber et al., 2014).

5.3.2.3 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, Individualised funding) were consulted. This syllabus provided 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 was used as a reference point for identifying and sourcing data from unpublished or ongoing studies and guided the hand-searching. Such hand searching led to the addition of 63 to the full-text screen.

Corresponding authors as listed on published works were contacted, when necessary, to request access to primary data, and/or to provide clarification during the data extraction process on, for example, demographic information and timelines to follow-up.

5.3.2.4 Timeframe (and other filters)

According to Leece and Leece (2011), the origins of personalised brokerage schemes and individualised funding 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). Thus, individualised funding appears to have emerged for the first time, around the mid-eighties. For this reason, the searches of published literature were limited to the period 1985 – quarter 1 of 2016. For example, date filters were applied to the Scopus search results (Appendix 2.1). Other filters were also applied where necessary to refine the search, such as exclusion of non-relevant subject areas (See Embase search string Appendix 2.1).

5.3.2.5 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) were searched manually to capture any relevant work published since the searches were last run. Seven journals were searched including: 1) British Journal of Social Work, 2) Disability and Society, 3) Health and Social Care in the Community, 4) Health Services Research, Journal of Integrated Care, 5) Journal of Health Services Research & Policy, 6) International Journal of Mental Health Systems, and 7) International Journal of Mental Health Systems. Key terms were used to search these journals resulting in the addition of two titles to full-text screen (Appendix 2.1).

5.3.3 Data collection and analysis

5.3.3.1 Data Extraction and Study Coding Procedures

As outlined in the protocol, titles were reviewed initially in Endnote by the lead author to remove any studies which were clearly irrelevant (e.g. non-human or pharmaceutical studies). However, due to the very large number of search results (n = 82,274 after duplicates and non-relevant grey literature excluded), an extensive, thorough and transparent 'results refinement process' was developed. In summary, this included a three-part process of 1) automatic text mining, 2) a failsafe check (to catch any studies inadvertently removed) and 3) a manual title screen. This process is detailed in Appendix 2.2. Excluded studies can be seen in Appendix 2.5.

Following this, the screening of studies in relation to inclusion/exclusion was undertaken in two stages. The first stage involved citation and abstract; the second involved full text documents. Three independent researchers (PF, MH, SOD) were involved at each stage. Both PF & MH were co-authors of the protocol, but all three had a deep understanding of the research questions and outcomes of interest. SOD was recruited as a third screener, due to the intensive nature of the screening process. PF screened all titles and MH / SOD acted as second screeners. Prior to data extraction and coding, the three independent reviewers met to discuss and pilot the extraction and coding procedures on a sample of abstracts. While PF reviewed all materials, MH and SOD acted (alternately) as intermediaries to resolve any disagreements between PF and the second reviewer in question (e.g. MH acted as an intermediary for, the albeit very small number of, disagreements between PF and SOD, where a resolution could not be agreed through discussion and consensus). This occurred on approximately 20 occasions (0.3%). Inter-rater reliability was calculated for the full sample of full-text papers screened using kappa statistic (as recommended). 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 is reported in the results section below.

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

Stage one: citation and abstract

Citations and abstracts which passed the first stage were 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 an individualised funding 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 were unsure, full text articles were retrieved to clarify and, if necessary, the corresponding author was contacted.

Stage two: full-text

Full text documents were retrieved for all documents that passed stage one. Two reviewers independently evaluated all studies. Studies had to meet all of the inclusion/exclusion criteria set out previously in order to advance to full review. It should be noted that not all studies precisely met the inclusion criteria; for example, the study population may have included minors, adults and older people without lifelong disabilities. Where this occurred, studies were included if the eligible population represented the majority of respondents (>50%) and where it was possible to disaggregate the findings. Reasons for exclusion were independently reported by both reviewers in the ‘research notes’ field within endnote reference manager. For studies that were included in the review, a standard set of data are reported such as: publication details; study design; participant demographics, intervention and control descriptors; and outcome measures and related statistical differences between intervention and control groups (Tables 5.1 – 5.4 in results section).

5.3.3.2 Risk of Bias

Risk of bias and quality of research were evaluated using a range of tools (depending on study design) by one reviewer (PF), except for a single paper (co-authored by PF), which was reviewed by a second independent reviewer (MH). While a detailed assessment was conducted by one reviewer, the intensive screening process involved a quality assessment - with the screening tool adapted to solicit feedback on study quality, particularly in relation to methodological considerations (Section 5.3.3.5). These assessments were discussed among the team of reviewers. 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' was used to appraise randomised, quasi-randomised and cluster-randomised controlled trials. The protocol specified that all non-randomised study designs would be appraised for quality and risk of bias using the appropriate tool from the Critical Appraisal Skills Programme (Critical Appraisal Skills Programme, 2014) However, upon application of the CASP, the criteria for measurement of quality did not seem appropriate or well matched to the study designs utilised in the included quantitative studies. For example, CASP does not have a specific tool for before and after studies or controlled cross-sectional surveys, (the most common designs utilised by eligible studies). Consequently, various tools were researched, sourced and piloted before selecting the 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies' (NHLBI, 2014). This tool was chosen due to its flexibility in terms of application, with clear guidance provided for how to treat criterion not relevant to the study design (e.g. measurement of exposure is not relevant for this intervention, but can be marked as 'No' or 'NA'). It should also be noted that the use of the Grading of Recommendations Assessment, Development and Evaluation (GRADE) for quantitative data was deemed inappropriate since the heterogeneous nature of the available studies / data precluded the possibility of a meta-analysis

As per the protocol, CASP tools were used to assess quality and risk of bias for qualitative studies. The results of such assessments are presented under the CerQual headings of: ‘methodological limitations’, ‘relevance’, ‘adequacy of data’ and ‘coherence’ (Lewin et al., 2015). Risk of bias is discussed in detail for both quantitative and qualitative studies in the results section to follow. (Figures 5.2 & 5.3 and Appendices 2.6 & 2.7)

5.3.3.3 Synthesis Procedures and Statistical Analysis

The interventions included in this review, whilst very diverse, successfully met the eligibility criteria outlined in the protocol as did the population of interest, comparison groups and outcomes. However, as data extraction progressed, it became apparent to the screeners that a wide range of economic, social and political factors, identified across different geographical contexts and jurisdictions, had hugely impacted design and delivery of the interventions. A number of examples will be described below to illustrate these differences.

- The population and comparison groups were very disparate, across the seven quantitative studies. For example, two quantitative studies focused solely on people with physical disabilities, whilst another was investigating only people with mental health problems. The remaining four studies represented people with various types of disabilities.

- Another example related to the comparison groups. For two studies, control group members wanted to avail of individualised funding, but were on a waiting list. For other studies, people were ‘happily’ in receipt of similar agency based services, rather than self-directed, while a third approach involved random assignment to intervention or control group.

- Finally, the ways in which people accessed funding were vastly different, whereby participants in the US studies had to meet pre-defined ‘Medcaid’ eligibility criteria, while UK participants often had multiple funding sources available to them, such as ‘Disability Living Allowance’, ‘Independent Living Fund’, and ‘Direct Payment’. The disparities in funding availability and allocation directly impacted the design and evaluation of included studies.

The differences documented above inherently affected the design and delivery of the intervention. Furthermore, study designs and data collection tools were vastly inconsistent, with most outcome measurement tools designed specifically for the study in question. As a result, it became apparent that the planned synthesis of quantitative data, as per the protocol, was not going to be feasible or meaningful. The above factors also affected the risk of bias (Figure 5.2), although quality scores remained reasonably good (Appendix 2.6). Therefore, a narrative analysis of quantitative data, as described below, was undertaken to best represent the results. Summary statistics for all studies are reported in Table 5.3.

Narrative analysis

Narrative systematic reviews serve several functions including reporting the effects of interventions as well as the factors impacting the implementation of interventions (Popay et al., 2006). Therefore, such an approach was well suited to the current review which aimed to examine quantitatively, the effects/impact of individualised funding whilst also qualitatively assessing factors related to implementation. The use of a narrative analysis vis-à-vis the quantitative data allowed for a coherent blending of findings within the mixed methods approach, particularly given the emerging contextual diversity. Specifically, this involved the following four main elements as identified by Popay et al. (2006): 1) developing a theory of how the intervention works, why, and for whom; 2) developing a preliminary synthesis; 3) exploring relationships in the data; and 4) assessing the robustness of the synthesis.

Continuous data

Ultimately, the original data were reported for each study in relation to the primary, secondary, adverse and other health and social care outcomes of interest. In those cases where no data were available, p-values were calculated using the RevMan tTest calculator.

Dichotomous data

In cases where binary or categorical data were used to compare intervention and control groups, Upton chi square was employed to test for significant between group differences (i.e. between the proportions of the two independent groups), as recommended by Campbell (I. Campbell, 2007). WinPepi (Abramson, 2011) was used for such calculations.

5.3.3.4 Treatment of Qualitative Research

Meta-synthesis

Two complementary approaches were utilised sequentially in this review in order to manage the qualitative data. Firstly, a meta-aggregation or meta-synthesis was conducted, involving a comprehensive and systematic search, data appraisal and extraction process using standardised tools where appropriate. Secondly, a standard thematic analysis was conducted to aggregate the findings from several studies. This involved four stages as recommended by Clark (2015), each of which is described below.

(1) Reading and coding the studies

Each eligible study included in the systematic review was read carefully and in detail. The main study characteristics are reported in Table 5.4.4. A thematic analysis was conducted for each individual study, at this stage, in order to identify the main themes reported. Line-by-line coding of the results was undertaken using MAXQDA, followed by an organisation of the codes into descriptive themes (MAXQDA, 2014; Thomas & Harden, 2008).

(2) Determining relations

Having identified the main themes reported in the results of individual studies, relationships between studies were explored. Common and recurring themes were categorised, leading to the development of analytical themes (Thomas & Harden, 2008). At this point, the CerQual score was also determined, (Appendix 2.7).

(3) Translating the studies

Having read all the studies at least once, each study was re-read to examine similarities and differences between the concepts.

(4) Synthesising translations

The studies were conceptually folded together, using the concepts from individual studies and the emergent analytical themes as a lens to understand the whole body of work, thereby producing new understandings and conceptual development (Clark, 2015).

5.3.3.5 Methodological changes to the study protocol

A number of changes to the protocol were required for two main reasons: 1) the unexpected scope and resource intensive nature of the review (despite recruiting an additional screener); and 2) the inconsistency in study design, analysis and reporting which was further compounded by the lack of eligible quantitative data. Further information is provided below.

(1) Changes relating to the resource-intensive nature of the review

- A 'results refinement' process was developed and agreed to manage and filter the unexpectedly high number of search results (Appendix 2.2).
- Data extraction was conducted by only one review member for the qualitative data only rather than the anticipated two, due to resource constraints. However, during full-text screening, the second screeners indicated where data were not relevant (e.g. data related to minors / older people without a life-long disability). These notes were captured in the screening form and were used to guide data extraction. Quantitative data were double extracted as per protocol.
- A detailed quality assessment was conducted by only one reviewer, rather than the anticipated two, due to resource constraints. The screening of data was prioritised and, in fact, the thorough screening process did, in part, assess the quality of studies with the exclusion of those that did not have sufficient methodological detail to assess eligibility.

These decisions were discussed among the review team, based on data captured in the screening tool. To facilitate these discussions, changes were made to the screening tool (compared to that published in protocol), in order to capture more detail, particularly regarding outcomes and methodology (Appendix 2.8).

- The use of GRADE for quantitative data was deemed unnecessary due to the lack of data and meta-analysis.

(2) Changes due to complex nature of study designs

- Eligibility criteria were amended (i.e. tightened or loosened) as deemed necessary given the complex nature of social interventions. This led to the exclusion of older people who did not have a 'lifelong' disability, but instead required age-related support. It was felt that including an older population without a life-long disability would add uncontrollable confounding factors to the analysis. In addition, the eligibility criteria were not always applied in a strict/absolute fashion; for example, studies involving minors were only included where data could be disaggregated and where the majority of respondents (>50%) met the eligibility criteria.
- The quality assessment using the CASP toolkit did not seem appropriate or well matched to the study designs utilised in the included quantitative studies. Therefore, various alternative tools were researched, sourced and piloted before selecting the 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies'.
- Given that a narrative synthesis of quantitative data was deemed most appropriate, many of the intended analyses were not conducted (e.g. examining the impact of sensitivity analysis or publication bias).
- As a point of clarification, the minimum intervention time of 6 months was not imposed for qualitative studies because the focus of this aspect of the study was on early implementation.

5.4 RESULTS

The search strategy which guided this review was purposely broad in order to identify all eligible quantitative and qualitative studies. This focused on: 1) the population of interest (itself expansive), including adults (18 and over) with any form of lifelong disability, mental health problem or dementia; and 2) the intervention, of which there were many terms used to describe the funding of disability supports on an individual basis (using state funds). Study design, comparator groups or outcomes of interest were not included at search stage. A wide range of academic databases (including general, psychological, medical, social, economic, business and policy), regional specific databases, sources of grey literature and search engines, were employed to gather the data.

5.4.1 Results of search

Due to the breadth of the search strategy, 82,274 potentially relevant titles were identified. For this reason - and as agreed by the two lead authors - an additional refinement process was necessary in order to reach a manageable number for title/abstract screening. This robust and transparent three-part refinement process is detailed in Appendix 2.2. In summary, it included: 1) automatic text mining; 2) failsafe check – for potentially relevant titles that may have inadvertently been removed; and 3) manual title screen for clearly irrelevant titles.

After this search refinement process was complete, 7,158 titles and abstracts were double screened for relevance. A total of 6,934 were excluded, as they did not meet the inclusion criteria. The full texts of 225 titles were double screened as well as 104 titles identified through ‘forward citation searching’ and ‘hand searching’. In total, 328 full texts were double screened. Appendix 2.5 outlines the reasons for exclusion. A total of 73 studies met the inclusion criteria and were included in the review, 66 (90%) of which were qualitative in nature (Figure 5.1).

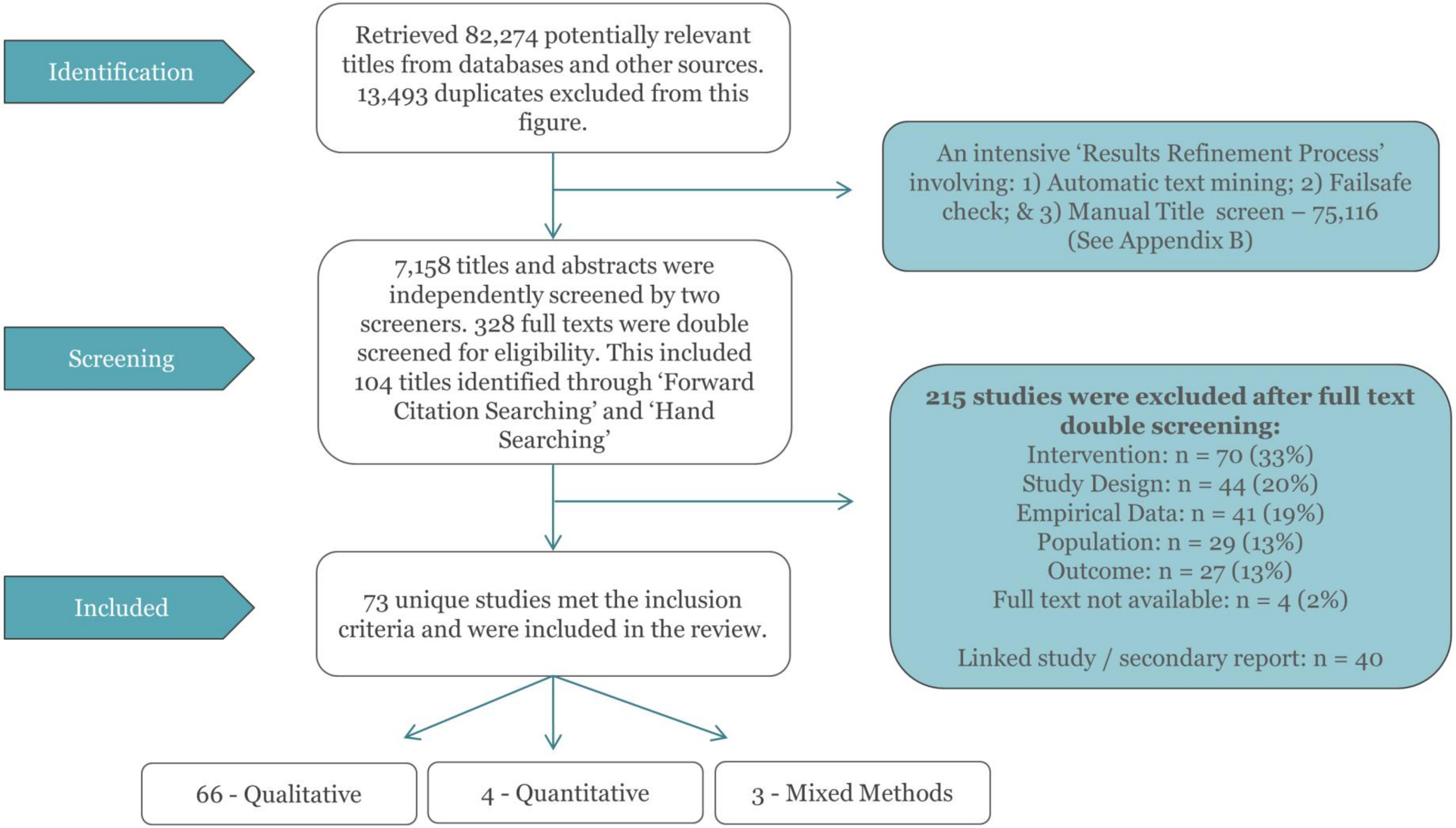


Figure 5.1 - Flow chart of study selection process

5.4.1.1 Included studies

As indicated above, a total of 73 studies were included, 66 (90%) of which contained eligible qualitative data only. A further three, had employed a mixed methods design whereby both the quantitative and qualitative data were eligible. Only four studies (4/73) were solely quantitative in nature.

A number of country-specific contextual factors impacted considerably on how the interventions of interest were described and implemented. For example, in some cases, both children and adults participated in the study. Where it was possible to disaggregate these data, the study was included, but the ineligible data were excluded. Therefore, the eligibility of many studies was unclear at first, resulting in an inter-rater reliability score of 0.6 for the double screening of full-texts (according to the criteria outlined by Higgins and Green (2011), whereby values from 0.60 to 0.74 reflect good agreement). In essence, this meant that 76 studies (23% of full-text screen) required in-depth discussion between two reviewers to resolve disagreements, while 21 (6%) were referred to a third reviewer.

5.4.1.2 Qualitative data

Almost half (45%, 31/69) of the eligible studies containing qualitative data were solely qualitative in nature and had collected/accessed qualitative data in a number of ways, including in-depth interviews, focus groups, workshops, telephone discussions, case studies, documentary analysis and open-ended survey responses. The remaining 38 studies contained *both* qualitative and quantitative data but only three met the eligibility criteria for inclusion in the quantitative element of the review (n=7). Six (primarily) quantitative studies also contained open-ended responses providing eligible qualitative data. Thus, the text-based data available for analysis varied considerably with a mean word count of c.9,500 (ranging from c.556 to c.134,260). Characteristics of the included studies containing eligible qualitative data (n=69), can be seen in Appendix 2.3.

5.4.1.3 Quantitative

A total of 7 studies contained eligible quantitative data - four were based on solely quantitative designs and three on mixed methods approaches. One was a 'quasi-experimental controlled longitudinal survey', three were 'controlled cross-sectional surveys of random sample' and three were 'randomised controlled before and after studies'. A meta-analysis was not possible due to the heterogeneity within all 7 studies (e.g. inconsistent and unstandardised measurement and reporting of data). Therefore, a narrative review was undertaken based on the outcomes of interest. Characteristics of the studies containing eligible quantitative data (n=7) are provided in Appendix 2.4.

5.4.1.4 Mixed Methods studies

As indicated above, mixed methods approaches were used in 38 of the 69 studies containing eligible qualitative data, only three of which contained quantitative data which were eligible for inclusion in the review.

5.4.1.5 Excluded studies

In total, 215 studies were excluded during full-text screen while a further 40 were identified as a secondary title linked to a study already captured within the review. Unique data from these 40 studies were included in the data synthesis. The largest proportion of studies (33%, 70/215) were excluded primarily because they did not meet the definition of the intervention as described earlier. The remaining studies were excluded for a number of reasons including issues related to: study design (i.e. not a controlled study or unrelated qualitative focus; n=44); empirical data (i.e. reporting data from previously published studies; n = 41); population (i.e. involving minors or older people without a lifelong disability or dementia; n = 29); and outcome (i.e. not measuring an outcome of interest; n=27). A full list of excluded studies, including the reason for exclusion, can be seen in Appendix 2.5.

5.4.2 Description of included quantitative studies

Seven studies with unique quantitative data, representing 19 titles, were included in the review. One was an unpublished report (available online), while the remaining five included both unpublished reports and published peer-reviewed journal articles. All studies were written in English and the majority (71%) were based in the United States (n=5). Two (29%) were conducted in England. Sample sizes ranged from 92 – 1,966, with a mean sample size of 761. The studies measured one or more outcomes of interest including quality of life (n=4), satisfaction (n=5); some level of physical functioning (n=4); adverse outcomes (e.g. unmet needs or psychological risk) (n=5); and costs data (n=3). Other outcomes of interest included community participation/integration (n = 2 studies), self-perceived health, safety (n =1), choice-making (n=1), challenging behaviour (n =1), and person-centred planning process. Table 5.4.1 provides a summary of study characteristics for all seven included studies.

5.4.2.1 Participant characteristics

A total of 4,834 adults are included in the narrative synthesis, representing a collective response rate of 73%. Of the 5 studies that reported average age, those in the intervention and control groups were of a similar age (43 and 42 years old respectively). However, one study (Benjamin et al., 2000) reported that 54% of the intervention group and 50% of the control group were over 65. In another study (Brown et al., 2007), 48% were aged 18 – 39 years. In the latter, the older age groups (over 64 in 2 sites and over 59 in 1 site) were excluded from the narrative synthesis as there was no way to determine if a life-long disability was present for the older cohort. All studies reported gender differences and ethnic/racial minority status; overall 61% were female (n=2,963) and 28% were from an ethnic or racial minority group (n = 1,372). A mix of disabilities was represented in the sample including physical, cognitive/intellectual, mental health, developmental, and/or multiple/secondary disabilities (Table 5.1). Breakdown by intervention and control group (where available) can be seen in Appendix 2.4.

Table 5.1 - Characteristics of included quantitative studies

Characteristic	***19 titles (%) [7 studies]***	**Characteristic**	***19 titles (%) [7 studies]***
Publication Year		**Intervention Type**	
1992 – 1999	3 (16) [1]	Consumer-directed	14 (74) [4]
2000 - 2005	7 (37) [2]	Self-determination	1 (5) [1]
2006 - 2010	6 (32) [3]	Individual Budget	3 (16) [1]
2010 - 2016	3 (16) [1]	Personal Budget	1 (5) [1]
Characteristic	**7 Studies N (%)**	**Characteristic**	**7 Studies N (%)**
Geographic Region		**Disability Type (primary)**	
Australia / NZ	0	Physical / Sensory	2 (29)
Europe	2 (29)	Learning / Developmental	0
Canada	0	Mental Health	1 (14)
United States	5 (71)	Various	4 (57)
Study Design		**Sample Size**	
Randomised/random sampling	6 (86)	< 1000	3 (43)
Non-randomised	1 (14)	1001 - 2000	3 (43)
		>= 2000	1 (14)
Language			
English	7 (100)	Non-English	0

5.4.2.2 Intervention characteristics

The included studies examined the effectiveness of a number of individualised funding models. These included four ‘consumer-directed’ services, one ‘self-determination’ programme, one ‘individual budgets’ programme and one ‘personal budgets’ programme. Six of the seven models permitted the purchase of a wide range of services/supports including, amongst others, payment of workers, home modifications, assistive equipment, and transport. In one of these studies, the services had to involve 'in-home' supports. The remaining seventh study limited purchases to 'personal assistance services', although the scope of these services was broad. All the interventions were financed by State funds.

The time period between baseline/commencement of the intervention and follow-up data collection, ranged from at least 6 months to 9 years. The monthly allocation of cash received by participants was presented differently for each study, with the monthly median payment (for two studies) ranging (between study sites) from £405 to £929 or between $313 and $1,097. Mean monthly payments for three other studies ranged from £1,288 to $1,656. These figures are based on best available data and do not take into consideration differences in, for example, exchange rates. Six of the seven studies involved the collection of data directly from people with disabilities, five of which reported the use of proxy respondents where necessary. Only the study by Caldwell (2007) was based on data collected from the primary caregivers of people with a disability.

5.4.3 Risk of bias in included quantitative studies

Only one study within the review was reported as a Randomised Controlled Trial and, as expected, this study was designed to assess the effectiveness of a social intervention. When assessed using the Cochrane risk of bias tool, this study by Glendinning (2008) was rated as 'low' (high risk of bias). As with most social interventions, however, it is often not ethically or practically possible to adhere strictly to the parameters that affect risk of bias. This is reflected in the low score above. As such, the Glendinning study was reassessed using the 'Quality Assessment Tool for Observational Cohort and Cross Sectional Studies' (as with the other six studies) and, as a result, the rating increased to 'good'. Nevertheless, as set out in the protocol, each of the domains used to assess risk of bias is discussed below. Using these criteria, the overall risk of bias across the 7 studies was high (Figure 5.2). The use of the 'Quality Assessment Tool for Observational Cohort and Cross Sectional Studies' (NHLBI, 2014) yielded a rating of ‘good’ for three of the included studies, ‘fair’ for three studies and ‘poor’ for one. Appendix 2.6 provides complete quality and risk of bias tables for each study. Note – both assessments are available for Glendinning (2008).

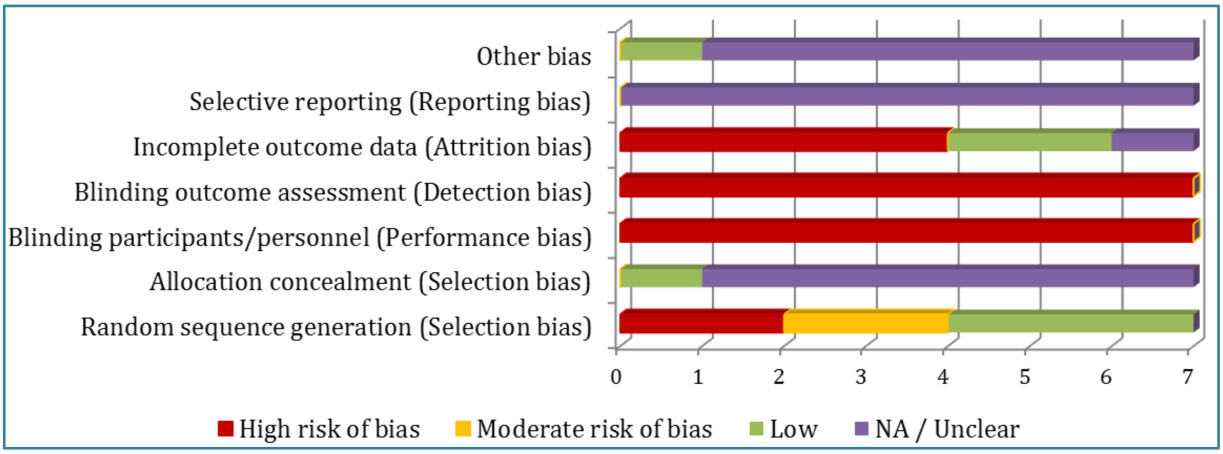


Figure 5.2 - Risk of bias across studies

5.4.3.1 Selection bias

Selection bias is based on random sequence generation and allocation concealment. Two of the 7 studies (Brown et al., 2007; Glendinning et al., 2008) involved random allocation of participants to either the intervention or control group, whilst a third used stratified randomisation across study sites for various reasons (e.g. age, level of service need, ethnicity, residential setting or geographic spread) (Conroy, Brown, et al., 2002). In three studies, the sample was selected randomly from a larger pool of potential participants, while participant recruitment in the final remaining study was organised through a gatekeeper (Beatty et al., 1998).

Only one study reported efforts to conceal allocation. This is not unusual in social interventions but nevertheless, studies that did not report allocation concealment were considered unclear in terms of risk. Random sampling was considered medium risk, except in one case where people with a severe cognitive disability were excluded from the sampling frame and case manager discretion was reported to have potentially biased intervention /

control assignment (Benjamin et al., 2000). This, together with the final study (in which no random allocation or selection was used), were rated as high risk (Figure 5.2).

5.4.3.2 Performance and detection bias

As with most social interventions, it is not possible to blind either participants or personnel in terms of the type of intervention received. Likewise, with individualised funding compared to traditional service provision, it was impossible to blind participants or outcome assessors and, therefore, these domains were inherently high risk for all studies. In fact, the inability to blind personnel led to negative feedback about the selection process in two of the three randomised studies, with staff questioning the acceptability of withholding the intervention from interested parties and control participants - pressing their care manager for the intervention immediately rather than in six months' time (Glendinning et al., 2008), while others suggested that a purposeful sampling process would have been more appropriate (Conroy, Brown, et al., 2002). This kind of problem is commonplace in community-based trials and especially when the intervention is viewed positively by those delivering it.

5.4.3.3 Attrition bias

Two of the studies were cross-sectional and therefore attrition was low (Benjamin et al., 2000; Woolham & Benton, 2013). One of these studies excluded 10% of the original sample due to gatekeepers wrongly identifying participants who did not match the inclusion criteria or, had moved away, been hospitalised or passed away (Woolham & Benton, 2013). Beatty et al. (1998) carried out a longitudinal survey, but it is unclear whether there were multiple data collection points; however, approximately half (48%) of the original control group were excluded from the study as they were not in receipt of any service with which to compare the intervention.

For the remaining four included studies, the risk of bias was considered high as all four had attrition/exclusion levels exceeding 20%. For the Glendinning et al. (2008) study, the total loss at follow-up was 29%. A total of 129 (10% of 1,356 original sample) were not approached because: they no longer received social services support; had passed away, were not contactable, or had moved away. A total of 221 (16%) did not complete a six-month follow-up interview for various reasons including illness and no longer wishing to participate. An additional 47 (3%) were also excluded post-interview because the randomisation group could not be validated. Finally proxy interviews were excluded for certain measures, where self-completion is intended (e.g. GHQ-12 and ASCOT) and for single item outcome measures, if a proxy completed the interview on behalf of the individual with a disability or when the proxy assisted that individual in answering the question.

The 'Cash and Counseling' pilots involved three study sites and a total eligible intervention group of 1,139 individuals. A significant minority (21% to 34%) had withdrawn from the intervention at the 12 month follow-up. Those who had withdrawn at the 9-month data collection point were excluded from the analysis. The most common reasons for drop-out included: a perception that the allowance was too low; that traditional agency services were meeting the needs of the person with a disability; or the individual with a disability had problems with employer responsibilities. Furthermore, where it was not appropriate for proxy respondents to answer questions (on, for example, perceived quality of life), these questions were not asked of proxies. In addition, it should be noted that only 81%, 67% and 68% of the three intervention groups respectively had received an allowance by the 9-month follow-up point. However, due to the intent-to-treat approach, all responses were reported which may have skewed the findings (Brown et al., 2007). With regard to the 9-year longitudinal study, a second intake of participants was included in the time 3 data, representing a total sample of 135 families in the intervention. Only 38 were available after 9 years, representing a 72% attrition rate at time three. Available data for the attrition group were reportedly limited, with the authors acknowledging unknown factors that may have biased the longitudinal group. Finally, Conroy et al. (2002) reported an overall 31% attrition rate at follow-up; furthermore, costs data was only available for 26% of respondents (due to limitations with data access).

5.4.3.4 Reporting bias

None of the included studies incorporated a study protocol. Therefore, is it unclear whether a priori outcomes were identified, or whether all outcomes of interest under investigation were reported. Therefore, reporting bias was considered unclear for the studies. Having said that, it appears that the measured outcomes are in line with the aims, as set out in the study results. However, not all studies reported the outcomes of interest for this review and, therefore, it cannot be determined if, for example, adverse effects data were collected for the four studies that did not report any.

5.4.3.5 Other biases

None of the studies reported any conflicts of interest. In terms of funding, two did not receive any funding (Conroy, Brown, et al., 2002; Woolham & Benton, 2013), three were government funded (Beatty et al., 1998; Benjamin et al., 2000; Glendinning et al., 2008) and two were a combination of government funding and other funding sources including: the Robert Wood Johnson Foundation (Brown et al., 2007); and the National Institute on Disability and Rehabilitation research (Caldwell et al., 2007).

Authors of the 'Individual Budgets Evaluation Network' (IBSEN) study (Glendinning et al., 2008) acknowledge two potential sources of bias. Despite the randomised design, the population from which the sample was drawn, was potentially biased. For instance, 26% of the intervention group (those with an individual budget) had previously been in receipt of a 'Direct Payment' (similar intervention). However, only 4% nationally were using a Direct Payment. Therefore, people with previous experience of a 'Direct Payment' were over represented in the study intervention, when compared to the national average. The authors felt that 26% of the intervention group may, therefore, have provided more positive responses due to previous experience with direct payments. Moreover, this over representation may have resulted in smaller differences in terms of costs and outcomes than may have been observed in a more representative sample, since comparisons were not being made with traditional services, but rather another form of individualised funding. As a result, the authors factored previous experience of a direct payment into their analysis and did not find any effect on the results for either of the aforementioned concerns (Glendinning et al., 2008, pp. 44-45 & 80).

Table 5.2 - Quality scores for quantitative studies

Study 1st Author (Year)	Score from 'Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies'
Beatty (1998)	6/10 (4 NA) = 60% (Fair)
Benjamin (2000)	7/10 (4 NA) = 70% (Good)
Conroy (2002)	6/10 (4 NA) = 60% (Fair)
Brown (2007)	7/11 (3 NA) = 64% (Good)
Caldwell (2007)	6/10 (4 NA) = 60% (Fair)
Glendinning (2008)	8/11 (3 NA) = 73% (Good)
Woolham (2013)	3/10 (4 NA) = 30% (Poor) The aims of the study are not clearly stated. While random assignment was used, the definition of the control group is ill-defined. There is no discussion of statistical power in relation to sample size. The two groups were considered broadly comparable on a number of demographic factors but no statistical data are presented.

Poor - <40%, Fair – 40% - 60%, Good – 61% - 80%, Excellent - >80%

5.4.4 Synthesis of quantitative results

Each outcome will be discussed in detail in relation to primary, secondary, adverse and other outcomes (Sections 5.4.4.1 – 5.4.4.7). Table 5.3 summarises the outcomes of interest for all 7 included studies, providing an overview of key significant differences and the direction of these effects (i.e. favouring intervention or control). Individualised funding was seen to statistically favour the intervention group with regard to quality of life (2 studies) client satisfaction (5 studies), adverse outcomes (2 studies) and sense of security (1 study). Cost-effectiveness results (2 studies) were more favourable for the control group, while one measure of unmet need (out of three) also favoured the control group (1 study).

Table 5.3 - Summary of outcomes across 7 included studies

Outcome → Study – ↓ 1st Author	Quality of Life	Client Satisfaction	Physical functioning	Cost effectiveness	Adverse	Other
Beatty (1998)	NR	+++	NR	NR	NR	NR
Benjamin (2000)	NR	m1: +++ m2: +++ m3: +++ m4: +++ m5: ND	NR	NR	m1: --- m2: ND m3: ND	Safety/ Security: +
Conroy (2002)	ND	NR	NR	NR	ND	ID
Brown (2007)	+++ (x2) ++ (x1)	m1: +++ (x2) m1: ++ (x1) m2: +++ (x2) m2: ++ (x1)	NR	m1: ND (x2) m1: - - (x1) m2: - - (x3)	m1: ++ (x1) m1: + (x2) m2: ++ (x2) m2: ND (x1) m3: ++ (x1) m3: ND (x2) m4: + (x1) m4: ND (x2) m5: + (x1) m5: ND (x2) m6: + (x1) m6: ND (x2)	NR
Caldwell (2007)	NR	+++	NR	NR	++	Comm. Participation: ND
Glendinning (2008)	m1: ND m2: ND	+	NR	m1: ND m2: ND	ND	Self-perceived health: ND ASCOT: ND
Woolham (2013)	+++	NR	ND	m1: ID m2: ID	NR	NR

'+', '++', '+++': Significant differences in favour of the intervention group representing significance level < 0.05, < 0.01, and < 0.001 (respectively).
'-', '--', '---': Significant differences in favour of the control group representing significance level < 0.05, < 0.01, and < 0.001 (respectively).
m1/m2: Different measures of each outcome, within the same study
(x2)/(x3): Multiple study sites, within the same study
ND: No difference between intervention and control groups / NR: Not reported / ID: Insufficient data

Primary outcomes of interest

This section provides a narrative synthesis of the primary outcomes of interest, as per protocol, including Quality of Life and Client Satisfaction. Intervention group (I) and control group (C) data are presented for each of the outcomes of interest. Data are presented in line with the original studies unless further statistical tests were required to measure significant differences. Such tests are reported where applicable. Data are presented for eligible participants only (adults with lifelong disability). All analysis that was conducted in RevMan and WinPepi are presented in the Data and Analysis section (Appendix 2.11, Table A2.11.1)

5.4.4.1 Quality of Life

Four studies reported 'quality of life' and/or 'psychological well-being'. A meta-analysis could not be conducted due to heterogeneity, insufficient data and randomisation differences. Where necessary, data were extrapolated to test significant differences between the intervention and control groups and mean differences were calculated using RevMan tTest calculator. A description of quality of life measures for each study can be seen in Appendix 2.9 (Table A2.9.1).

(Brown et al., 2007)

Data were available for 1,822 (93%) of the eligible sample (working-age adults). Means were calculated using a logit model (i.e. a logistical regression model where the dependent variable is categorical). Satisfaction levels, based on the reported findings (i.e. those very satisfied with way spending life), were significantly higher amongst participants from the intervention group when compared to the control group across the three study sites: Site 1 (I: 43.4 / C: 22.9, MD = 20.5, ($p < 0.001$)); Site 2 (I: 63.5 / C: 50.2, MD = 13.3, ($p < 0.01$)); and Site 3 (I: 37.5 / C: 21.0, MD = 16.5, ($p < 0.001$)). Combined data for the three sites were not reported, nor were standard deviations. Furthermore, it should be noted that not all recipients received an allowance, but an 'intent-to-treat' approach was utilised regardless.

(Conroy, Brown, et al., 2002)

Before and after mean scores were presented for the 'Quality of Life changes', but no standard deviations were reported. Significant differences were reported, overall, for both the intervention and the control group indicating that quality of life had improved for everyone participating in the study. There were three separate intervention groups, one of which was recruited from the same geographic location as the control group. When all three intervention groups (combined) were compared to the control group, the change is more marked for the intervention group, with the quality of life score increasing by 12.1 points (moving from 69.2 before to 81.3 after). A similar but smaller change in the control group (mean difference (MD) = 8.4) was also observed (69.6 to 78.0). The figures for the single geographically similar intervention group also show a comparable pattern moving from a score of 66.7 to 78.0 (MD = 11.1). Significant differences between intervention and control groups are not reported and could not be calculated due to insufficient data.

(Glendinning et al., 2008)

Quality of life responses were provided for 504 (99%) of the intervention group and 439 (98%) of the control group at six-month follow-up. Data were presented by disability type. Only one group, mental health service users (I: n = 65 / C: n = 64), reported a significant difference - in favour of the intervention group - (I: 3.78 vs. C: 4.31, MD = -0.53, $p < 0.05$). Note: Higher GHQ scores indicated poorer outcomes.

Combined sample means could not be calculated as no standard deviations were presented. Therefore, the proportion of those responding positively (at follow-up) on the 7 point scale (227 (I), 215 (C)) were compared to those who were ambivalent or negative for both controls and interventions, with no significant differences detected using Upton's Chi square (p = 0.28). When proxies were excluded, the sample was reduced to 308 intervention respondents and 302 controls. Once again, there was no significant difference between the two groups (p = 0.77) (Table A2.11.1).

5.4.4.2 Quality of Life – Psychological well-being

Relevant data on psychological well-being are presented for two studies below. Although the GHQ was used in both, a meta-analysis could not be conducted as Glendinning et al. (2008) randomly assigned participants to either the intervention or control group, while Woolham and Benton (2013) randomly selected their sample from within the relevant populations (i.e. those in receipt of individualised funding and those receiving traditional supports).

(Glendinning et al., 2008)

The total number of respondents on the GHQ-12 included 448 (88%) intervention group and 380 (85%) control group participants. A higher score on the GHQ-12 indicates worse overall well-being. There were no significant differences observed when comparing intervention and control groups (I: M = 13.83, SD = 6.74 / C: 13.80, SD = 6.85, MD = 0.03, (p = 0.95), 95% CI [-0.899, 0.959]) (Figure A2.11.1).

(Woolham & Benton, 2013)

Relevant data were presented separately for the older versus younger service users, but older participants were excluded from this review since there was no way to confirm a 'life-long disability'. This led to a reduction in the total sample to 126 (70%) in the intervention and 276 (71%) in the control groups. GHQ scores, for eligible adults, indicated that the intervention group had significantly better psychological well-being when compared to the control group (I: M = 10.12, SD = 6.93 / C: M = 13.28, SD = 7.37, MD = -3.16, (p <0.001), 95% CI [-4.65, -1.67]) (Figure A2.11.2).

5.4.4.3 Client Satisfaction

Five studies reported 'Client satisfaction'. Three of these were non-randomised, but all used different measures of client satisfaction. Data are presented as reported (where means and standard deviations were available), or extrapolated to test for significant differences between categorical data using Upton's Chi square (as recommended by Campbell (2007)). A description of the client satisfaction measures for each study can be seen in Appendix 2.9 (Table A2.9.2).

(Beatty et al., 1998)

The full eligible sample of 60 intervention respondents and 32 individuals from the control group took part in the study. An overall satisfaction score was calculated based on 16 responses to the 'Personal Assistance Satisfaction Index' (ranging from 16 -80). Responses were then collapsed into two categories representing: 1) those who were 'very satisfied' or 'extremely satisfied', and 2) those who were 'not at all satisfied', 'slightly satisfied', or 'somewhat satisfied'. The higher the score, the higher the overall levels of satisfaction. Intervention and control groups were compared within the positive category, with the intervention group reporting significantly higher scores (I: 61.4, SD = 9.7 / C: 52.1, SD = 10.9, MD = 9.3, ($p < 0.001$), 95% CI [4.80, 13.80]) (Figure A2.11.3).

(Benjamin et al., 2000)

A total of 511 intervention and 584 control group participants were involved in this study. Five items of client satisfaction were measured and reported separately. The higher the reported score, the greater the levels of satisfaction experienced. The intervention group reported significantly higher satisfaction scores on four of the five items (Figures A2.11.4 to A2.11.7) including:

- 'technical quality' (I: 20.90, SD = 3.31 / C: 20.07, SD = 3.82, MD = 0.83, ($p < 0.001$), 95% CI [0.41, 1.25];
- 'service impact' (I: 8.09, SD = 1.98 / C: 7.63, SD = 1.96, MD = 0.46, (p <o.oo1), 95% CI [0.23, 0.69]);
- 'general satisfaction' (I: 9.06 , SD = 1.65 / C: 8.66, SD = 2.07, MD = 0.40, ($p < 0.001$), 95% CI [0.18, 0.62]); and
- 'interpersonal manner' (I: 7.45, SD = 1.80 / C: 6.43, SD = 1.92, MD = 1.02, ($p < 0.001$), 95% CI [0.80, 1.24]).

There was no significant difference between intervention and controls for 'provider shortcomings' (I: 10.64, SD = 3.47 / C: 10.65, SD = 2.91, MD = -0.01, (p = 0.96), 95% CI [-0.39, 0.37]) (Figure A2.11.8).

(Brown et al., 2007)

In order to compare mean differences, client satisfaction data were collapsed into two categories - the way the caregiver helped around house/community and overall care arrangement. Means were predicted using logit models. Data were available for 1,822 (93%) of the eligible sample across three sites. With regard to the first category above, significantly more intervention group members reported being very satisfied across all sites: Site 1 (I: 90.4 / C: 64.0, MD = 26.4, (p < 0.001)); Site 2 (I: 85.4 / C: 70.9, MD = 14.5, (p < 0.01)); and Site 3 (I: 84.4 / C: 66.0, MD = 18.4, (p < 0.001)). In relation to overall care arrangements, higher mean scores were also seen across the intervention groups: Site 1 (I: 71.0 / C: 41.9, MD = 29.2, (p < 0.001)); Site 2 (I: 68.2 / C: 48.0, MD = 20.2, (p < 0.01)); and Site 3 (I: 51.9 / C: 35.0, MD = 16.9, (p < 0.001)). There were insufficient data to combine data from the three sites. Furthermore, it should be noted that not all recipients received an allowance, but an 'intent-to-treat' approach was utilised regardless.

(Caldwell et al., 2007)

Time 3 data are presented for both the intervention group (n = 38) and control group (n = 49). Means and standard deviations were reported. At time 3, the intervention group was significantly more satisfied with the service than the control group (I: M = 3.89, SD = 0.85 / C: M = 2.82, SD = 1.25, MD = 1.07, (p < 0.001), 95% CI [0.63, 1.51]) (Figure A2.11.9).

(Glendinning et al., 2008)

Categorical data were presented for levels of client satisfaction ranging from 'extremely satisfied' to 'extremely dissatisfied'. A total of 478 (94%) intervention group and 431 (96%) controls reported satisfaction data. The proportion of those responding positively on the 7 point scale (378 (I), 306 (C)) was significantly greater in the intervention group than in the control group when compared to those who were ambivalent or negative in both groups ($p < 0.01$ using Uptons Chi square). When proxies were excluded, the sample was reduced to 268 intervention respondents and 288 controls. Once again, significantly more of those in the intervention group were satisfied when compared to their control group counterparts ($p < 0.05$) (Table A2.11.1).

Secondary outcomes of interest

This section provides a narrative synthesis of the secondary outcomes of interest (as per protocol), including Physical Functioning and Costs Data. Intervention group (I) and control group (C) data are presented for each of the outcomes alongside results from statistical tests of difference. Upton chi square was used to compare proportions from two independent samples whilst RevMan was used to conduct t-tests. Data are presented for eligible participants only (working-age adults).

5.4.4.4 Physical Functioning

Four studies collected data related to physical functioning, but only one reported such data in terms of measuring differences between intervention and control groups. The remaining studies used the data as coefficients for further analysis. A description of physical functioning measures for each study can be seen in Appendix 2.9 (Table A2.9.3).

(Woolham & Benton, 2013)

Activities of Daily Living (ADL) data were presented separately for the older versus younger service users; the former were excluded from this review since there was no way to confirm a life-long disability. The resulting sample comprised 126 (70%) in the intervention group and 269 (71%) in the control group. There was no significant difference between the two groups in terms of physical functioning (I: $M = 11.77$, $SD = 3.59$, C: $M = 11.93$, $SD = 3.72$, $MD = -0.16$, ($p = 0.69$), 95% CI [-0.93, 0.61]) (Figure A2.11.10).

5.4.4.5 Costs Data

While most studies present costs data in some form, only three did so for *both* the intervention and control group. Two of these studies report cost-effectiveness analysis, one of which involved a randomised trial (Glendinning et al., 2008). Furthermore, the authors of the more recent study caution against any direct comparisons with the former due to methodological differences. For this reason, all studies are reported separately. Data are reported as seen in the original papers, with the exception of Woolham, where non-eligible adult respondents are excluded for part of the narrative results. A description of costs data measures for each study can be seen in Appendix 2.9 (Table A2.9.4).

(Brown et al., 2007)

Within the 'Cash and Counselling' study, the effect on Medicaid and Medicare expenditures was compared between intervention and control groups. The overall sample of working-age respondents comprised 2,109 participants (92% of the baseline sample) across three study sites. The average monthly cost for eligible intervention group members was $1,183 compared to $1,040 for control group individuals. However, the costs varied considerably across the three sites, ranging from a monthly average of $513 in Arkansas to $1,884 in Florida (intervention) and from $422 to $1,593 for controls (respectively). The average monthly cost was significantly higher for the intervention group across all three sites ($p < 0.01$ for Arkansas and Florida, $p < 0.05$ for New Jersey).

Intervention-control group differences were used to measure the effect of Medicaid costs overall. This was also divided into 'Personal Care/Home & Community Based Services (HCBS)' and 'Other Medicaid costs'. With regard to the overall Medicaid costs, there were no significant differences observed for mean differences in two study sites (Arkansas I: M = 14,125 / C: M = 12,862, MD = 1,263, ($p = 0.14$), New Jersey: I: M = 26,863 / C: M = 26,049, MD = 814, ($p = 0.59$)), whilst a significant increase among the intervention group was observed in the Florida site (I: M = 27,433 / C: M = 24,106, MD = 3,327, ($p < 0.001$). When examining Personal Care /

HCBS alone, there was a significant increase for the intervention group across all three sites (Arkansas I: M = 5,435 / C: M = 2,430, MD = 3,005, ($p < 0.001$), Florida I: M = 22,017 / C: M = 18,321, MD = 3,696, ($p < 0.001$), New Jersey I: M = 11,166, C: M = 9,220, MD = 1,946, ($p < 0.001$)) (Brown et al., 2007, Table V.1; Dale & Brown, 2005). Combined data for the three sites were not reported, nor were standard deviations.

(Glendinning et al., 2008)

Within the IBSEN study, cost-effectiveness was analysed by using the mean difference in outcomes of interest (e.g. the GHQ-12), and dividing it by the mean difference in costs. This allowed 'incremental cost-effectiveness ratios' (ICERs) to be examined for each outcome of interest. Prior to doing this however, costs were compared descriptively across three domains including: 1) social care costs; 2) health care costs; and 3) costs of care and support planning and management.

Data for social care costs were available for 268 (53%) of the intervention group and 250 (56%) of the controls. An average weekly cost of £279 and £296 was reported for each group respectively with no significant between-group differences. The mean weekly health care costs for the intervention group were significantly higher than the control group (£83 vs £59; $p< 0.05$). It should be noted however, that the potentially non-eligible 'older population' had the highest mean cost (£107 per week) compared to people with a physical disability (£76), learning disability (£23) or mental health problem (£76). With respect to care management, the intervention group had significantly higher costs (£217 vs £128 mean cost, $p < 0.001$) which was most probably due to the significantly higher mean number of visits (I: 1.66, C: 0.98, $p < 0.001$).

In terms of cost-effectiveness, Incremental Cost-Effectiveness Ratios (ICERs) were presented with bootstrapped estimates of standard error (se). ICERs were examined using ASCOT and GHQ scores, and while trends indicated a positive direction for the intervention group, these were not statistically significant. Notably, a sub-group analysis (using scatterplots) showed that the potential for cost-effectiveness is strongest with people with mental health problems as reflected in responses on both the ASCOT and GHQ-12.

(Woolham & Benton, 2013)

Data were presented for the entire intervention group (n = 177) and 72% of the control group (n = 271). The total number per group fell to 124 (72%) and 191 (51%) in the intervention and control groups respectively after non-eligible older people were removed. The mean weekly package costs for the (eligible) intervention and control groups were £355 and £268 respectively. Standard deviations are not presented and therefore statistical testing was limited, although it is clear that packages are more costly for the intervention group.

Similar to Glendinning et al. (2008), bootstrapping was used to draw comparisons based on outcomes of interest, in this case the ADL and GHQ measures. Although exact figures are not presented, scatterplots reveal some intervention versus control group differences. It should be noted that overall cost-benefit analysis represents the whole sample, including older adults. When comparing ADL scores, there is little difference between the two groups (both relatively independent), but based on this outcome, the package costs are higher for the intervention group. The scatterplots for GHQ scores show that the control group was experiencing 'some degree of ill-being'. While the intervention group were experiencing better well-being, the costs were again higher on average. Woolham & Benton's comparison of working-age and older intervention individuals, showed that the former cohort had better outcomes (well-being and independence levels), but the costs were also higher for the working-age adults. The authors suggest that findings should be treated with caution since the one of the measures used to inform the cost-benefit analysis (ADL) did not report statistical differences between intervention and control groups (Section 5.4.4.4).

5.4.4.6 Adverse Outcomes

Adverse outcomes are reported in some form, in five of the seven included studies, although there was considerable variation in the outcomes measured. The only commonality was seen in the two non-randomised studies (Benjamin et al., 2000; Caldwell et al., 2007), which both measured unmet needs, albeit using different tools. Data are narratively presented as in the case of original studies, with further analysis reported as necessary. A description of adverse outcomes measures for each study can be seen in Appendix 2.9 (Table A2.9.5).

(Benjamin et al., 2000)

There are two adverse outcomes reported within this study. The first, 'unmet need', is broken down into two further domains i.e. Activities of Daily Living (ADL) and Incremental ADL. The second main adverse outcome reported is physical and psychological risk. Both outcomes are presented for the intervention (n = 511) and control group (n = 584). With regard to ADL, the control group reported significantly fewer needs (I: M = 5.07, SD = 1.54, C: M = 5.38, SD = 1.21, MD = -0.31, (p < 0.001), 95% CI [-0.48, -0.14]). There were no significant differences detected on IADL (I: M = 4.37, SD = 1.24, C: M = 4.28, SD = 1.18, MD = 0.09, (p = 0.22), 95% CI [-0.05, 0.23]). Similarly, there were no significant differences detected for physical or psychological risk: (I: M = 29.25, SD = 1.95 / C: 29.05, SD = 2.31, MD = 0.20, (p = 0.13), 95% CI [-0.05, 0.45]). (Figures A2.11.11 to A2.11.13)

(Brown et al., 2007)

Data for eligible participants (working-age adults) from the Cash and Counselling study are presented below. Data were available for 1,822 (93%) of the eligible sample on the first two adverse outcomes below. A further four care-related health problems / events were reported for 1,938 (99%) of the working-age sample.

1) Based on the reported findings, significantly fewer intervention group members had unmet needs with regard to helping with daily living activities across the three study

sites: Site 1 (I: 25.8 / C: 41.0, MD = -15.2, ($p < 0.01$)); Site 2 (I: 26.7 / C: 33.8, MD = -7.1, ($p < 0.05$)); and Site 3 (I: 46.1 / C: 54.5, MD = -8.4, ($p < 0.05$)).

2) The second adverse outcome measured, related to rudeness or disrespect on the part of the caregiver. Fewer people in the intervention group reported such adverse outcomes across the three sites, although these differences were only statistically significant in two of the three sites: Site 1 (I: 10.5 / C: 29.5, MD = -18.9, ($p < 0.01$)); and Site 3 (I: 18.7 / C: 30.1, MD = -11.4, ($p < 0.01$)).

3) There was no significant difference in those reporting having had a fall in two of the three sites. However in the third site, significantly fewer individuals from the intervention group had experienced a fall: Site 3 (I: 18.7 / C: 28.0, MD = -9.3, ($p < 0.01$)).

4) Once again, only one of the three sites witnessed a significant difference between intervention and control members who reported contractures developing / worsening, with significantly more of the control group reporting such developments: Site 2 (I: 9.0 / C: 14.0, MD = -5.0, ($p < 0.05$).

5) For those reporting bedsores developing / worsening, only one site reported significant differences, with controls reporting such developments more often than the intervention group: Site 1 (I: 5.9 / C: 12.6, MD = -6.7, ($p < 0.05$)).

6) Finally, significantly more control group members reported having had a urinary tract infection in one of the three sites: Site 2 (I: 7.7 / C: 11.7, MD = -4.0, ($p < 0.05$)).

Combined data for the three sites were not reported, nor were standard deviations. Furthermore, it should be noted that not all recipients received an allowance, but an ‘intent-to-treat’ approach was utilised regardless.

(Caldwell et al., 2007)

Unmet needs were compared for intervention group at time 3 (n = 38) and the control group (n = 49). Significantly fewer people from the intervention group had unmet needs at time 3 compared to the control group (I: M = 3.11, SD = 3.30 / C: M = 7, SD = 5.31, MD = -3.89, (p < 0.001), 95% CI [-5.71, -2.07]) (Figure A2.11.14).

(Conroy, Brown, et al., 2002)

Challenging behaviour was compared between people in the intervention and control groups, providing before and after data. Since this is a scale, containing various maladaptive behaviours, means appear to be presented but no standard deviations are reported. No significant differences were reported. As with other outcomes of interest reported in this study, there were three intervention sites and only one control site. The control site was geographically similar to one of the intervention sites. However, the overall findings changed following a comparison of the mean difference for all intervention sites versus the geographically similar site; the score in the combined intervention groups increased from 86.3 at baseline to 88.2 at follow-up (MD = 1.9), while the control group scores also increased from 84.2 to 89.6 (MD = 5.4), both changes indicating an improvement in challenging behaviour.

(Glendinning et al., 2008)

Within the IBSEN study, the GHQ-12 was used to indicate a risk of 'psychological ill-health'. The bimodal (0-1) GHQ scoring method was used to indicate the likely presence of psychological distress according to a designated cut-off score of 4 or more (Glendinning et al., 2008). A total of 448 (88%) of the intervention group and 380 (85%) controls responded to this item. For the overall sample, 36% (n = 161) of the Intervention group obtained a score of 4 or more whilst the same was true for 33% (n = 125) of the control group. The differences between intervention and control were not statistically significant using Upton Chi Square (p = 0.36). This did not change when proxy respondents were excluded (Table A2.11.1). Furthermore, there were no significant differences by user group.

5.4.4.7 Other health and social care outcomes of interest

Upon review of the evidence, it became apparent that there were other health and social care outcomes reported that were not categorised exactly as anticipated within the review protocol, but which were still considered very relevant. These were evident in three of the seven studies (see below). The RevMan tTest for testing significant differences between outcome means are reported. A description of other outcomes measures for each study can be seen in Appendix 2.9 (Table A2.9.6).

(Benjamin et al., 2000)

Sense of security was an outcome reported (for both the intervention (n=511) and control groups (n=584)) under ‘safety’ along with physical and psychological risk (previously reported under adverse outcomes). Significantly more people in the intervention group felt safe with the provider and felt they got along with the provider when compared to the control group (I: M = 9.18, SD = 1.57, C: 8.96, SD = 1.65, MD = 0.22, ($p < 0.05$), 95% CI [0.03, 0.41]) (Figure A2.11.15).

(Caldwell et al., 2007)

Community participation was measured at time three for both the intervention (n = 38) and control group (n = 49). There was no significant difference reported between the two groups in this respect (I: M = 2.39, SD = 0.68 / C: M = 2.26, SD = 0.84, MD = 0.13, ($p = 0.439$), 95% CI [-0.19, 0.45]) (Figure A2.11.16). Interestingly, over the three study periods, community participation increased significantly for the intervention group, but similar data could not be presented for the control group since data were not collected at time 3 for this group (I-T1: M = 1.98, SD = 0.73 / I-T3: M = 2.39, SD = 0.68, MD = -0.41, ($p < 0.05$), 95% CI [-0.73, -0.09]) (Figure A2.11.17).

(Glendinning et al., 2008)

Two additional outcomes of interest were reported in the IBSEN study, including changes in self-perceived health and in the Adult Social Care Outcomes Toolkit (ASCOT) scores.

With regard to self-perceived health, 507 (99%) intervention group members responded along with 446 (99%) controls. There was no significant intervention-control group difference (p = 0.138) when Upton's Chi square was used to compare proportions of those who responded positively (I: n = 177, C: n = 178) with those who responded with neutral or negative responses. This finding was similar when proxy responses were excluded (I: n = 103, C: n = 108, p = 0.87) (Table A2.11.1). Subgroup analysis conducted by the authors did not demonstrate any significant differences within or between groups.

When examining the ASCOT scores, 90% of intervention group members (n=457) and 86% of controls (n=385) responded. A comparison of mean scores showed no significant between-group difference (I: M = 3.55, SD = 0.79 / C: M = 3.48, SD = 0.89, MD = 0.07, (p = 0.227), 95% CI [-0.045, 0.185]) (Figure A2.11.18) nor did a subgroup analysis conducted by the authors.

5.4.5 Description of included qualitative studies

As outlined earlier, 69 unique studies (representing 96 titles) were included in the review. Twenty-eight of these studies were published at least once, while the remaining 41 were sourced from grey-literature, most of which were published online as a government, research organisation or NGO report. The vast majority of studies were conducted in the UK (n = 41, 59%) or the US (n = 14, 20%), followed by Australia (n = 7), Canada (n = 3), Ireland (n=2), Belgium (n = 1) and Germany (n = 1) (Table 5.4). All studies were written in English with the exception of the Belgian study which was in Dutch. Studies varied from individual case studies, in-depth interviews and focus groups to surveys with open-ended questions and qualitative secondary analysis (Appendix 2.3).

Sample sizes ranged from 1 individual case study to 3,103 respondents who provided open-ended survey responses. The mean sample size was approximately 134 (median=44). As per protocol, the studies reported implementation experiences from the perspective of individuals with a disability, or their representative respondent. Implementation successes and challenges were also reported from the perspective of funding / provider organisations.

5.4.5.1 Participant characteristics

Approximately 9,224 eligible people were represented in the included studies. Of these approximately three-quarters (73%, 6,689) were people with a disability or a family member/advocate; the remaining 27% (2,535) were paid/unpaid support or organisational staff. Exact figures are not available due to inconsistent or insufficient reporting of sample sizes. However, when sample size outliers were excluded, the total sample was over 3,700 (66% individuals with a disability / representatives). Ages ranged from 3 to 85+ years, although children and older people without a life-long disability were excluded from the analysis, where possible.

The mean age was 38 years (for the 11 studies in which this was reported) and more than half (56%) of the sample was female according to the 43 (62%) studies in which the gender of participants was indicated. Eight per cent of the sample was from an ethnic minority (28 studies provided such details, n = 6,713). A mix of impairments was represented in the sample including physical, cognitive/intellectual, mental health, developmental, and/or multiple/secondary disabilities. Breakdown by intervention and control group (where available) can be seen in Appendix 2.4 (where available).

Table 5.4 - Characteristics of included qualitative studies

Characteristic	*69 studies (%)*	Characteristic	*69 studies (%)*
Publication Year		**Geographic Region**	
1992 – 1999	6 (9)	UK	41 (59)
2000 - 2005	16 (23)	United States / Canada	17 (25)
2006 - 2010	23 (33)	Australia	7 (10)
2010 - 2016	24 (35)	Other European	4 (6)
Intervention Type		**Disability Type**	
Direct / In-direct payment	21 (30)	Various	41 (59)
Self-directed / determination / managed	12 (17)	Mental Health / Dementia	10 (14)
Personal Budget	12 (17)	Physical / Sensory	7 (10)
Individual Budget	7 (10)	Learning	5 (7)
Mixed / Other	17 (25)	Not specified	6 (9)
Study Design		**Sample Size**	
In-depth interviews	20 (29)	< 25	24 (35)
Mixed qualitative	19 (28)	26 - 50	16 (23)
Case study (mixed methods)	18 (26)	51 - 100	16 (23)
Survey (8 primarily quant.)	9 (13)	>= 101	13 (19)
Other	3 (4)		
Language			
English	68 (99)	Non-English	1 (1)

5.4.5.2 Intervention characteristics

At least 17 different names were used to describe the intervention of interest including: 'direct payment', 'in-direct payment', 'self-directed', 'self-determined', 'self-managed', 'consumer-directed', 'microboard', 'user-controlled', 'person-centred supports', 'individualised supports', 'individual budget', 'private hire', 'individualised funding', 'participant direction', 'personal budget', 'individualised packages' and 'individualised recovery budget'. Indeed, a combination of models was used within some studies, whilst others included supplementary use of intermediary brokerage or other formal and informal supports. A full list of names and accompanying descriptions is provided in Appendix 2.4.

The vast majority of participants utilised a direct payment (30%) or a combination of models (25%) (Table 5.4). Irrespective of the type of intervention/model, the person with a disability (or their family/representative) had some degree of control over the budget, which could be used for achieving a range of personal, health and social care outcomes, although different restrictions applied across studies. Studies were excluded if a budget was restricted to one purpose only, such as supporting people in the workplace, since choice and control were limited from the outset; such models did not clearly fit the intervention as described in the study protocol. All of the interventions were financed by State funds. Nineteen studies indicated a minimum and maximum value of budgets, ranging from \$139 to \$12,500 per month in the United States, £92 to £7,800 in the UK, \$203 to \$5,708 in Australia, \$167 to \$7,500 in Canada and €100 to €13,000 in other European countries. These values are only indicative as they are applicable to a number of countries and time periods and do not, therefore, take into account changing currency values or other economic considerations.

5.4.6 Risk of bias in included qualitative studies

As per protocol, quality and risk of bias within qualitative studies are based on CASP and overall CerQual scores (Appendix 2.7). Furthermore, the discussion below was guided by, and structured according to, the relevant CerQual headings (i.e. methodological limitations, relevance, adequacy of data and coherence). This is intended to provide transparency in terms of assessing the robustness of individual study findings. However, CerQual scores, as indicated in Appendix 2.7, should be interpreted with caution, since CerQual is intended to assess reviews/syntheses of qualitative findings (retrospectively) rather than individual studies per se (Lewin et al., 2015). Thus, the CerQual analysis below was conducted prospectively, providing insight into how much confidence should be placed in individual studies when analysing and interpreting the data.

Most studies (70%) had an overall CerQual score of 'high' or 'moderate', whilst only 6 studies (9%) were rated as 'very low' (Figure 5.3). To this end, a sensitivity analysis was conducted by removing studies with a very low CerQual score and comparing results to the analysis conducted with all studies included (Alakeson, 2007; Blumberg, Ferguson, & Ferguson, 2000; Jordan, 2004; Secker & Munn-Giddings, 2011; Waters & Chris, 2014; Williams & Tyson, 2010).

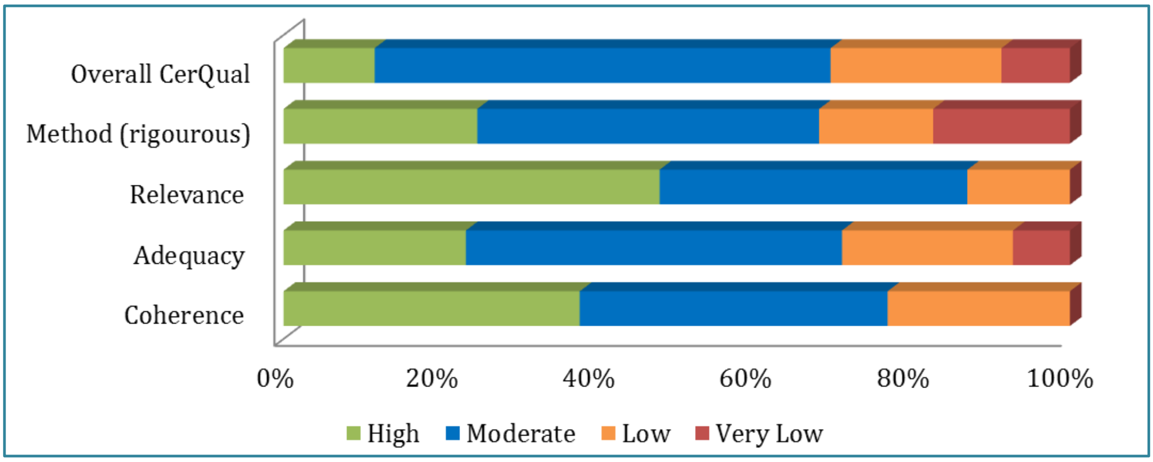


Figure 5.3 - Confidence in individual studies based on CerQual headings

5.4.6.1 Methodological limitations

The methodological limitations of individual qualitative studies were determined - as recommended by Lewin et al (2015) - by using the appropriate assessment which, in this case, was the CASP toolkit. As shown in Table 5.3, a substantial proportion of studies had methodological limitations, with 22 rated as 'low' (n=10, 14%) or 'very low' (n=12, 17%). Despite that fact that the lowest CerQual score was obtained in relation to methodological rigor, more than two-thirds of studies (68%) were rated as 'moderate' to 'high'. Very often these low scores related to insufficient detail to assess quality or the use of a primarily quantitative study design. Full details are provided in Appendix 2.7.

5.4.6.2 Relevance

Relevance was judged according to the extent to which individual studies related to the overall review question in terms of context - including population, phenomenon and setting. As discussed earlier, whilst the descriptions and implementation of the interventions varied considerably across studies, their core elements were fundamentally in line with the intervention as defined in the protocol. Consequently, 'relevance' had the highest CerQual rating with 87% scoring 'high' to 'moderate' and only 9 studies rated as 'low'.

5.4.6.3 Adequacy of data

Adequacy was assessed based on the degree of richness and quantity of data presented in each individual study (Lewin et al., 2015). Most studies fared very well in this respect with 71% achieving a 'high' to 'moderate' CerQual score. Twenty studies were rated as 'low' (n=15) or 'very low' (n=5). As outlined in Appendix 2.7, the quantity of data was assessed by examining the quartile represented by the sample size and the amount of relevant data coded in the initial line-by-line coding exercise. The mean sample size was 44 and the mean number of codes per study was 376. The richness of data was assessed by the depth of detail, the amount of raw data provided, and the uniqueness of the data was in terms of context (e.g. population, geography and type of disability).

5.4.6.4 Coherence

Coherence was a little more difficult to assess as outlined by Lewin et al. (2015) since the overall review findings were not clear when the CerQual assessment was being conducted. Having said that, the first round of coding had been completed and a deeper understanding of the combined data was emerging, along with preliminary patterns within the data. In order to make an assessment of coherence, the data were assessed in terms of the extent to which the findings were grounded in the data, how the authors had triangulated the findings in terms of study design (mixed qualitative methods), multiple-respondent groups and how the findings related to international evidence. Overall, 77% of studies were rated as 'high' to 'moderate', with the remaining studies obtaining 'low' scores.

5.4.7 Synthesis of qualitative results

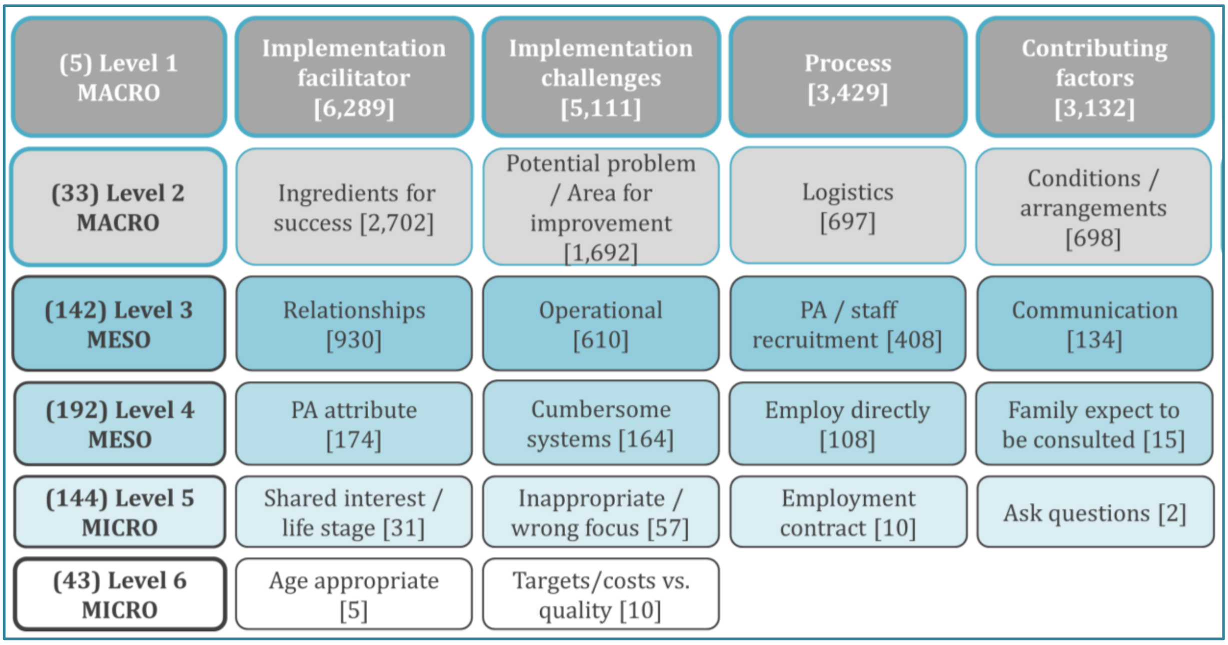
5.4.7.1 Analysis

The analysis of qualitative data was informed by, and conducted within a realist evaluation framework which considers 'Contexts, Mechanisms and Outcomes' (CMOs) (Pawson & Tilley, 1997). As such, critical realists not only concentrate on outcomes of interest, but also the context and mechanisms under which certain outcomes are achieved. According to Jagosh (2017), context can be interpreted as anything in the backdrop, that may not formally be part of, but can impact upon, the intervention such as cultural norms and values, history, existing public policy or economic conditions. Mechanisms may be defined by underlying entities, processes or structures (Astbury & Leeuw, 2010). For social interventions, mechanisms can be a cognitive process, which stimulate or demotivates stakeholders - including those delivering the intervention (Jagosh, 2017). Context and mechanisms can, therefore, affect the outcomes or effectiveness of an intervention.

During stage one of the analysis (reading and coding the studies), five general themes emerged all of which were colour-coded and which included: positive (green); negative (red); potential for adverse effects (orange); contributory factors (blue); and process (purple) (MaxMaps – Appendix 2.11.2). At the end of stage one, there were 18,279 individually coded pieces of text, representing 696 possible individual themes, of varying weight - ranging from 1 piece of coded text (represented by 114 codes) and up to 894 pieces of coded text (pertaining to 1 code: negative/challenging). At this stage in the analysis, the first set of codes was discussed in detail with the second reviewer, who had screened full texts. Any unexpected themes were examined to ensure conceptual agreement between reviewers.

During stage two, the themes were refined by exploring relationships between the codes. The first step was to re-examine all codes that represented just one piece of text and merging themes together, where appropriate. This reduced the total number of codes to 599. At this point, the relationships between themes were explored, leading to their subsequent refinement and the identification of 4 superordinate themes, under which all remaining subordinate themes were categorised.

Once studies had been conceptually folded together, a total of 544 final themes were identified including all subthemes (Appendix 2.10). However, these were categorised into six levels of detail, based on Bronfenbrenner's terminology (1995), ranging from macro [Level 1] to micro [Level 6] (Figure 5.4) – and consistent with the approach adopted by Fleming, McGilloway, & Barry (2016c) and Laragy & Ottmann (2011). With regard to overarching themes, most fell within the 'implementation facilitators' category, representing 6,289 coded pieces of text, followed by 'implementation challenges' (n = 5,111), and finally the mechanisms affecting the implementation and effectiveness of the intervention, namely the 'process' of implementation (n = 3,429) and 'contributory factors' (n = 3,132). The last two categories were 'cross-cutting' themes, often overlapping with 'implementation facilitators' and 'challenges'. Indeed, categorisation was sometimes not straightforward or blurred due to the complex and individualised nature of the social intervention in question. This is addressed in more detail below.



(5) Level 1 MACRO	Implementation facilitator [6,289]	Implementation challenges [5,111]	Process [3,429]	Contributing factors [3,132]
(33) Level 2 MACRO	Ingredients for success [2,702]	Potential problem / Area for improvement [1,692]	Logistics [697]	Conditions / arrangements [698]
(142) Level 3 MESO	Relationships [930]	Operational [610]	PA / staff recruitment [408]	Communication [134]
(192) Level 4 MESO	PA attribute [174]	Cumbersome systems [164]	Employ directly [108]	Family expect to be consulted [15]
(144) Level 5 MICRO	Shared interest / life stage [31]	Inappropriate / wrong focus [57]	Employment contract [10]	Ask questions [2]
(43) Level 6 MICRO	Age appropriate [5]	Targets/costs vs. quality [10]		

Figure 5.4 - Example of coding levels 1 to 6 (Macro, Meso, Micro)

As shown in the example below, MAXMaps were used to examine relationships between codes and, in particular, 'co-occurring codes'. Co-occurring codes relate to a piece of text that had two or more codes assigned to it. Generally, co-occurring codes which appeared 10 per cent of the time were examined, but when this produced too much (or too little) data, the percentage was adjusted accordingly until meaningful results emerged. For example, 662 coded pieces of text were identified as pertaining to the theme of 'perceived benefits' and therefore, 10 per cent of this figure (or 60) were used to filter the co-occurring codes (i.e. codes that co-occurred 60 times or more (across all 69 studies) in relation to 'perceived benefits' (Figure 5.5).

The remainder of this results section will summarise the qualitative findings in a narrative manner, using illustrative quotations to support and amplify key points. A more detailed analysis based on the use of MAXMaps and the identification of key concepts, theories and co-occurring themes, is provided in Appendix 2.11.2. As mentioned previously, a sensitivity analysis was carried out to determine if the MAXMaps of co-occurring themes were affected by the removal of studies with a very low CerQual score from the analysis. The results from this sensitivity analysis generally led to little or no change to the analysis. The detail of each sensitivity analysis is presented in Appendix 2.11.2.

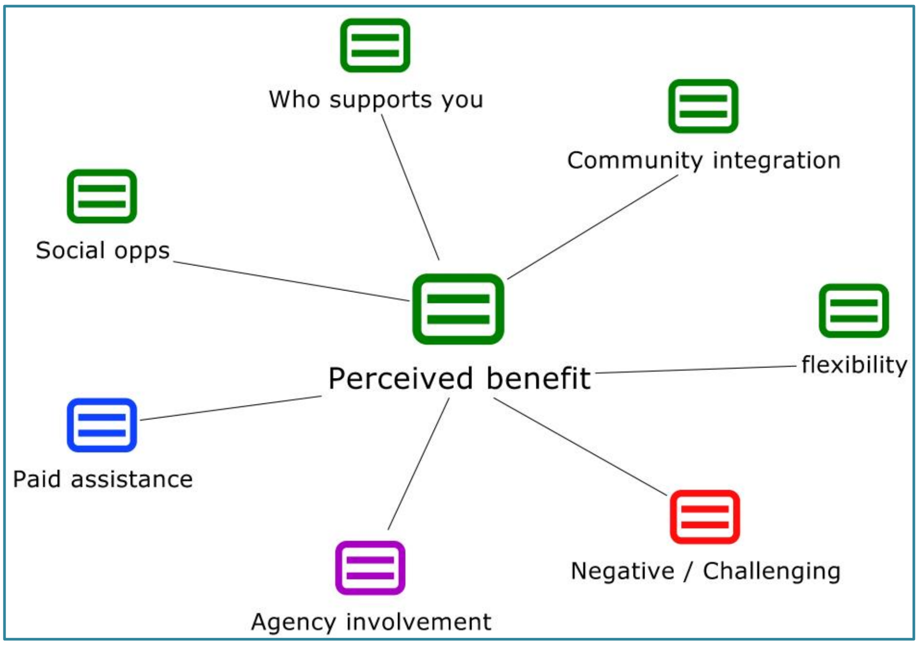


Figure 5.5 - Codes co-occurring with 'perceived benefits' 60 times of more

Data will be presented in two main sections, which examine respectively the successes or implementation facilitators (Section 5.4.7.2) and challenges to implementation (5.4.7.3). Two cross-cutting themes - 'processes' and 'contributory factors' - will be discussed in parallel and intermittently dispersed throughout the results sections, as appropriate. Some of the key messages from these themes will be expanded below, informed by the use of more MAXMaps and contextualised with the use of selected illustrative quotes transcribed directly from included studies and based both on participants' actual responses as well as comments from the authors.

5.4.7.2 Overarching (Macro) theme 1: Implementation facilitators

The first overarching (Macro - level 1) theme – 'implementation facilitators' - contained three macro (level 2) categories or subthemes relating to: (1) 'perceived benefits' for people with a disability or their representative (Appendix 2.10 – rows 379 – 454); (2) 'mechanisms of success' (Appendix 2.10 – rows 291 - 378); and (3) the perspectives of staff or organisational representatives (Appendix 2.10 – rows 103 – 127) (Figure 5.6). Each is described in more detail below.

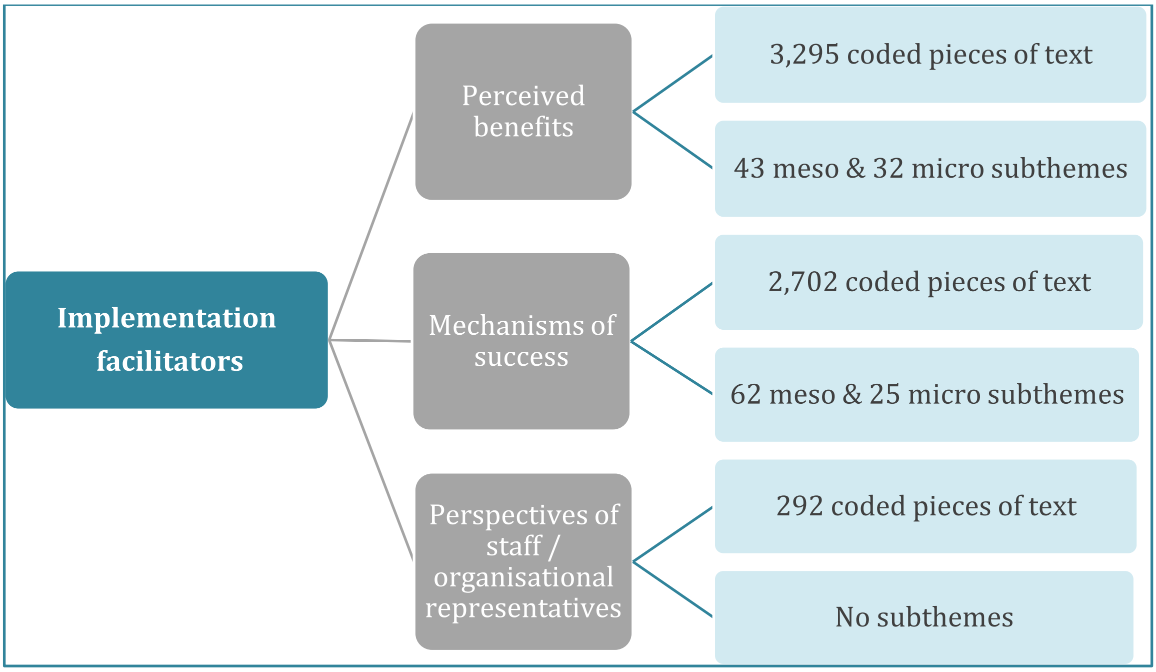


Figure 5.6 - Coding structure of 'Implementation Facilitators'

Perceived benefit

Perceived benefits was, by far, the most commonly occurring theme across the whole qualitative analysis, accounting for 18% of all codes, including 79 subordinate themes (rows 379 – 454, Appendix 2.10). The most frequently cited co-occurring themes are displayed in the MAXMap shown in Figure A2.11.19. These included: flexibility, a needs led approach, continuity of care / life, community integration, improved family life and social opportunities. It should be noted that perceived benefits did not only refer to positive outcomes, but also highlighted contextual factors and mechanisms that facilitated successful implementation, for example: network of support, paid assistance and agency involvement.

Flexibility

Flexibility was generally associated with increased choice and control, but specific aspects frequently mentioned were: the extent to which the intervention was seen as 'needs led'; the flexibility of the intervention in terms of type and timing of support; and flexibility in how the funding could be used (Figure A2.11.20). The quotes below reflect some of these commonly reported views:

Box 5.1 - Selection of illustrative quotations pertaining to flexibility

Needs led

"Respondents universally expressed the belief that participant direction enabled them to tailor the individuals' supports and services to their specific needs." (Gross, Wallace, Blue-Banning, Summers, & Turnbull, 2013)

Type and timing of support

"*With an individual budget, this consumer in Michigan has been able to hire an assistant to work with her on social skill development at times that meet the consumer's need and not vice versa."* (Alakeson, 2007)

How funding can be used

"Consumers were able to get therapies and equipment such as communication devices and lifts that were not accessible before or took years to get." (Vinton, 2010)

Freedom to choose who supports you

"I wanted to choose a male the same approximate age as my son to hang out with and do appropriate activities."

"I wanted to choose the person who was coming into my house and our lives."
(Butler, 2006)

In relation to the latter quotation, people usually valued particular attributes in their personal assistants, which influenced their decision in terms of who supported them (rows 363 – 369, Appendix 2.10).

Freedom

'Freedom', was the most cited perceived benefit overall, representing 23% (773) coded pieces of text. Some of these freedoms have been discussed above, i.e. freedom to choose 'who supports you', as well as, 'how', 'when' and 'where' the support is provided. However, freedom also extended to personal freedoms such as 'perceived autonomy', 'self-determination', 'self-direction', 'self-reliance', 'sense of empowerment', 'space and freedom' and 'freedom to make mistakes' (rows 394 – 408, Appendix 2.10, for full list of 'freedom' themes).

> *"I get to choose who, where and what. I wasn't comfortable when we had the lady coming in, putting me to bed at 6 and getting me up at 9, I'm 25, I don't want a complete stranger coming in to my house and washing my hair for me. Now, I can choose somebody that I trust and that I'm comfortable around." (PSI service user) (Sheikh, Vanson, Comber, & Watts, 2012)*

> *"…freedom to make our own choices, and to fail. Let us fail if need be. By failing, we can learn from our failures. If we do fail, do not blame it solely on our disability. We are only human after all". (Participant) (A. O'Brien, 2015)*

Improved self-image

Improved self-image, self-belief and self-esteem were frequently cited benefits for people with a disability, representing 12% (402) pieces of coded text. As can be seen from Appendix 2.10 (rows 412 – 435), these improvements were multi-faceted. Participants reported feeling more confident, having hope and a more positive outlook in life, in turn, feeling less stress and anxiety. They also reported feeling more resilient with self-managing behaviour which had the knock-on effect of improving perceived self-worth. People also reported enhanced emotional experiences, feeling more safe and 'cared for':

> *"It's hard to describe, the feeling you get inside when you feel so positive you know, the feeling that you're moving in the right direction… (Tim)" (Coyle, 2009)*

> *"Everything in my life is just better, have a direction for my future…feel more confident, happy and really excited about my future" (Buchanan, Peterson, & Falkmer, 2014)*

'More bang for buck'

This theme was considerable in size (representing 12% (384) pieces of coded text) and incorporated two conceptually different subthemes (rows 439 – 445). The first was a perceived value for money, in the conventional sense, with people reporting being able to shop around for the best value, or indeed make savings by removing the middle man:

> *"I get more so that's wonderful... I never could have afforded to go to pool therapy on my own. ... You get so much more bang for your buck. You get more for the money as far as product goods, and hours of service." (San Antonio & Niles, 2005)*

The second, perhaps more important theme in relation to value for money, was the perception that people could avail of better opportunities in terms of social and recreational opportunities, getting outdoors and being able to contribute to society and the community through civic participation. Unsurprisingly, many of these 'new opportunities' were closely associated with community integration (Figure A2.11.21). The importance of this community integration cannot be understated, and is threaded throughout the results (Box 5.2).

Box 5.2 – Illustrative quotations pertaining to community integration

Community integration
"We run into some of his friends around town. He has become a part of his own community. I have lived here for 30 years, but people didn't know my son. Now they do." (Conroy, Brown, et al., 2002)

Recreational Opportunities
"I got a mountain bike. I enjoy having a bike and use it to go out with friends to places like Reddish Vale. I think it's a good social thing and I think it's fun and I like being out in the fresh air" (Eost-Telling, 2010)

Social Opportunities
"I'm able to go out with my friends as and when I can and it means that I feel more positive about things than I did when I had more limited opportunities to do things." (Homer & Gilder, 2008)

Having paid assistance
"direct payments have 'permitted' disabled people to employ personal assistants, a facility that, in turn, has enabled them to participate in many activities outside the home, such as shopping trips, attending education and training courses, and leisure activities: pursuits which many non-disabled people take for granted." (Carmichael & Brown, 2002)

Blurring of themes – Food for thought

Before moving onto the second major subtheme here, it is worth noting some of the contradictions within the data. For example, one of the key themes for ‘perceived benefits’ illustrated in the MAXMap (Figure A2.11.19) was ‘negative / challenging’. It may seem odd that the ‘negative /challenging’ theme would co-occur with ‘perceived benefits’ but this demonstrates a blurring of concepts which can be explained by the individualised nature of the intervention; thus, for one person, directly employing support workers might be perceived as empowering, whilst for another, it may be stressful. This is illustrated by the following quotes:

Perceived positively

> *"I cannot begin to describe the difference employing my own care has made to me – Being able to choose has given me freedom in myself." (Mike Oliver & Zarb, 1992)*

Perceived negatively

> *“There are times when I just put my head in my hands and wonder why on earth I am putting myself through all the hassle of employing people when I could theoretically receive an equivalent service—it is a lot of extra work and a lot of extra stress and strain.” (Carmichael & Brown, 2002)*

Agency involvement

Another example of a, conceptually ‘blurred’, co-occurring theme is ‘Agency involvement’. This theme is, in fact, categorised as a ‘cross-cutting theme’, as mentioned previously. Cross-cutting themes are, generally, associated with both positive and negative responses, as is demonstrated in the MAXMap associated with ‘agency involvement’ (Figure A2.11.22). In terms of perceived benefits, there was a strong association with the positively perceived ‘continuity of care / service’.

> *“Once they received the direct payment they continued to use the same agency they were already using to purchase care privately; Angela had a good*

> *relationship with the agency, and the agency could ensure the carer provided was familiar to Catherine." (Kinnaird & Fearnley, 2010)*

Receiving help from agencies was often reported to relieve stress for people with a disability or their representative(s), stress that was often associated with staff recruitment or general management of an individualised fund.

Mechanisms of success

Mechanisms of success was the second major subtheme within 'implementation facilitators' and involved 2,702 coded pieces of text and 87 subthemes (rows 291 – 378, Appendix 2.10). The main subthemes will be discussed in this section and again supported with the use of selected illustrative quotations. These included: relationships, network of support, trust, financial recognition for voluntary work, appropriate pay, shift in power and thinking creatively.

Relationships

'Relationships' was the most common theme, with 'network of support' the most frequently occurring sub-theme (rows 347 -374, Appendix 2.10).

Network of support

A MAXMap analysis highlighted the integral role that the 'network of support' for the person with a disability plays in the complex processes associated with receiving and managing an individualised fund. This network of support typically comprised unpaid supports, such as family, friends and colleagues, but the analysis (Figure A2.11.23) clearly indicates that paid coordinators or support brokers were also strongly associated with the person's network of support. The types of support offered, included sourcing information, recruiting staff, helping to broaden the person's network and finally providing assistance with administrative and management tasks. It should be noted that the network of support was also sometimes perceived negatively by people with a disability and staff / organisational representatives, aspects which are discussed later.

> *"Find a family or a good friend you can count on for back-up because you never know when your daily caregiver isn't going to show up. You'd have some sort of emergency back-up that you know will be there." (Young & Sikma, 2003)*

Collaborative relationships

Collaborative relationships were also often cited as important. This was frequently linked to 'shared learning' and 'shared understanding'. Such collaborations ranged from individual / family dynamics to shared learning among support organisations and government agencies. People with a disability often spoke about PAs and their network of support having a 'better understanding' as a result of individualised funding, while others hired their family because they felt that they had a better understanding of their needs.

Collaborative relationships between individuals and providers

> *"Key factors for successful partnerships included having positive, collaborative relationships between support workers, person with disability and family members and regular communication between family and service providers." (A. Jones et al., 2015)*

Collaboration between agencies / departments

> *"One fiscal manager that we interviewed felt that a real benefit of the project was that it forced fiscal and program people to work together and gain an understanding of how all their jobs impact peoples' lives." (Conroy, Brown, et al., 2002)*

A closely related cross-cutting theme was 'interpersonal relationships' (rows 68 – 77, Appendix 2.10). Among these were consumer attributes, with certain characteristics enabling a more successful and collaborative relationships - including being proactive and open to new ideas.

> *"His strength, humour, and flexibility have helped him to attract and maintain a group of supports who share his interests, appreciate his individuality, and view him as their friend." (Malette, 1996)*

Other important aspects that affected relationships were 1) 'financial recognition for voluntary work' (amongst others - Appendix 2.10, rows 305-308), and 2) 'trust'; the latter emerged throughout the results.

1) *Financial recognition for voluntary work*

In the context of relationships, a MAXMap (Figure A2.11.24) revealed that 'financial recognition for voluntary work' was one of the reasons why people choose to take up individualised funding. It was related to the ability to hire family or friends, and sometimes meant that people with a disability no longer viewed themselves as a burden, since they were able to financially reward work that had previously been provided voluntarily:

Control over life

> *"It makes me happier that someone is now getting paid to do the jobs, like showering me. I think it is a job someone should get paid to do. It has given me more control over my life." (Adams & Godwin, 2008)*

Valued role

> *"You get something and it's nice to get something for the care you provide. So it is socially valued." (carer) (Breda et al., 2004)*

Less of a burden

> *"Well I had to rely on my friends to come and help us. And I didn't like it. I couldn't pay them anything, so I just had to rely on people fitting us in really. There is a big difference now because I feel like they're not doing it for nothing. I don't feel as guilty because they're getting something." Personal budget holder (Lambert, Lister, & Keith, 2011)*

2) *Trust*

Trust was discussed in relation to all relationship types, paid and unpaid, and often directly impacted continuity of care/service/life. When non-family members were hired, people often spoke of hiring a person 'known to the individual / family' (sometimes a friend), again reinforcing the importance of trust (Figure A2.11.25).

> *"Many people have very personal needs, such as assistance with bathing, and this program allows them to choose people with whom they are comfortable. As one person put it, 'I can choose people I trust.'"(Walker et al., 1996)*

Other important (albeit less frequently cited) 'relationship' subthemes can be seen in Appendix 2.10 (rows 347 – 378).

Other important 'meso' and 'micro' subthemes

There were many other meso and micro themes relating to 'mechanisms of success' (rows 292 – 346). A small number will now be highlighted before moving onto the final subtheme under 'implementation facilitators'. One such mechanism of success was the changing dynamics when employing supports directly. The 'shift in power' from 'agencies' to the person with a disability/representative was a common theme, empowering users to ensure high quality supports are in place.

> *"I didn't actually know I could be the boss of him instead of him being the boss of me." (Recipient) (Witcher et al., 2000)*

> *"If they don't do it for you, and it is a reasonable need, then you have the authority to fire them and get somebody else...[the most important benefit is] to get back in control of your life again." (Eckert, San Antonio, & Siegel, 2002)*

Furthermore, participants identified a number of mechanisms as integral to success including being a good employer, treating staff well and offering an appropriate rate of pay.

> *"I get to select my PAs pay rate; I like to pay my PAs as much as possible on Sundays and Bank Holidays. This way, they do not mind working on these days".(A. O'Brien, 2015)*

Thinking creatively / long-term vision with short term gaols

'Thinking innovatively / creatively', 'transparency', 'inclusivity', and 'positive-risk taking' were all viewed positively. Having a 'long-term aspirational vision / plan', facilitated by 'achievable short term goals' was often cited, and was linked with a perceived 'sense of purpose'.

> *"For another person, one of his family members spoke of him identifying a long term goal of moving out of his family home but that he needed some help in identifying the smaller goals needed in order to realise this goal." … "Cooking healthier meals and buying appropriate ingredients were some of her current goals." (A. Jones et al., 2015)*

Implementation facilitators from staff/organisational perspectives

This macro subtheme of 'facilitators of success' represented a minority of respondents (27%), and subsequently accounts for the smallest grouping of themes, totalling 292 with no meso or micro subthemes. However, MAXMaps were used to demonstrate the most common co-occurring themes (Figure A2.11.26). There was some cross-over with the perceived benefits (from the perspective of budget users), particularly around flexibility, network of support and collaborative relationships. Many of the remaining key facilitators (from perspective of staff/organisation representatives) related to the process of implementation, such as the use of 'local support organisations', the 'assessment' process, 'governance' and having a 'stakeholder forum'.

Local support organisations

In relation to local support organisations, further MAXMaps (Figure A2.11.27) revealed that the strongest associations were with other cross-cutting themes, namely the 'provision of information', 'guidance and advice', 'support with staff recruitment' and support with 'administrative tasks' such as 'payroll and tax'.

> *"In looking at why direct payments have expanded more quickly in some parts of the country than others, the link between strong user-led support and political commitment from local authorities/trusts was highlighted." (Priestley et al., 2010)*

> *"There has to be and there are good partnerships that are in place. There has been increasing recognition of the important role user led organisations can play." (Commissioner) (Bola et al., 2014)*

It should be noted that there were major concerns raised about the limited capacity (of small local organisations) as numbers increased, with no alternatives in place to offer the much needed support outlined above:

> *"Seven respondents said that the limited capacity of local support services had been a barrier to increasing uptake of direct payments." (Jordan, 2004)*

Assessment

Assessment (of need) was another process theme that was associated with implementation facilitators from the perspective of staff. Network of support was strongly associated with assessment (Figure A2.11.28). Although family members highly valued and sometimes had to fight to be present during assessment, staff were more concerned about assessing whether the person with a disability had a strong network of support, and therefore a suitable candidate for individualised funding. It should be noted, that this assessment of available support, in itself, sometimes caused discomfort for some carers.

Assessing network of support

> *"In terms of a duty of care, I think our staff are quite clear that everyone can get a direct payment as long as there's a circle of support to help them with it, and I think we're doing that. (Team Leader)" (Riddell et al., 2006)*

Carer discomfort with assessment of available support

> *"…during service user assessments practitioners are required to ask carers whether they are 'willing and able' to continue providing support and about any help they may need to do so. … some carers reported feeling uncomfortable being asked about their 'willingness' to continue providing care in front of the service user." (Glendinning, Mitchell, & Brooks, 2015)*

In terms of the approach towards assessment, a 'holistic or comprehensive approach' was valued, as was being 'outcome focused' - specifically focusing on personal, health, social care, mental health, quality of life and emotional well-being.

Training and Human Resources

Finally, analysis revealed that ‘training’ and ‘human resources’ were cross-cutting contributory factors which facilitated (or in some cases challenged) implementation. In terms of facilitators of successful implementation, MAXMaps (Figure A2.11.29) revealed a strong association with the availability of well-trained and informed professionals / practitioners including individualised funding coordinators / support brokers. Having a clear understanding of individualised funding was a perceived benefit whilst training was often suggested as a means of improving knowledge and understanding (for staff). Furthermore, provision of training (to people with a disability / representatives), particularly around staff recruitment and management / administrative skills, was often cited as a facilitator to successful implementation.

> *“The supporting organisation saw its role as giving advice on purchasing services, providing advocacy and a payroll service, and offering support with recruitment and the employer role. Providing, or accessing, training for recipients was another of its tasks.” (Witcher et al., 2000)*

‘Human Resources’ - itself a macro (level 2) process theme - had 18 subordinate themes (rows 50-67 – Appendix 2.10), most of which related to different types and quality of human resources available to people with a disability. However, MAXMaps (Figure A2.11.30) revealed other key aspects associated with HR, such as ‘thinking innovatively / creatively’, ‘community integration’ (both previously discussed – 4.7.2.1 & 4.7.2.2) and the use of ‘intermediary services’.

> *“This created a sense of trust and assurance for HSE staff who were otherwise cautious about releasing funds to individuals. Governance issues were of less concern due to the presence of an ‘intermediary body” (Fleming, McGilloway, et al., 2016c)*

5.4.7.3 Overarching (Macro) theme 2: Implementation challenges

Overall, there were fewer coded pieces of text directly linked to challenges when compared to those linked to facilitators of success (5,111 vs. 6,289). Three macro 'level 2' themes were identified here including: (1) 'perceived challenges / negative aspects' for people with a disability of their representative (2) 'potential problems / areas for improvement'; and (3) the perspectives of staff or organisational representatives (Appendix 2.10 - rows 103 – 287) (Figure 5.7).

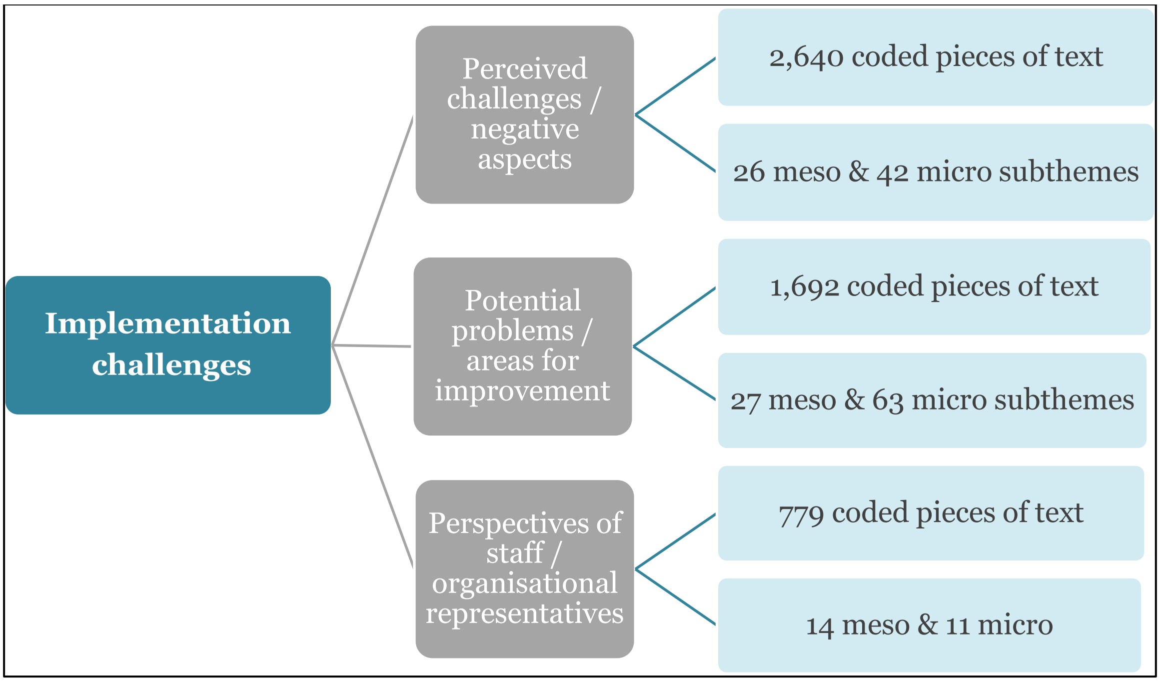


Figure 5.7 - Coding structure of 'Implementation Challenges'

Perceived Challenges / Negative aspects

There were 2,640 coded pieces of text associated with this theme, including 68 subordinate themes, categorised under 'individual factors' (rows 180-196), 'external factors' (rows 139 – 179) and 'cross-cutting challenges' (rows 129 – 138). 'Perceived challenges / negative aspects' was also an independent theme, associated with 820 pieces of coded text. A MAXMap revealed that the majority of co-occurring themes related to implementation ‘processes’ - including ‘staff recruitment’, ‘administration / management’ (particularly around forms and paperwork) and ‘information needs’ (Figure A2.11.31).

> *“Frequently the management of the budget – particularly the complex paperwork – was associated with additional burden” (Hatton & Waters, 2013)*

Agency involvement

Agency involvement was another of these processes – reflecting difficult past experiences, very often cited as the reason for choosing individualised funding in the first place.

> *“Some people had been keen to apply for a direct payment as soon as they heard about it, seeing this as a way to stop using services which were restrictive and denied them choice and control: ‘as soon as I heard about it I wanted to do it: to take charge of my own care was wonderful’.” (Witcher et al., 2000)*

The other main concerns related to agency involvement (Figure A2.11.22) included: a perception that individualised funding was ‘too rigid or inflexible’; a need for more information; and the lack of ‘available support’ within agencies.

Inflexible

> *“The Council can be inflexible in how they decide what to claw back - Gillian needs to spend much more on support during university terms so our spending is quite erratic. On one occasion they tried to take back funds that we needed later in the year – not very helpful!’ (Carer)” (Homer & Gilder, 2008)*

Information needs

> *“One [representative] raised a formal complaint against a practitioner after being misinformed about direct payments for people with dementia lacking capacity and the practitioner was removed from her case.” (Laybourne et al., 2014)*

Available support

> *“The available labor pool was a barrier for some, particularly in rural areas.” (Young & Sikma, 2003)*

Delay in process

One final challenge, commonly associated with perceived challenges (Figure A2.11.31), was the 'delay in process'. The types of processes that were reported to cause delays related to 'governance' and specifically the 'sign-off' of budgets or agreement on the proposed use of funds.

> *"Participants in both groups experienced long delays at the stage of validation of their personal budget. One LA participant summed up the frustration of this process: 'They agree it, it goes back to the social worker - I don't know - goes back to the finance board for them to agree. Well if one board agrees it at the council, why does it have to go all the way round the houses…why can't they just bang, do it.' LA group user"* (N. Campbell et al., 2011)

Delays were also linked to the 'review' process, either in terms of receiving a review in a timely manner or awaiting feedback after the review had taken place. These delays were a source of 'stress' for individuals and their representatives. There were other challenges related to 'delays in payroll' (and associated tax issues) which were occasionally linked to payment of staff, but more often relating to gaining 'access to funds' in the first place.

Delay receiving review appointment

> *"On the other hand, there are a number of service users who continue to experience stress and anxiety associated with delays after the set-up phase, for example in trying to schedule reviews." (Sheikh et al., 2012)*

Delay in processing payments

> *"Almost every month, I make a phone call in the middle of the month and call [the local funding agency] and say: 'Dear Mrs …, what is going on? Where is our money? Please remember, we need it in time. […] we have certain dates, when the health insurance will debit our account'. (Margret, mother of budget user, Group 3)" (Junne & Huber, 2014)*

Lastly, ‘human resource’ issues, particularly around ‘available support’, also caused delays in the process, with little information available to people to proactively address these issues (i.e. how and where to access support workers).

> *“A few pointed out that sometimes they were left without a carer, if one person left and they had to take the time to recruit another. They suggest perhaps a list of approved carers in the local area would help.” (McGuigan et al., 2016)*

The above text describes the co-occurring themes associated with perceived challenges, as an independent theme, but as can be seen from Appendix 2.10 there were also many subordinate themes categorised under individual, external and cross-cutting mechanisms. Some of these will now be discussed.

Individual

Challenges at an individual level related to ‘fears of losing funding’ and attendant services in the future as well as personal issues such as ‘self-neglect’ or ‘managing ill-health’.

> *"I could worry myself sick over whether funding changes might devastate my plans. I try not to think about it because I feel that my life is in their hands." (Zarb & Nadash, 1994)*

‘Negative emotions’ also presented challenges, such as ‘lack of motivation’ or ‘feeling isolated and lonely’; these were often linked to the transition from institutional settings to more independent living arrangements.

> *“Most seemed happy to be living independently, but some mentioned that they were still learning to be on their own and did not have any friends to come over to visit.” (Smith, Taub, Heaviland, Bradley, & Cheek, 2001)*

Indeed, a minority of participants noted that they did not think that individualised funding was appropriate for everyone.

> *“It is a great idea but it can’t be a cure all for everyone…it will be too distressing to go through the process” (Service user) (Rogers et al., 2009)*

External

External factors were cited much more frequently than the above ‘individual factors’ (1,225 pieces of coded text vs. 180) and were divided into 40 subordinate themes (rows 139 – 179, Appendix 2.10). The most common of these related to the interaction with ‘third parties’. This included experiencing a ‘negative or hostile attitude’ which was most commonly associated with agency involvement or with professional / practitioners. One example was a sense of being ‘discouraged’ from availing of individualised funding in the first place, or an ‘unresponsiveness’ of staff toward users.

> *“there is no information available from his social worker. In fact his social worker got really quite angry and upset with me, which was . . . interesting! ... It was as if they didn’t want it. Nothing positive was said about direct payments. (SP4)” (Laybourne et al., 2014)*

Others reported that third parties were ‘serving their own interests’, rather than the interests of the person with a disability.

> *“When one participant expressed an interest in self-directing his arrangement with his service provider, he was asked, ‘What would happen if everyone wants to go elsewhere? Where does that leave us [as an organization]?’(P3).” (Rees, 2013)*

Finding the right balance of power was also challenging, due to perceived ‘paternalistic’, ‘authoritarian’ or ‘patronising’ behaviour towards people with a disability or their representatives. This among other things (e.g. ‘a weak network of support’ or ‘increased bureaucracy’ related to administration and management) was perceived to have taken a ‘toll on carers’ which, in turn, had impacted negatively on the overall experience of individualised funding.

> *“I do think it’s a terrific amount of work that’s on top of your caring time and sometimes I feel we’d be as well just doing the caring. (Parent of adult with complex needs, Local Authority 1)” (Riddell et al., 2006)*

> *"Brilliant idea as long as a family member can undertake all of the paperwork involved. Has improved my sons quality of life 100% but has given me 100% more work." (Wilson & Pickin, 2010)*

'Increased bureaucracy' - often linked to 'logistics' such as the 'need for additional bank accounts' (rows 466 – 494, Appendix 2.10) - also meant there was no time for other pressing matters, such as 'finding competent staff'. This was compounded by 'staff turnover / retention'; these were commonly associated with other external factors such as 'rurality' or 'low pay', the latter feeding directly into the second most common 'external factor' i.e. 'financial issues'.

Additional bank accounts

> *"I keep 3 separate bank accounts, one each being for DLA, ILF and DP. I have been told that I have to have these separate accounts, but this involves me in a significant amount of additional hassle, having to work out the proportion of each PAs time that needs to come out of each funding stream/account." (Homer & Gilder, 2008)*

Low pay

> *"In some cases, families were worried that they would lose their support workers if they could not provide them with enough paid hours, or enough pay." (Leahy, Ong, de Meyrick, & Thaler, 2010)*

Another major financial issue commonly cited was 'disappointment in terms of the level of funding received', which was exacerbated by a 'lack of clarity' about 'how the allocated money could be used'. This 'lack of clarity' was exacerbated by mixed messages or experiencing inconsistent, inflexible or rigid approaches.

> *"There is not a list available that tells me what I can and what I can't spend my direct payments on. Also it varies from council to council what they think you can spend your direct payment on." (Wilson & Pickin, 2010)*

Cross-cutting challenges

Lastly, cross-cutting challenges related to both people with a disability and staff / organisational representatives. These challenges related to: 'increased workload'; systems and processes that were 'too complex'; processes that were 'not inclusive' or perceived to be 'intrusive'; 'inequitable distribution of funds'; and a 'lack of trust' and 'risk aversion' which, in turn, often led to difficulties 'relinquishing control'. Ultimately, these factors, along with the many other challenges previously discussed, led to a high degree of 'stress' for many involved (Box 5.3).

Box 5.3 - Selection of illustrative quotations pertaining to stress

Increased workload

"The main focus was on the increased workload, a perception of high levels of pressure and stress and competing demands such as eCPA, audits, Safeguarding and new computer systems." (Rogers, Ockwell, Whittingham, & Wilson, 2009)

Complexity of systems

"The sheer complexity of arrangements was difficult for both workers and recipients to grasp: 'It really needs someone in the DSS or I don't know where, to sit down and get an overview of all the systems…because they're a mess. As someone who's working at the coal-face, they're a mess.'" (Witcher, Stalker, Roadburg, & Jones, 2000)

Inequitable distribution of funds

"Really, who do we cherry pick or … for SDS. It's not equitable because we don't have the time to do it or offer it to all our clients. I don't" (Practitioner) (Eost-Telling, 2010)

Relinquishing control

"Releasing control is the issue. We're such paternalistic agencies with well defined infrastructures. For years, we've had individual budget money in small sums ($3-5,000) available through our Family Support program. Now that more money is involved, there is more tension." (Olmstead, 1999)

Potential problems/Areas for improvement

This second macro sub-theme relates to perceived problems or areas for improvement as distinct from challenges in the sense that, whilst problematic, most participants were able to adjust to, or overcome, the difficulty in order to proceed with the intervention. However, it was felt by many respondents that, if left unaddressed, these potential problems would become untenable over time. There were five categories amounting to 89 subordinate themes (rows 198-287 – Appendix 2.10).

The most commonly discussed concerns related to 'operational challenges' (rows 264 – 287). Among these, 'information needs' was by far the most cited problem with 'inaccurate information', 'mixed messages' and 'inaccessible information' confounding the issue further.

Inaccurate information

> *"Well in fact the social worker gave us the wrong information, so I was never fully aware how all the bits fitted together. ULO participant" (N. Campbell et al., 2011)*

Mixed messages

> *"Receiving inconsistent or contradictory information served to confuse individuals more and generate extra stress and anxiety." (Shaw, 2008)*

Inaccessible information

> *"Others were overwhelmed with the sheer volume of information received on entering the scheme." (McGuigan et al., 2016)*

A MAXMap confirms these confounders, with a strong link to the theme 'lack of clarity' (Figure A2.11.32). Co-occurring themes indicated that people required information from professionals/ practitioners and agencies about basic aspects of implementation, namely: a deeper understanding of individualised funding, what kind of supports were available, where that support could be accessed, and what the money could be used for (amongst other things).

> *"One manager explained that '[Support Planners] are giving clients missing information about what their entitlements are'. This manager felt that the Support Planners were not sufficiently informed about the SLF, which was why they did not always provide clear information." (A. Jones et al., 2015)*

Cumbersome systems

The next potential problem area (operationally) was a 'cumbersome system'.

> *"The difficulty comes – not with what is trying to be achieved, but rather the systems and culture within services." (Bola et al., 2014)*
>
> *"But then she warned: 'this envisaged flexibility has been hampered by the use of systems such as performance indicators and target-setting in the work environment; which limits the time of interactions with service users, a crucial social work function'." (Williams & Tyson, 2010)*

Micro subthemes reveal a perception that systems had an 'inappropriate focus' (particularly during needs assessment).

> *"Some people with mental health problems raised concerns that the forms used for the questionnaire were not geared towards their needs so that they had to go through a lot of questions that were not relevant to them." (Newbronner et al., 2011)*

Others held negative views around the utilisation of the 'medical model' and targets / costs being the focus for staff rather than quality of services.

Medical model

> *"This potentially results in a tendency to medicalize, compartmentalize, and intrude upon daily living freedoms that would not be tolerated by those without disabilities." (Young & Sikma, 2003)*

Targets vs. quality

> *"But subsequent contract negotiations raised concerns about moving away from a person centred approach, posing difficult questions of targets versus quality" (N. Campbell et al., 2011)*

In fact, some people felt that implementing individualised funding equitably was not really a priority for staff, but rather 'firefighting' the more challenging or acute cases. Others perceived the system to be 'inflexible and too rigid', often duplicating work. 'Inconsistent approaches' (level 4 meso theme) were also highlighted as operational challenges, which led to frustrations, further confounding the information needs, as previously discussed.

Human Resources

'Human resources' (HR) was the second most discussed potential problem or area for improvement (rows 224 – 246, Appendix 2.10). The biggest issue relating to HR was the lack of 'available support', which is a theme that has come up numerous times previously.

> *"My carers seem to come and go all the time; I only receive direct payments to pay for a few hours a week. So it is not enough for someone to leave an [other] employment for and a few hours don't always appeal." (Shaw, 2008)*

At a micro level, people reported an 'under or over-estimation of need', also reflecting the 'need for additional help', having to 'rely too much on informal supports' or becoming 'over-reliant on one person'. Others felt they now had 'less contact with formal services', which posed a concern for them.

Under-estimation of needs

> *"My only concern relates to the fact that I am not getting enough money to cover each month. I really need someone to come in every day, rather than no-one being here on Tuesday and Friday as happens at the moment" (Adams & Godwin, 2008)*

Rely on informal supports

> *"A family from a non-English speaking background reported particular difficulty, as translation services were not provided, meaning that they had to rely on a family member living overseas to translate and assist in filling out the SLF application via Skype." (A. Jones et al., 2015)*

The next HR issue was the lack of training with many reporting little or no training. People with disabilities reported ‘needing skills and knowledge’ (e.g. in areas such as ‘vetting of support workers’, ‘placing adverts’, ‘rostering’ or ‘disciplinary role as employer’) but, in fact, those who supported them (paid and unpaid) also required training (e.g. facilitating a ‘journey of discovery’ as part of the person-centred-planning process).

Lack of training

> *“This person’s family member felt that support workers were not adequately trained in how to support her daughter’s mental health needs.” (A. Jones et al., 2015)*

Needing skills and knowledge

> *“Managing personal assistants was not, however, always straightforward. Again, there did not seem to be much proactive practical support or training available from local authorities or third party organisations on how to manage staff, beyond completing the necessary paper work. … aspects which participants found challenging included addressing poor performance, asking someone to leave, and employment law.” (Lambert et al., 2011)*

Another HR challenge concerned working relationships and the need to develop ‘respectful boundaries’, in order to avoid ‘conflict’.

> *“For other users, although happy with the much better relationship they enjoyed with staff since using direct payments, there was a feeling that boundaries between work and friendship needed to be clear. Some people had experienced problems where staff had not respected this.” (Stainton & Boyce, 2004)*

Sometimes this reflected the need for paid or unpaid supporters to adjust their approach to supporting individuals with a disability (e.g. moving from paternalistic to empowering dynamic), but other times it required ‘behaviour changes’ for the individuals with a disability themselves. Such changes reflected the need to move away from ‘learned passivity’ where people (often formerly institutionalised) needed to become more independent and self-reliant, sometimes linked to the need to let go of previous arrangements; for others it was learning to accept help on offer.

Move from paternalistic to empowering dynamic

> *"She has also suggested to me to back off. She is good! She felt he could deal with less help from me. We worked on it and she was right. He now lives without assistance from both of us." (Parent talking about support worker) (Butler, 2006)*

Learned passivity

> *"Similarly, some participants, particularly those with longer experiences of service use, did not find it easy to adjust to the opportunity to think and take responsibility for themselves: 'I wasn't really participating . . . because it's sort of the [practitioner's] job to do things like that. . . . I didn't really want to get my hands dirty with it' (A03, budget ongoing)." (Hamilton et al., 2015)*

Disabling practices

Another potential problem or area for improvement related to 'disabling practices' (rows 198 – 210, Appendix 2.10). This category reflected, amongst other things, the sense that professionals / practitioners or agencies were acting as 'gatekeepers to funds' (particularly at assessment) and 'over-riding' the wishes of the end users. At a micro level people sometimes felt that their 'hands were tied', being pressurised around decision-making, with 'no alternative options' provided and therefore choice and control was limited. In a small number of cases people felt even 'more restricted' than before the intervention. People felt that disabling practices also extended to the wider public, with a lack of understanding of individualised funding, with the need for 'disability awareness' generally within society, ultimately facilitating community integration, itself heralded as a perceived success of the intervention.

> *"More concerning was when this seemed to reflect a more pervasive (although not necessarily explicit) enactment of power differentials in which it was the professionals rather than the service user that set the agenda: 'It's probably me, but I get the feeling that they think that I'm lower than them and I . . . shouldn't question things, I should just go along with it' (B03, budget ongoing)." (Hamilton et al., 2015)*

The final two potential problems or areas for improvement related to 'financial issues' and 'negative emotions / perceptions'.

Financial issues

Anxiety and stress was experienced when participants spoke about future problems that could emerge due to, for example, 'budget cuts' whereby funders may try to 'claw back funds' or discontinue individualised funding. Other financial issues raised concerned 'charges for people with a disability' to cover, for example, administration costs. 'Hidden costs' were also flagged amongst the 'unsustainable' aspects of implementation, as were disappointment with level of funding and financial issues more generally. Finally, 'keeping funding sources separate' was another concern for people with a disability; further complicating spending restrictions / criteria (with different needs being addressed by different funding streams), causing undue confusion and stress (Box 5.4).

Box 5.4 - Selection of illustrative quotations pertaining to financial issues

Multiple funding streams
"The third area of concern related to a situation which arises when there are multiple funding streams and systems are not properly integrated, leading to an increased administrative burden" (Rummery, Bell, Bowes, Dawson, & Roberts, 2012)

Hidden costs
"For the two people who were faced with advertising, the start up payment was woefully inadequate: an initial newspaper advert was placed and $25 did not cover the cost... Respondents also detailed a range of other start up costs involved, which they had to pay for themselves: insurance, payments for a personal assistant to go on a lifting and handling course, overalls and plastic aprons for personal assistants. The start up payment clearly needs to be substantially increased." (Leece, 2000)

Unnecessarily bureaucratic and burdensome process
"I keep 3 separate bank accounts, one each being for DLA, ILF and DP. I have been told that I have to have these separate accounts, but this involves me in a significant amount of additional hassle, having to work out the proportion of each PAs time that needs to come out of each funding stream/account". (Homer & Gilder, 2008)

Negative emotions

'Negative emotions or perceptions' are presented in terms of subthemes (rows 247 – 263, Appendix 2.10) including 'increased responsibilities' associated with individualised funding, which were often apprehensively undertaken, with people sometimes feeling 'daunted' by the new role and responsibilities. Others felt a sense of 'guilt' or that they were 'asking for too much' or perceived themselves as a 'burden'. This feeds into the 'vulnerability' experienced by people with a disability, highlighted by concerns as to 'what would happen to them when their parents pass away'. This was exacerbated by a perceived dependency on an imperfect system that, sometimes, was not challenged for fear of 'rocking the boat', potentially jeopardising the supports in place.

Finally people were often 'suspicious' of the system due to negative previous experiences or because of the perceived restrictive / disabling processes in place. For example, people felt that they were 'penalised for working', or that individualised funding was 'set up to fail', with agencies occasionally accused of 'paying lip service' to the concept of individualised funding. Left unchecked, such negative perceptions could adversely affect the delicate relationship balance, previously discussed, and therefore the need for information, communication and transparency is further reinforced.

Implementation challenges from perspective of staff / organisational representatives

This third and final macro theme, within implementation challenges, represents 779 coded pieces of text and 24 subordinate themes (rows 104 – 127, Appendix 2.10). As with facilitators of implementation, many cross-cutting 'processes' and 'contributing factors' fed into implementation challenges, from the perspective of staff or organisational representatives. A MAXMap was produced to demonstrate the main areas of concern for this cohort of stakeholders (Figure A2.11.33). Many of issues highlighted, repeat the concerns of end users (previously presented), such as 'available support', 'information needs', 'financial issues', problems associated with 'delays in process', 'governance', 'administrative tasks', and 'HR' issues. However a unique concern relates to fear, one of the three subordinate themes discussed below.

Fear

In terms of subthemes, 'fear' was the most common theme associated with staff / organisational representatives (rows 104 – 119, Appendix 2.10). A MAXMap revealed that many fears were linked to perceived 'risks' for people with a disability (Figure A2.11.34). This included fears of 'abuse' (by directly employed staff or even their own network of support), with 'vulnerabilities' potentially being exploited by various parties. The data also revealed that risk was closely linked to 'safeguarding' individuals with a disability (as perceived by staff), which was sometimes linked to 'risk aversion' when assessing, planning and delivering activities (particularly in relation to community integration).

> *"'Concerns from social workers regarding their accountability'; 'Social work practice is still rather paternalistic in some quarters staff have concerns re: risk and control'; 'Perceived vulnerability of some groups/individuals'" (Jordan, 2004)*

There were also fears associated with the perception that individualised funding was 'unsustainable', the 'impact on existing services' and 'financial issues'. An associated concern, for organisation representatives, related to people with disabilities 'poaching agency staff' for direct employment, thereby reducing the workforce within agencies.

Impact on existing services

'Impact on existing services', related to fears that individual purchasing power would lead to the 'privatisation of care' which, in turn, would lead to loss in jobs and a potential decline in quality of supports. Furthermore, it was perceived that 'economies of scale' would be jeopardised - with the knock-on effect that larger service providers would dominate the market, in turn, reducing choice (Box 5.5).

Box 5.5 - Illustrative quotations pertaining to impact on existing services

Poaching agency staff

"The agency we were using couldn't guarantee the continuity of carer that I wanted for my wife so, when I got to know a good one, I asked her to leave the agency and come and work for my wife as a PA. Now she gets better pay and conditions, even paid holidays, so we are all happy." (Homer & Gilder, 2008)

Privatisation of care

"The use of private, not-for-profit and voluntary bodies to provide services was a form of privatisation and would inevitably lead to job losses for existing council workers." (Riddell et al., 2006)

Quality of supports

"This issue of private contractors not having a background in Personal Budgets, not understanding the development history or meaning of 'choice and control', and therefore missing the key point of personalisation when delivering on contracts is something that concerns service users and carers." (Bola, Coldham, & Robinson, 2014)

Job losses

"Another care manager, who was also a day centre manager, experienced some conflict of interest in that, if all users went on to direct payments, the day centre would close." (Witcher et al., 2000)

Domination of market by larger providers

"Smaller providers voiced concerns that if provider organisations were not able to develop systems that could cope with varying and flexible demands from SDS users, they might not be able to continue operating if a large amount of business came that way. This would mean that fewer, larger providers could dominate the market, potentially reducing choice, increasing costs and increasing prices for SDS users." (Rummery et al., 2012)

Financial concerns

At a micro level, financial concerns often related to fears of 'fraud' or 'misuse' (of money) by people with a disability or their representative. However, as a number of people with a disability pointed out, it would be 'self-destructive to misuse' the money, potentially leaving people in vulnerable or unviable situations.

It should also be noted that there was very little evidence of reported misuse of funds across the body of research. Another unsubstantiated fear was that people with a disability would ‘flood the system’ looking for individualised funding. In fact, uptake was generally lower than expected, often requiring additional and substantial efforts to boost uptake.

> *“P1 pointed out that ‘it is in my interest to make sure that my money is being used well ... If I spend foolishly I can’t get out of bed in the morning ….. it’s not in people’s interest to let money go missing’.” (A. O'Brien, 2015)*

Accommodating diverse levels of need

Another challenge for staff, that frequently emerged, related to difficulties accommodating diverse levels of need. This was particularly challenging when transitioning, from delivering information and supports, between people with ‘high support needs’ and those with ‘ongoing support requirements’ and conversely to those who required ‘little support’. This challenge was heightened by trying to deliver individualised supports to people from ‘different backgrounds’, with ‘different life experiences’ and attendant expectations.

> *“People were in vastly different situations: some were lifelong service users, others new to social care, while many had changing health conditions.” (N. Campbell et al., 2011)*

> *“There are a range of experiences for people whilst an inpatient – some feel it necessary, others hate it so clearly need a range of crisis options to respond to the range of experiences.” (Bola et al., 2014)*

Staff scepticism

The final challenge related to staff scepticism about individualised funding. Some of these scepticisms relate to fears and other factors (previously discussed) but staff members were also concerned about process issues such as ‘governance, ‘calculation of allocation’, ‘assessment’ (particularly ‘self-assessment’), ‘inter-personal relationships’ and other ‘HR’ issues. Such scepticism would likely impact on the delivery of services, with some participants reporting a lack of knowledge, engagement and commitment from some staff members.

"I just thought it was another fashionable thing that's coming in and then it'll all be finished by… when something else replaces it, to be honest" (Eost-Telling, 2010)

5.5 DISCUSSION

5.5.1 Summary of main results

The present study involved a mixed methods review which identified 4 quantitative, 66 qualitative and 3 mixed-methods studies that met the inclusion criteria. Data pertain to a 24 year period from 1992 to 2016 and represent the outcomes and/or views and experiences of over 14,000 participants/respondents, including people with disabilities and their carers/family members as well as practitioners/staff. The quantitative studies included 3 randomised, 3 randomly-selected study samples and 1 non-randomised study, representing 19 titles in total. The qualitative studies represented 96 titles in total and a range of designs including in-depth interviews, mixed qualitative methods, case studies, open-ended survey questions and other methods, such as secondary qualitative analysis.

The complexity of the intervention and inherent methodological limitations may be reflected in the low number of quantitative versus qualitative studies, which represented just 9% of the included studies. Notably, many other descriptive quantitative studies were found, but they were not investigating effectiveness and/or did not meet the inclusion criteria. Furthermore, the very high level of heterogeneity did not allow for a meta-analysis of these quantitative data. In addition, the risk of bias was either unclear or high in the majority of studies (Figure 5.2), although the quality of the quantitative research was judged to be fair to good for most studies.

Quantitative findings

In all, 35 measures were used to test the various health and social care outcomes of interest, as outlined in the protocol. Some studies reported multiple measures for the same outcome of interest (e.g. 5 different measures of client satisfaction (Benjamin et al., 2000)). Brown et al. (2007) and Glendinning et al. (2008) reported most of the outcomes of interest - four and five respectively. The remaining five studies only reported between one and three outcomes of interest. Of the 35 measures reported, there was no difference detected between the intervention and control group for 13 (37%), with a further 6 (18%) reporting no difference in (at least) one of the three study sites (Brown et al., 2007) (Table 5.3).

For those that did report statistical differences across the relevant health and social care outcomes reported, most were in favour of the intervention group, with the (partial) exception of cost-effectiveness and adverse effects.

In terms of primary outcomes of interest, the most consistently positive outcome for the intervention group was 'client satisfaction; five of the seven studies reported this primary outcome, with all five showing intervention group participants to be significantly more satisfied than their control group counterparts. The four studies that reported on the second primary outcome - Quality of Life – were evenly divided between 'no difference detected' and a significantly positive result for the intervention when compared to the control groups.

In terms of secondary outcomes, one study reported 'physical functioning' with no difference detected between groups. Five studies reported adverse effects across a range of outcomes, with no difference detected in two studies and significantly positive results in favour of the intervention group in one study. The remaining two studies (reporting several adverse outcomes and several study sites) were evenly divided between no difference detected and significantly positive results in favour of the intervention group.

Cost-effectiveness data (a secondary outcome of interest) were available for only two studies, with no difference detected in one and statistically significant differences in favour of the control group in the other, but only on one of two measures. It should be noted that the study by Brown et al. (2007), had three study sites and two measurements. One cost-effectiveness measure favoured the control group across all three sites, while the second measure reflected no difference between intervention and control groups in two of the three sites, with the last site favouring the control group (Table 5.3).

The penultimate outcome of interest, adverse effects, was presented for five studies. One study favoured the intervention group, while there was no difference between intervention and control groups for two of the five studies. Benjamin et al. (2000) presented two measures of adverse effects, with one showing no difference between groups, while the second favoured the control group - representing one of the eleven measures (used across 5 studies). Brown et al. (2007) presented 6 separate measures with one measure favouring the intervention group across all three study sites. Differences between study sites were seen across all of the remaining five measures, ranging from no difference to favouring the intervention group. None of the adverse effect measures favoured the control group in this study.

Finally, data were available for four 'other' relevant health and social care outcomes with no difference detected in three of the four. The remaining outcome - 'Safety / Sense of security' - was significantly different in favour of the intervention group.

Qualitative findings

The qualitative meta-synthesis presented the experiences of individuals participating in an individualised funding intervention, as well as documenting implementation successes and challenges from the perspective of multiple stakeholders. The views of over 9,000 people were captured in the 69 studies, 73% from the perspective of individuals with a disability or their representative. As with the quantitative findings, the intervention was positively received overall despite, amongst other things, considerable issues accessing funding, implementation challenges and process delays. Most people reported, even those who were somewhat aggrieved, that they preferred the intervention over traditional service provision.

The improved levels of satisfaction, consistently reported in the quantitative data, are most likely linked to the many perceived benefits which were identified in the qualitative findings and, in particular, improvements in self-image and self-belief. Participants reported feeling more empowered, self-determined, and confident with an enhanced sense of purpose and freedom. They also reported a sense of control over their lives - self-directing their supports with an active involvement in decision-making, identification and procurement of supports and activities.

These perceived improvements, in people's sense of self-belief and self-worth, are most likely reflected in the positive changes demonstrated in the quality of life outcomes. Where no differences were detected, it is reasonable to suggest that the many challenges experienced and discussed in the qualitative synthesis, particularly at early implementation stage, may have adversely impacted on perceived quality of life. Participants often reported feeling more burdened with the complexity and level of bureaucracy involved in the new process than in their formerly more passive role in traditional services. This was most prevalent in the early stages of implementation with perceptions generally improving over time and once people had settled into their new way of life. This suggests, from a research perspective, that six months is not an appropriate follow-up time point for assessment in the sense that there may not be sufficient time for the intervention to be put in place and to bed down appropriately. It is interesting to note that Brown et al. (2007), who conducted a large-scale, high quality, relatively 'low risk' study, collected data 9 months after baseline, and found highly significant differences in favour of the intervention group.

Regardless of duration between baseline and follow-up, the implementation challenges associated with the overly complex systems - seemingly framed around existing assessment, review, governance and financial arrangements - continued to present problems over the 24 year period covered by this review. Therefore, perhaps it was these systemic issues that negatively impacted participants' quality of life over longer periods of time. Importantly, the qualitative findings emphasise a need to simplify processes, predicated on respectful, inclusive and trust-based working relationships, rather than the perceived authoritarian dynamic, whereby informal unpaid carers reportedly feel there is an assumption that they will provide unconditional 'free' support, for fear of losing (the highly prized) individualised funding and attendant supports or because no alternative exists. Participants often perceived staff as focusing too narrowly on finances and costs, rather than on the quality of supports provided. Participants also felt that the review process was inequitable and one-sided, whereby very high standards of reporting and transparency was expected from end users, but unresponsive, delayed and poor quality support was perceived to reflect the funding bodies and providers. While these examples may not be true for the majority of cases, such perceptions fed into the tension and conflicts that sometimes seriously challenged the success of the intervention. The lack of clarity and lack of information as well as inconsistent approaches were all compounding factors and indeed, these were most commonly reported challenge/complaint across all studies. Thus, the provision of timely, accessible and transparent information is a priority.

Unfortunately, there was extensive evidence of disabling practices and attitudes among some funding bodies and support agencies. Staff members were often fearful of misuse of funds or other fraudulent activities by individuals with a disability or their network of support. Staff often perceived people with a disability to be vulnerable to these kinds of situations and they tended, therefore, to be very risk averse in order to safeguard their clients. Interestingly, only one quantitative study reported on client safety and a significant difference was found in favour of the intervention group. This finding strengthens the reported qualitative experience that staff fears were generally alleviated with regard to safeguarding and risk when the intervention was implemented successfully, with strong networks of paid and/or unpaid support in place (Coyle, 2009; Dimitriadis, Laurie, Lane, & Lyall, 2007; Olmstead, 1999; Phillips, Mahoney, & Foster, 2006; Witcher et al., 2000). In fact, the intervention group generally experienced significantly fewer adverse outcomes when compared to their control group counterparts, including unmet needs, with the exception of one study (representing 1 out of 11 adverse measures collected across 5 studies). This is not to say that risk and safety concerns were absent from the qualitative data, with some instances of conflict and abuse reported, although this was far from the predominant experience.

Finally in terms of value for money, many studies descriptively reported the costs of delivering individualised packages of support, but only two looked at the more important question of cost-effectiveness, with a third conducting a cost-benefit analysis. Based on the available data, the evidence of cost-effectiveness was inconclusive. Glendinning et al. (2008) found no difference, while in the 'Cash and Counseling' study, one measure of cost-effectiveness was seen to favour the control group while the other measure was inconsistent between study sites (with two of the three sites showing no difference) (Brown et al., 2007). Woolham and Benton (2013) found costs to be considerably higher for the intervention group, but the attendant cost-benefit analysis also showed the control group to be experiencing 'some degree of ill-being' when compared to the intervention group (Woolham & Benton, 2013).

As outlined earlier in this review, early studies have shown individualised funding to result in cost savings (Conroy, Fullerton, et al., 2002; Zarb & Nadash, 1994) or cost neutrality (Stainton et al., 2009). This cost neutrality is consistent with more recent findings from Canada and New Zealand, where costs were found to be generally lower or on par with traditional methods (Field, 2015; Stainton, Asgarova, & Feduck, 2013) and cost neutral - as far as the level of care and support package is concerned (K. Jones et al., 2012). While Woolham and Benton (2013), in this review, tentatively suggest better well-being for the intervention group, Stainton et al. (2009) suggest that certain modes of delivery (such as microboards) may in fact offer equal or better value for money when other considerations such as building social capital, ongoing network support and ability to support persons with complex support needs, are taken into consideration.

In line with this thinking, the qualitative data also support the concept that individualised funding offers value for money, both financially and in terms of opportunity. Participants reported the ability to 'shop around' in order to find the best value for money. Perhaps more importantly, however, the qualitative data also revealed that people placed equal, if not more, importance on the value to purchase services from within mainstream, community based settings, in turn, increasing community integration and attendant experiences and opportunities.

Furthermore, the qualitative findings showed that staff and organisations were often surprised by the modest requests for funding from people with a disability, perhaps because such individuals reportedly, did not wish to be a burden on the system or to potentially use funding that would be more beneficial to somebody else. This burden and guilt, sometimes reported from recipients of individualised funding, could be avoided if a universal, robust and equitable resource allocation system was in place, whereby every individual is assessed on the same basis, rather than subjective and informal assessment processes often described in the findings reported here.

It is also important, when considering the issue of cost-effectiveness, to take into account the possible longer term benefits or cost savings of individualised funding such as 'Quality Adjusted Life Years' (QALYs) or 'Disability Adjusted Life Years'. While these longitudinal data are not currently available, the benefits reported from our qualitative findings, in terms of for example, perceived health improvements, greater self-reliance and more independent living arrangements, would tentatively suggest that quality of life, mental health, wellbeing and other health and social care outcomes improve for service users as a result of individualised funding. If this is indeed the case, resource use within the formal healthcare system may be substantially reduced. An urgent need for more economic evaluations is indicated.

5.5.2 Overall completeness and applicability of evidence

The very broad search strategy adopted for this review (as described in Appendix 2.2) outlines the totality and breadth of the evidence presented. The large proportion of grey literature (n = 42 studies, 55%), in particular, highlights the amount of government- funded and organisation-commissioned research that has been conducted during the 24 year-period. The exclusion of these data would have compromised the completeness and applicability of the review and especially given the strong implementation focus adopted throughout, with organisation-commissioned research often prioritising implementation. Having said that, the considerable list of excluded studies (Appendix 2.5) which, albeit did not meet our eligibility criteria, highlights the very strong interest in, and increasing awareness of the importance of, individualised funding across the world.

Only 7 studies, with eligible quantitative data, were identified to address the first aim of the review - to assess the effectiveness of the intervention across a range of primary and secondary outcomes. As indicated earlier, the heterogeneity of the studies and other analytical limitations precluded the possibility of undertaking any kind of sub-group analysis. However, this was balanced by the very rich and abundant qualitative data (69 studies) which represents a very large group of >9000 intervention participants and provide important and useful insights into the particular contexts and mechanisms under which individualised funding is more (or less) successful and the factors that impact implementation. Importantly, these findings are based on the experiences of a very wide range of stakeholders including individuals with a disability, their representatives / advocates and support workers, funders and organisational staff/representatives.

5.5.3 Limitations and potential biases in the review process

The published protocol was closely followed. However, given the unexpected scale of the review and the complex nature of study designs, a number of changes were required as outlined in section 5.3.3.5. For example, a 'results refinement' process had to be developed to deal with the unmanageable number of search results and to filter the studies in a robust, transparent and replicable manner. The changes to protocol, that may introduce bias, include the fact that, due to the huge number of studies involved, only one reviewer conducted the detailed quality assessment, although double screening of full texts did involve a degree of quality screening, as outlined previously. Qualitative coding was also conducted by only one reviewer, although emerging key themes were discussed with a second reviewer, with unexpected themes explored and discussed in detail.

Another change, that may introduce bias, related to the tightening of eligibility in terms of population. Older adults (>65) without evidence of a life-long disability were excluded (e.g. age-related frailty vs. life-long disability). This was implemented to ensure that the population of interest, those with a disability, was appropriately represented in the evidence presented. However, there is a possibility, that by removing older people, there may have been older people, with a life-long disability who were inadvertently excluded, due to insufficient data to assess their disability status. However, every effort was made to include older adults who did report a life-long disability or another eligible disability, such as dementia.

As with both previous reviews (Carter Anand et al., 2012; Webber et al., 2014), the evidence presented in this review is limited methodologically with the subsequent impact on quality and risk of bias clearly reported. However, having reviewed the extensive body of literature, we would argue that such limitations are inherent in complex social interventions (as discussed previously), and, as such, these limitations provide useful implementation insights, and a depth of understanding that directly impact on future policy development and future research in this area. Furthermore, it should be reiterated that the evidence in the current study was subjected to a more thorough screening process than in the two previous reviews, with more robust inclusion criteria utilised around methodological design and rigour.

5.5.4 Agreements and disagreements with other studies or reviews

As outlined in the protocol, the authors were aware of only two previous systematic reviews prior to commencing this study (Carter Anand et al., 2012; Webber et al., 2014). In one sense, the eligibility criteria within the current study were broader and more inclusive; for example, Webber et al. limited their review to mental health users only. The need for a results refinement process (Appendix 2.2) further highlights the broad scope of the current review. In another sense, however, this review was more restrictive in terms of the quality of evidence. To this end, quantitative studies were excluded if they were not designed to robustly evaluate effectiveness or did not have a control group, while previous reviews included studies without control groups (for example). Therefore, the studies included in this review are very different, in some respects from those captured in the above reviews.

At the same time, however, the findings from this review were consistent in many respects with the two reviews previously identified. For example, Carter Anand et al. (2012) concluded that: participants were positive about the experience of individualised funding; collaborative relationships between government, providers, users and carers are integral to the success of individualised funding; resource allocation models are essential and require government involvement and leadership, and that objective needs-based assessments should be used to determine individual budgets. Periods of transition also need to be carefully planned with supports established to empower a change in practice among existing services providers. Advisor, management and support-broker services should be widely available for those who require them. A person-centred approach should be at the centre of the design and delivery of individualised funding and people with a disability should be empowered and supported in the decision-making processes with appropriate safeguards in place to manage risk and promote safety (Carter Anand et al., 2012).

While safeguarding is always important when working with vulnerable groups, the evidence from this review would caution against over-emphasising this area. Staff and the wider network of support for the person with a disability, can inadvertently have a disabling effect, potentially inhibiting the community integration and fulfilment of personal potential. An over emphasis on safeguarding also carries the risk of people 'falling back on the system', when inherent implementation challenges present themselves, rather than focusing on the facilitators of successful implementation, such as building a strong and supportive network of support, and training advocates to help individuals with a disability navigate the new, independent, self-reliant path. As reiterated throughout the review, every situation is different and some people will have higher support needs than others, but the starting point should be one of trust, enablement and empowerment, fully exploring the most self-determined path and subsequently ensuring necessary supports are in place either temporarily or permanently.

There were also a number of similarities with the review by Webber et al (2014) and especially where similar studies appeared in both reviews. For instance, perceived benefits were reported in relation to choice and control, flexibility, improved satisfaction, quality of life, greater independence, empowerment, confidence among other personal, health and social care outcomes. Conversely, one study in the Webber et al review found individualised funding to be cost-effective (Forder et al., 2012) but that study did not meet the eligibility criteria for this review because only 26% of the study population had a disability/mental health problem.

A considerable number of additional literature reviews were excluded when screening titles and abstracts (Harkes et al., 2014), or when screening full text (which led to the exclusion of five reviews). Harkes et al's systematic review focused on published evidence and intellectual disabilities only and as such, the review was more limited in scope. However, the recommendations were consistent with the findings reported here, including the need for more accessible information, the need for staff training, more local support organisations and the streamlining of funding streams. The authors also highlighted the problematic reluctance amongst practitioners to promote individualised funding. None of the remaining studies identified in the screening process were systematic reviews although, importantly, the references contained therein, informed the hand-searching for this study.

5.6 AUTHORS’ CONCLUSIONS

5.6.1 Implications for practice and policy

Previous reviews have concluded that there is little evidence to suggest that governments in the past (e.g. in the UK) had clear strategies underpinning the implementation of individualised funding (Harkes et al., 2014). However, recent years have seen a considerable and growing interest in individualised funding as a means to improve the lived experience of people with a disability and their wider network of support (paid and unpaid). This review provides a comprehensive synthesis of evidence to help inform the decision making of governments, funders and policy makers, whilst also providing researchers in the field with useful information and recommendations for future research.

Practitioners - Shift the focus!

This review presented evidence that those delivering health and social services, for people with a disability, may be sceptical about individualised funding due mainly to concerns for their occupational role (e.g. job loss) and for those they serve (e.g. safeguarding, risk aversion). Furthermore, organisations responsible for delivering services sometimes perceive individualised funding as a top-down Government led cost-cutting measure. All three of these notions, amongst many other misconceptions presented in this review, (e.g. misuse of funds, recipients flooding the system), are not grounded in evidence. In fact, the limited cost-effectiveness data are inconclusive. The findings of this review suggest that those in charge of implementing individualised funding, might need to shift their focus from one of resistance and scepticism, to one of openness and enthusiasm.

Many services sell themselves as ‘person-centred’, in line with international best practice. If that is the case, the overwhelmingly positive response in terms of client satisfaction, both quantitatively and qualitatively, should inform practitioner responses and positively influence their attitudes toward individualised funding. In terms of outcomes, with the exception of one adverse measure, all the evidence points to no difference or improvements - based on the use of individualised funding. Therefore, the concerns associated with safeguarding and risk aversion are, by and large, unfounded. This is, of course, a reflection of the hard work, in terms planning and delivery, from both paid and unpaid supports. Practitioners should therefore trust in their ability to engage with the end user and their network of support to safely deliver services, through this new mode of funding and, in turn, provide better quality and highly valued services.

Finally, in terms of job losses, there is a need to shift the focus to one of potential opportunity. This review highlights that one of the most substantial implementation challenges was the lack of available support. This is consistent with the notion that those working within the health and social care services may lose their jobs as a result of individualised funding. Whilst it is possible that the job descriptions, in terms of day-to-day tasks, may change, ultimately this may lead to better job satisfaction, since inter-personal and working relationships were seen to improve as a result of individualised funding. Whilst the evidence from this review is overwhelmingly positive, more research is needed to assess the impact of individualised funding on workplace relations. The reported challenges generally arose from attempts to shoehorn the new mode of service delivery into traditional systems, thereby leading to unnecessary bureaucracy, stress, anxiety and burden for those delivering and receiving services. As such, this review also suggests that an overhaul is required in terms of governance, and the associated assessment, monitoring and review processes that were traditionally used, but which are no longer fit for purpose within the individualised funding model of service delivery.

Training

One area requiring further investment is education and training across the board. Practitioners need to acquire or improve upon their skills in order to fully realise the potential of individualised funding. Firstly, more education is required outlining the background and philosophy of individualised funding. This review highlighted that those with a better understanding of individualised funding were highly valued by end users. It instilled confidence in those receiving services, but those practitioners also acted as a valuable source of information and guidance. Unfortunately, however, many practitioners did not fully understand individualised funding, or the implementation plan (if any existed). This in turn, led to inconsistent approaches, mixed messages and misinformation – aspects which caused distress and frustration for those in receipt of services. If those implementing individualised funding are well informed, then a 'trickle-down' effect should ensure consistent messages to end users and their representatives.

While such education may be delivered for end-users, training is also required for the informal support network, in order to move from a paternalistic to empowering relationship. This move is challenging, as highlighted in this review, often causing tension and conflict, but with the right 'behaviour change' training, family and friends may learn to adjust their learned behaviour, to one that is more enabling, trusting and equitable. Finally, this behaviour change is also required for individuals with a disability, who sometimes require guidance in moving from a passive role to one of self-reliance and self-direction. The findings of this review indicated that simply moving to individualised funding encouraged such behaviour change, but in other circumstances, a prolonged history or institutionalisation warranted more directive action.

Lastly, as highlighted throughout this review, the network of support is integral to success. As part of this, paid supporters need to have the communication and facilitation skills to guide, for example, the journey of discovery, whereby a person (perhaps for the first time) explores what they want to achieve in the short and longer term, and the steps that are required to achieve those goals. Developing a plan, detailed enough to allow progression, but flexible enough to respond to changing (physical and health) needs or personal preferences, is also something that requires training and experience.

Financing individualised funding

The changing economic and social landscapes, in recent times, amongst a number of countries throughout the world with many years' experience of implementing individualised funding (e.g. Scotland and England) - has meant that the delivery of such supports has had to be amended and adjusted. These changes reflect how the 2008 -2013 recession adversely affected health and social care spending, with European countries such as Greece, Ireland, Spain and Portugal (arguably some of the hardest hit European countries of the recent global financial crisis) having seen substantial cuts in these areas (Charlotte Pearson & Ridley, 2016). With many European countries still feeling the effects of the recent financial crisis, the Irish government, for example, is expectant that plans to implement individualised funding can be framed within a cost-neutral paradigm (Department of Health, 2016).

However, policy makers, in countries planning initial implementation of individualised funding, need to be cognisant of the inevitable set-up and transitionary period, whereby the whole sector shifts their thinking and practical approach to delivering services. As outlined above, this requires, amongst other things, significant investment in training. Furthermore, there will be costs associated with changing the traditional governance, monitoring and review systems, an essential step to ensure successful implementation. Indeed, on a more practical level, there will be a period of time when a person may be availing of traditional services, while trialling new supports, often within the mainstream, community setting – perhaps requiring dual-funding. It is inevitable that additional set-up costs will be required. If cost neutrality however, continues to be a driving force, then policy needs to be in place to release funds from ‘block funding’, thereby providing the flexibility to part fund traditional services while also part funding new and emerging sources of support.

Indeed, those countries which are striving to improve the delivery of individualised funding are not limited to economic casualties of the recession; others with little austerity - having avoided the 2008 – 2013 recession - are also striving to improve the delivery of individualised funding, such as efforts under the new National Disability Insurance Scheme (NDIS) in Australia (Reddihough et al., 2016). Policy makers can look to such countries, that are utilising a social insurance scheme, for guidance into the future, but this review would suggest that vast amounts of money are being spent on services with which many people are dissatisfied and simply do not want to use. Arguably therefore, the first step could involve an overhaul of current systems, including the allocation of funding. As such, service providers should be included in this process, encouraged to develop business plans that outline the necessary steps to transition from traditional service delivery to one that embodies the philosophy and ethos of individualised funding.

Final thoughts

Regardless of the intention (or evidence base for effectiveness), it seems that individualised funding is consistently being adopted and supported globally as shown by the overwhelmingly positive response amongst individuals with a disability and their representatives, highlighted in this review. It is also seen as a mechanism that helps achieve the goals outlined in the United Nations Convention on the Rights of People with Disabilities. This review provides an important and comprehensive resource and robust evidence base for policy makers and funders wishing to make informed decisions around the implementation of individualised funding. It presents the most robust effectiveness data currently available, whilst also specifically highlighting the all-important implementation successes and challenges. The latter can directly impact planning and cost-effectiveness. Indeed, such cost factors are important in highlighting successful aspects worthy of investment whilst also demonstrating potential (and costly) pitfalls that can be avoided with prudent planning and careful consideration.

5.6.2 Implications for research

This review clearly highlights and synthesises the extensive and rich qualitative evidence from studies conducted in many countries - across changing social, political, economic, social care and healthcare landscapes - and over a considerable period of time. It also points to the inherent difficulties associated with collecting quantitative data on complex social interventions of this nature, with a subsequent lack of robust effectiveness data. As a result, the authors suggest the need for more methodologically rigorous evaluation studies ideally forming an integral element of any implementation plan for countries considering the piloting or national roll-out of individualised funding. The authors also suggest the use of more appropriate methods for real world evaluations of complex interventions within complex systems, such as realist evaluation (Pawson & Tilley, 1997).

The time frame for evaluating complex social interventions should be carefully considered. Six months was the minimum follow-up period for studies included in this review, with some (excluded) studies collecting data before the six-month period had lapsed. The qualitative meta-synthesis underscored the significant challenges experienced during early implementation, and a perception that a true sense of benefits, challenges, processes, procedures and inter-personal relationships only emerged after sufficient time had passed. Therefore, future researchers should consider (resources permitting) conducting studies which incorporate longer follow-ups (minimum 9 months), and ideally at multiple time-points over a longer period of time. Due to ethical considerations, and the individualised, needs-led nature of the intervention in question, methodological limitations, such as potential loss/attrition at follow-up, are unavoidable. However, as Glendenning et al. and Brown et al. have effectively demonstrated, the use of large randomised samples goes some way toward addressing this issue.

This review highlights that the evidence on cost effectiveness is inconclusive (as is arguably the case for many social care interventions) and any perceptions that individualised funding is more expensive (or cost efficient) are not grounded in evidence. Indeed, this review also highlights the fact that robust financial data are often not available at national or local level. Researchers need to work closely with policy makers and practitioners to outline the type, level and depth of data required to conduct an in-depth cost-effectiveness analysis. In fact, considerable thought needs to be given to all evaluative data required, considering ways to avoid duplication of effort. Such collaborative relationships need to be developed in the early planning stages, well before initial implementation has commenced.

Mixed methods designs are also recommended for future research in the field of individualised funding (and social care interventions more generally). The (limited) quantitative data presented in this review, if considered on a stand-alone basis - would potentially cast doubt on the continued promotion and implementation of individualised funding, notwithstanding the considerable methodological limitations of the studies in question. By contrast, the qualitative findings provide a useful insight into when, how and for whom the intervention works and the many challenges/pitfalls. For example those with an intellectual disability or mental health problem, often need more input from brokerage/facilitation or intermediary supports, particularly at initial set-up stage.

However, there is an urgent need for more effectiveness studies and perhaps more standardised approaches to data collection to ensure better comparability across studies and countries. The development of the ASCOT scale (PSSRU, 2014) is a good example of such standardisation and not least given the relative lack of reliable and validated measures with which to assess outcomes (as indicated by the disparity between measures used in studies included in this review). At the same time however, it is important that researchers feel able to respond appropriately to country-specific contextual factors and issues of national interest without an over-emphasis on global comparisons. In direct response to these contextual factors, the majority of studies, within this review, adopted a methodologically tailored approach. This inevitably meant that a meta-analysis was not possible, but valuable data was still available to inform future policy and practice. As such, robust data, even if very localised and context-specific, are better than poor quality data or no data at all.

Finally, the authors of this review would encourage the adoption of mixed-methods approaches in further systematic reviews when assessing the effectiveness of complex 'real-world' interventions in the field of health and social care. Our experience indicates that mixed-methods reviews are certainly more complex and time consuming than more traditional approaches. However, the rewards are considerable, not only in terms of providing a more thorough synthesis of available evidence which takes into account the experiences and views of potentially many more participants, but also offering a wealth of detail and useful insights to improve our knowledge and understanding around important health and social care issues across the world.

SUPPLEMENTS

List of appendices

1. Appendix 2.1 – Search strings for various electronic databases / search engines
2. Appendix 2.2 – Paper outlining results refinement process: *Identifying and tackling challenges in undertaking mixed-methods systematic reviews: an exemplar from the field of disability*
3. Appendix 2.3 – Qualitative study characteristics
4. Appendix 2.4 – Quantitative study characteristics
5. Appendix 2.5 – Excluded studies
6. Appendix 2.6 – Risk of bias in included quantitative studies
7. Appendix 2.7 – Risk of bias and quality in included qualitative studies
8. Appendix 2.8 – Amended screening tool
9. Appendix 2.9 – Description of primary, secondary, adverse and other outcomes reported
10. Appendix 2.10 – Complete list of qualitative themes, subthemes and levels of coding
11. Appendix 2.11 – Data and analysis

CHAPTER SIX: DISCUSSION

This final chapter comprises the following sections: (1) an outline of the contextual factors, mechanisms and outcomes that would appear to facilitate or inhibit the implementation of individualised funding; (2) a discussion of how the findings relate to relevant theories on choice, capability and self-determination; (3) an exploration of a number of options for implementing individualised funding on a national basis; and (4) an evaluation of the study including a discussion of the findings and their implications for both national and international policy and practice.

6.1 THE CONTEXTUAL FACTORS, MECHANISMS AND OUTCOMES OF INDIVIDUALISED FUNDING

As outlined earlier, this research was conducted within a realist evaluation framework. This theory driven model focuses, not only on the outcomes of interest but also, and perhaps more importantly, the 'context' within which these outcomes are possible / achievable and the 'mechanisms' that facilitate these outcomes. This CMO configuration is used to describe the interplay between context, mechanism and outcomes (Gilson, 2012; Jagosh, 2017; Pawson & Tilley, 1997), recognising that there is some degree of overlap between the three. The outcomes of this study will be summarised first before considering, in detail, the context and mechanisms that led to these outcomes.

6.1.1 Outcomes

Study One (Chapter Three) provided trends data at a national level both for the largest group of service users in the disability sector in Ireland - those with intellectual disabilities - and for the most commonly utilised services in Ireland (day services). Importantly, these findings highlighted potential disengagement with services, an urban/rural divide and a largely unchanged, rigid and outdated system of data collection which seems incapable, in its current form, of capturing (much needed) information on new and innovative forms of supports, such as those resulting from individualised funding arrangements. This study also provided the historical context/background for Study Two which involved an evaluation of four pilot individualised funding initiatives in Ireland with a view to identifying in particular, the successes and challenges of implementation. The findings indicate that, despite a number of barriers to implementation, the new initiatives were welcomed as a progressive development beyond traditional service provision.

Study Three (Chapter Five) examined the effectiveness of individualised funding in improving health and social care outcomes, based on an extensive systematic review of the literature. The review findings indicate that statistically significant differences between the intervention and control group (when they were detected) generally suggested improvements in outcomes for those receiving individualised funding and self-directed supports. These included enhanced quality of life and increased client satisfaction, fewer adverse effects (in two out of five studies) and a greater sense of security. Although considerably fewer in number, positive outcomes were also seen in the control group in terms of cost effectiveness and fewer adverse effects. However, the latter only represented one out of twelve measures across five studies, whilst the evidence on cost-effectiveness was also very limited. Therefore, these findings should be interpreted with caution.

The findings of the systematic review also provide a deeper understanding of the complexities underpinning these kinds of initiatives/supports and how they lead to particular outcomes. For example, quality of life and client satisfaction were most likely influenced by reported improvements in self-image, self-belief, self-worth, and self-esteem. Participants explicitly reported an improved sense of confidence, independence, resilience and personal freedom, as well as a more positive outlook on life, greater hope, and less stress and anxiety.

Implicitly, the themes that emerged from the qualitative findings reported in the review – and also linked to relevant outcomes - include a change in the mind-set of those who provided both paid and natural supports, who tended to move from a position of fear and anxiety toward an appreciation of the abilities, passions and interests of those whom they supported. Individualised funding recipients reported a new appreciation for money, money management and the benefits garnered from the flexibility of 'shopping around', often referring to value for money.

Conversely, the limited findings on cost-effectiveness tentatively suggest that individualised funding is more costly than traditional services. However, the recurring positive reactions towards individualised funding seen both in the evaluation reported in Study Two and in the literature - particularly when compared to previous experiences of traditional service provision - would suggest that value for money should be assessed in the context of properly conducted cost-effectiveness analyses (CEA). These should consider the full range of costs alongside a wide range of outcomes including personal, social and health outcomes, experiences and opportunities. This kind of approach (and its associated complexities) was demonstrated within the review by the study conducted by Glendinning et al., (2008) which used Incremental Cost-Effectiveness Ratios (ICERs) based on results from ASCOT and GHQ-12 outcome measures. However, this study found no statistical difference between intervention and control group.

Interestingly, many of the challenges to implementation reported in the systematic review were also seen in the evaluation of the pilot initiatives in Study Two. A prominent example was difficulty in accessing funds in the first instance as well as rigid and disabling processes. Study Three highlighted assessments of need as one example of such a disabling process which often had an inappropriate focus due to a 'one-size-fits-all' approach. As a result, assessments reportedly under- or over-estimated need which meant that some individuals were left without sufficient funding for basic support needs, whilst others were left feeling they had too much, which was often accompanied, in turn, by attendant feelings of guilt or apprehension. On the other hand, the needs of individuals changed sometimes slowly over time, or at other times quite suddenly due to ill health or an emergency situation. Unfortunately, the 'review' systems in place did not seem equipped to respond in a timely manner, often leaving people in a vulnerable position and overly-reliant on informal supports.

A constant challenge seen in the national and international evidence, was obtaining timely, accessible and appropriate information in order to alleviate fears and confusion. Interpersonal relationships with practitioners were also problematic due to a lack of knowledge and training on their part. Practitioners reportedly struggled with relinquishing control, yet paradoxically also reported challenges associated with an increased workload. Agencies and staff themselves often feared individualised funding, its sustainability in the longer-term, and its impact on existing services. Furthermore, some staff feared the potential impact of individualised funding on end users, such as poor quality supports, fears around accountability and safeguarding, or indeed a loss of person-centred services due to the commodification of care through the domination of large (privatised) providers. Finally, there were implementation challenges that threatened the long-term sustainability of individualised funding, such as complex and cumbersome processes and systems, resulting in end-users being over burdened with bureaucratic tasks.

6.1.2 Context

Context may be interpreted as anything in the backdrop that may not formally be part of the intervention, but which can impact on the intervention including, for example, cultural norms and values, history, existing public policy or economic conditions (Jagosh, 2017). As discussed earlier in this thesis, the terminology used to describe individualised funding is, itself, influenced by country-specific contextual factors such as pre-existing financial systems or even familiarity of language (e.g. cash and counselling, microboards, shared management, or individual budgets). However, a number of specific contextual factors that impact the development and implementation of individualised funding were identified from the collective findings reported from the series of studies reported in this thesis. One of the most important factors - the political context - is examined below.

6.1.2.1 Political Context

The introduction of individualised funding was the result of decades of incremental political change. These changes in international and national policy and practice were examined in Study One (Chapter Three). For example, in Ireland, international policy and trends directly influenced national policy decisions when the 'UN Standard Rules on the Equalisation of Opportunity for People with Disability' led to the development of the 'Commission on the Status of People with Disabilities' in Ireland - now known as the 'National Disability Authority' - as well as the development of 'A strategy for equality' (Commission on the Status of People with Disabilities, 1996). Government-driven national policy (e.g. Health Acts of 1953 and 1970) can (and should) directly impact the implementation of services on the ground. In the past, this was most notable in the transition from services dominated by the church to largely advocate-led, voluntary organisations. These changes, however, led to the unforeseen professionalisation and medicalisation of disability services in Ireland and elsewhere, whereby services were streamlined within group-based institutions which, in turn, led to eventual deinstitutionalisation.

However, the above changes were also influenced by other contextual factors, such as the economic environment. For example, the economic recession (2008-2013) meant that many countries, including Ireland, were unable to accelerate the process of deinstitutionalisation due to heavy cuts in funding/resourcing. Indeed, Ireland was identified by the European Association of Service Providers for Persons with Disabilities (EASPD), (Ward, 2015) as one of six underperforming countries in this regard (Study One).

Study Two (Chapter Four) describes how the UK was at the forefront of policy development that directly influenced the global paradigm shift towards individualised funding, namely the National Health Service and Community Care Act 1990, followed by the Direct Payments Act 1996. Together, these saw the UK leading the way toward the national implementation of individualised funding which was accompanied by one of the first ever large-scale evaluations – the IBSEN study. However, despite strong policy and political will, the execution of this study was also influenced by changes within the political landscape. Most notably, the authors reported that a single political announcement, by the then Minister for Social Care - that 'individual budgets' represented the future of social care in the UK - had resulted in participant disengagement with the evaluation; participants no longer saw the value in testing the effectiveness of individual budgets because national implementation was viewed as a foregone conclusion – thereby ultimately affecting intervention fidelity. As a result, the researchers were required to change the focus of their study from testing the effectiveness of individual budgets to assessing models of implementation for future roll-out (Glendinning et al., 2008).

At a micro level, practices on the ground were also sometimes seen to be directly influenced by policy as demonstrated in Study One (Chapter Three), whereby the utilisation of person-centred plans for people with a disability in Ireland increased from 37.1% to 78.7% over a nine year period (2004 – 2013) following a number of policy recommendations before and during the same period (NDA, 2005). However, as discussed later in this chapter (Section 6.1.3.5), the perceptions of person-centred plans varied considerably.

6.1.2.2 Location

A second contextual factor that potentially influences the implementation of, and outcomes associated with, individualised funding is geographical location. For example, as shown in Study One, despite a national trend towards urbanisation, the greatest increase in day services was seen in rural areas which might suggest a lack of alternative options for people with a disability. The provision of services in specific areas and attendant funding prioritisation is therefore an important contextual factor influencing implementation. Indeed, a UK study showed that the uptake of individualised funding initiatives was lowest in areas that prioritised traditional residential care expenditure when compared to other forms of community care, once again highlighting how a limited choice of services dictates practice (Fernandez, Kendall, Davey,

& Knapp, 2007). Interestingly however, the same authors also highlighted the greatest uptake of individualised funding in areas of low density population, perhaps indicating that access to traditional services was too demanding in more rural areas due, perhaps, to a lack of available services or issues with accessibility. The findings of Studies Two (A3.4) and Three (A2.10) lend some support to this notion with transport, access and rurality emerging as key themes in each.

Furthermore, evidence of an increased uptake in rural areas might suggest that the trend toward rural provision of services in Ireland, as demonstrated in Study One (Chapter Three), might prove beneficial to the success of individualised funding in the longer term.

6.1.2.3 Personal characteristics / circumstances

Unsurprisingly perhaps, contextual factors which relate directly to a person with a disability or their representatives, also impact the perceived acceptability and appropriateness of services on offer. As reported in Study Three (Chapter Five), those requiring services are from a wide range of socio-demographic backgrounds with diverse cultural and religious norms and expectations; indeed, these often challenged the implementation of individualised funding initiatives.

Residential settings also vary greatly from group-based staffed homes, to independent living arrangements. Such individual circumstances or lived experience are also often influenced by socio-demographic factors, as well as types of disability and varying levels of complexity, all of which have been identified to challenge service providers. These are examined in more detail below.

6.1.2.4 Type / level of disability

Many studies described in the systematic review highlighted the capacity of people with a disability, particularly those with cognitive impairments, to comprehend and manage individualised funding. For some, their network of support took on this responsibility, whilst others engaged with service providers to manage more complex administration; others decided that individualised funding was not for them and chose to return to traditional services which they considered better suited to their needs. Thus, although people's capabilities and personal circumstances varied, the fact that a number of options were available to them was important in supporting their self-determination. It is this focus on self-determination that seems to set individualised funding apart from traditional service provision.

Traditional service provision is clearly not suitable for everyone and in Study One a cohort of people, with low levels of need and / or relatively mild impairments, were highlighted as often relying on mainstream services and activities. The findings reported later in both Studies Two and Three indicated that traditional service provision does not provide many benefits for this cohort, a realisation that frequently only emerges after the person commences the service. However at that stage, funding has typically been tied into a block grant which, in Ireland at least, limits that person to one service provider for up to five years. This, in turn, can lead to many frustrations for individuals with a disability, or their families. The findings from the evaluation of the pilot initiatives in Ireland – and also from the wider systematic review - showed that individuals or their representatives reportedly tried unsuccessfully to change service provider or their existing services, but were left feeling burnt out from 'fighting' an inflexible system. This reportedly led to people disengaging with services, opting instead to stay at home, or to privately fund community based activities, although this, of course, is not an option for those who are disadvantaged socially and economically.

6.1.2.5 End-user disengagement

A disengagement with services may explain the unusual trends seen in Study One whereby the number of younger people with disabilities (<35) availing of day services had declined during the 15-year period, despite figures to show an increase in the number of under 35s in the general population. Alternatively, this may simply be due to a lack of services / new places becoming available, a common implementation challenge reported in Study Three. The lack of available supports may also explain the fear of losing traditional support when engaging with individualised initiatives, as reported in Study Two. Indeed, this fear and associated sense of vulnerability were also seen in the findings from the systematic review and were often reported to affect uptake in the first instance. Personal feelings of fear, stress and anxiety or more positive emotions such as hope, enthusiasm or 'a sense of purpose' are all influenced by the contextual factors described above.

6.1.2.6 Practitioner buy-in

A final contextual factor that can impact the implementation of individualised funding, relates to human resources within the sector. For example, the findings of Study Two show how a level of disengagement by frontline staff and practitioners can adversely affect implementation. The lack of practitioner buy-in was also consistently highlighted as a concern within the systematic review, with risk aversion, conservatism, protectionism of existing services and the 'attitudinal' attributes of practitioners, all potentially adversely affecting implementation. Indeed, frontline staff members often act as gatekeepers and without active engagement and willingness to source and share relevant information, or to participate in training activities, the success of individualised funding may be jeopardised.

The evidence from the systematic review also indicates that organisational staff members and practitioners who embraced the new initiatives were deemed indispensable by end-users. Similarly, the existence of local support organisations can positively impact implementation, but the findings from the Study Three also suggest that these organisations are often under-resourced and do not have the capacity to expand in line with growing numbers, with end users therefore forced to rely more heavily on informal supports. While the existence (or absence) of reliable, well-trained staff in appropriately resourced organisations are certainly contextual factors, they are also relevant to the mechanisms that facilitate successful implementation. These are discussed below in more detail.

6.1.3 Mechanisms

Mechanisms may be defined as underlying entities, processes or structures that operate in particular contexts to generate outcomes of interest (Astbury & Leeuw, 2010). In the case of social interventions, mechanisms can be a cognitive process which stimulates or demotivates stakeholders - including those delivering the intervention (Jagosh, 2017). Jagosh (2017) explains that mechanisms can be conceptualised as an interaction between 'resources' and 'reasoning'. For example, with regard to individualised funding, a resource could be the availability of a network of support, while reasoning could refer to how that resource is perceived which, in turn, can facilitate or inhibit implementation. As shown by the findings reported in Study Three, this perception can change from person to person and between stakeholders; for example, a practitioner may feel relieved to know that a network of support is available to support the person with a disability, whilst the latter may feel guilty for relying on 'unpaid' support; at the same time, the carer may feel burdened or conversely may feel that it is their duty to provide support to a family member with a disability. Some of the key mechanisms identified within all three studies reported in Chapters Three to Five are discussed below, with a particular focus on how these resources and the associated stakeholder reasoning, impacts implementation.

6.1.3.1 Funding

The availability of funding was a key mechanism underpinning the success of individualised funding initiatives/supports and indeed, this was seen in all three studies reported here. For example, the results of Study One clearly demonstrate: (a) that the menu of day services available to people with an intellectual disability did not substantially change over a 15-year period and (b) more importantly, that the national database used to inform policy and funding decisions was not capturing new and innovative activities and services. Both of these key findings point to a lack of <u>available</u> funding. Indeed, the results of Study Two suggest that access to funding was one of the most significant challenges during early implementation, with funds tied up in 'block grants' within traditional services. This not only jeopardised the success of the pilots, but also affected how people perceived individualised funding. Frontline staff, for example, reported becoming demotivated by the lack of buy-in from senior management and political figures. Families and members of wider support networks also reported feeling "burnt out" from a life-time of "fighting the system".

The findings from the systematic review further demonstrated that these experiences are not unique to Ireland, but instead are consistently reported across the international literature. Unclear eligibility criteria and 'application processes', mixed messages and inadequate information provision, all added to the long delays when attempting to access funding. Once people became aware of individualised funding, the rigid and inflexible assessment procedures and restrictive spending criteria were a source of considerable stress and anxiety. Furthermore - and as also shown in the national evaluation - the overly complex and bureaucratic processes involved with monitoring and reviewing the use of funding, weighed heavily on all stakeholders involved in the process.

These challenges highlight the importance of carefully planning the introduction of individualised funding. Familiarity with a largely unchanging sector means that transparency during the introduction of any new system/initiative is vitally important in order to alleviate fears and confusion. This is particularly the case when stakeholders are sceptical about the intentions of government and funders (as illustrated throughout Studies Two and Three), in which case, such transparency is important to the development of collaborative and trusting relationships, a key aspect of successful implementation. As such, clear, accessible, timely and up-to-date information should be prepared in advance and readily available (e.g. in a wide variety of media), before individualised funding is rolled out.

6.1.3.2 Available support

The availability of support was flagged as a central cross-cutting mechanism amongst all those involved in the lives of a person with a disability; it was also related to, and dependent upon, a number of contextual factors such as rurality, access to transport, and residential setting. For example, the findings of the systematic review showed how rurality can impact on the recruitment and retention of staff. While many would prefer a support person who lives close by, those living in rural areas must recruit people who sometimes live a considerable distance away. However, due to restrictions on allowable funding, a person with a disability cannot always pay for travel costs for support workers and therefore staff turnover can be quite high since paid support staff could not justify the commute based on the level of compensation.

On a related point, many end users valued the ability to set the terms of employment despite variation in the reasoning around rates of pay. Some saw it as an opportunity to increase wages to a level they felt was more appropriate, whilst for others it was seen as an opportunity to lower the rate of pay, thereby receiving more hours of care. For funders, on the other hand, the recruitment of untrained and often unvetted support workers was perceived as risky, leaving people with a disability vulnerable to physical or financial abuse, or simply open to poor quality care. However, for those with a disability, this shift in power from a top down paternalistic approach was seen as empowering, enabling them to take control, not only of who was supporting them, but when, where and how they are supported. Of course, this was not always the case, particularly for people with more complex needs who were more dependent on a network of support. If this network was not fully informed and skilled to facilitate self-determination, a more paternalistic approach towards support and decision making was maintained.

The tendency to maintain a paternalistic dynamic demonstrates, once again, the importance of information, which was often raised when discussing available supports. People with a disability (and their support network) frequently felt stressed or anxious when discussing recruitment simply because they did not know where to find support workers, often falling back on agency-provided staff. For some, agency staff members were perceived to provide familiarity and continuity of care, but for others, they were considered to be inflexible and unreliable, instead preferring to hire friends, neighbours or other trusted individuals known to the person with a disability. For individuals with a disability the ability to financially recognise the contribution of friends or family, who had previously provided support voluntarily, meant that they had more self-esteem, no longer seeing themselves as a burden. For carers, this contribution often enhanced relationships, whereby the carer role was more socially valued, even if the financial contribution was only nominal (compared to the contribution required or provided).

As previously discussed, the availability of a network of support was consistently highlighted throughout the findings reported in this thesis, as a fundamental mechanism for achieving success. This network of support included both unpaid informal supports as well as paid supports. Paid supports usually consist of: (a) personal assistants and others paid to provide day-to-day support with activities of daily living, health and social care needs; and (b) centralised staff within local support organisations or funding agencies who provided ongoing administrative guidance and assistance. The evidence suggests that implementation strategies often focused on the former, ensuring paid support for day-to-day activities were vetted, trained, and of a certain standard (although this was not always the case). However, those providing administrative support were often overlooked. This was a fundamental error since many of the principal implementation challenges captured in Studies Two and Three often related to the interaction with such centralised staff. Without trusting, transparent and collaborative relationships, major challenges emerged which, in turn, negatively influenced the motivation and perceptions of all stakeholders involved.

6.1.3.3 Freedom to choose

Another mechanism that was discussed at length in the systematic review, but which was also highlighted in the national evaluation reported in Chapter Four, relates to the freedom for people with a disability to choose who, how, when and where they are supported. Indeed, this facilitates choice and control, a recurring international policy goal. Whilst this is more of an intangible or conceptual mechanism, it had many practical and substantial implications for the ultimate success of individualised funding initiatives and was therefore important in determining outcomes. For example, by self-directing supports, people with a disability could often participate in 'positive risk taking', thereby increasing their opportunity to develop independent life skills as well as social and recreational activities that often enabled community integration and participation. This, in turn, reportedly broke down social barriers, stigma and preconceptions from people with a disability but also members of the general public (Studies Two and Three).

These new opportunities often emerged from the freedom to purchase previously unattainable assistive technology. However, overly restrictive spending criteria sometimes limited these opportunities when funders could not understand the value being placed on certain items (e.g. mobility scooter vs. electric wheelchair), or could not justify the use of public funds on certain activities (e.g. attending recreational activities). These findings, once again, underline the need for collaborative, transparent, trusting relationships, whereby all stakeholders should understand the philosophy and ethos, but also the limitations, of individualised funding. If clarity is provided from the outset, then tensions or misperceptions can be avoided. Having said that, there needs to be flexibility in order to respond to changing needs and preferences as well as regular and timely reviews. Furthermore, centralised staff members also need to be trained and resourced to fulfil this very important role.

6.1.3.4 Systems and processes

Many of the mechanisms discussed above are dependent on the processes and systems that are put in place to support individualised funding. All three studies illustrated the processes and systems utilised to plan, assess, implement and review services, ultimately facilitating (or inhibiting) the associated outcomes of interest. Indeed, the results from the systematic review showed how an outcomes-focused process of assessment, for example, facilitated the achievement of goals and was, as a result, perceived very favourably. Unfortunately however, the available evidence suggests that the assessment process is more often focused on targets rather than outcomes, which were perceived as serving the interests of staff and organisations rather than those of the person with a disability. Furthermore, the collective findings across all three studies suggest that these processes and systems are often based on historical procedures and systems, often inhibiting the full potential of organisations, staff, networks of support and ultimately the person with a disability. People with a disability repeatedly valued an organic/informal process which was needs-led, innovative, harnessed community spirit and peer support, as well as using existing (and often free) resources within the community.

The availability of appropriate and accessible information was a factor often missing, but highly valued, when in place. The provision of information was not just essential for end users, but also for providers who sometimes feared the sustainability of individualised funding, thereby leading to a resistance toward adopting new systems and a suspicion that individualised funding was merely the 'latest fad'. However, when staff members were provided with the knowledge, resources and time to implement the new processes and systems, they often played a crucial role in, amongst other things, identifying and building a network of support, particularly when none had previously existed.

Indeed, when no formalised system of assessment and allocation existed, practitioners had no option but to depend on pre-existing systems. These often relied on personal and organisational relationships that had developed through the provision of traditional services which in many cases, often limited the scope and vision of those implementing the new initiatives. Ironically, relying on these relationships could in fact, jeopardise sustainability since organisational knowledge and expertise would be lost if key personnel leave – a risk that is all too real in a sector with such high staff turnover. Therefore, the availability of robust and equitable resource allocation systems is another mechanism which is vitally important during early implementation.

6.1.3.5 Person-centred plans

Person-centred plans (PCPs) have been mentioned throughout this body of research as one way to creatively determine how individualised funding can be used to meet the self-determined needs of an individual with a disability. However, they are only one approach and some would argue that they have been used inappropriately for example, expecting people with a disability to plan their whole life and then to stick to that plan (Duffy, 2012a). Study One highlighted the substantial increase in the use of PCPs in Ireland over a 15- year period. Interestingly, the results from Study Two suggest that these are occasionally perceived with scepticism and as a “box-ticking” exercise, for many providers of care who want to be seen to be implementing national policy, but with plans sometimes being duplicated without appropriate review. However, this is not to discredit PCPs since evidence would suggest that they can lead to positive outcomes when their existence is widely publicised (often not the case), and when they are implemented in an appropriate manner (rather than just developed) (Barton, 2012; Broadhurst, Yates, & Mullen, 2012; Davies & Morgan, 2010). Furthermore, some plans require more time than others when, for example, accommodating complex needs (Gridley, Brooks, & Glendinning, 2014).

As demonstrated in Study One, it is not simply the provision of such plans that lead to positive outcomes, but the delivery of necessary training for all stakeholders to facilitate a better understanding around their purpose and use. Indeed, the qualitative findings from the systematic review highlighted the need for short-term goals to be identified in order to reach longer term aspirations. The absence of this vital stage represents a gap in the planning process, resulting in unattainable, aspirational plans that provide little practical day-to-day use.

These findings, amongst others outlined in this chapter thus far, point to the need for a 'whole-system', integrated and people-centred approach to the delivery of health and social care, whereby people are empowered to play an active role in their own health, and in this case, their lives more generally. Importantly, this goal is enshrined in a WHO framework which comprises five interwoven implementation strategies designed to promote equal access to quality, co-produced health services (Figure 6.1); this framework heavily influenced the recent 'SláinteCare' report on the future of healthcare in Ireland (Houses of the Oireachtas, 2017; WHO, 2017).

Figure 6.1 – WHO framework on integrated people-centred health services

Source: (WHO, 2017)

Implementation strategies regarding individualised funding - and similar to those shown above - will be discussed further in Section 6.3. However, the key theoretical underpinnings of individualised funding will be briefly explored first in the sections that follow.

6.2 CHOICE, CAPABILITY AND SELF-DETERMINATION

The current section will depart briefly from the practical, real-world application of the research findings to consider the theory behind many of the concepts summarised above. Some of the key theoretical foundations within which, the above findings are grounded, will be discussed in order to shed light on the apparent popularity of individualised funding and what sets it apart from traditional forms of service provision.

While not without its challenges, the findings from the research reported here overwhelmingly suggest that individualised funding is coveted by many who do not have it, and valued by those who do. However there are also many who value traditional services, with no desire to embrace an alternative. This points to the crux of the paradigm shift in the sense that when individualised funding is a real, tangible, well-functioning option for people with a disability, it offers choice, even to those who decide to continue with traditional services. Choice is the empowering mechanism that can lead to control and self-determination.

6.2.1 Choice

Simon Duffy, one of the early adopters of individualised funding in the UK, has pointed to the links between choice and control. He argues that choice, in its most basic form (i.e. saying yes or no/choosing A or B) while it does represent choice – is limited and does not necessarily open up options for people. When choice is fully embraced, however, this can lead not only to purchasing services, but to building, innovating and creating services and supports. This is fully realised, according to Duffy, when choice is coupled with cooperation, with others facilitating choice and working collaboratively to shape new solutions (Duffy, 2016). Indeed, this type of collaborative approach is supported by the international evidence presented in Study Three.

This conceptualisation of choice, shifting from a primitive view of A vs. B, to one of unrestricted possibilities, was captured in the 'porridge' quote in Study Two (see p. 94), a quote which repeatedly resonated with stakeholders during conference panel discussions (Fleming, 2016a, 2017a; Fleming, McGilloway, et al., 2015c; Fleming, McGilloway, & Barry, 2016b). Here, a facilitator of individualised funding explains that it is not about offering a limited menu of options (options A, B or C), but instead, facilitating the person with a disability on a journey of discovery to identify what they want from life, and in turn, collaboratively determining a set of achievable short-term goals to achieve that vision. The individualised funding can then be used to purchase, innovate or build the life of your choosing.

6.2.1 Capability

A concept related to choice is that of capability. According to Amartya Sen (1999), while it is important that people have choices in what they can be or do, capability refers to the freedom to choose from a variety of 'feasible' options, termed the 'capability set' (Kaushik & Lòpez-Calva, 2011, p.153). In his book, 'Disability and Justice', Riddel (2014) succinctly explains that it is not what people possess in terms of goods or resources, but what they are able to be, or do, as a result of these resources. Furthermore, Mitra (2006), when applying the capability approach to disability, points to the importance of context and the fact that a capability set will be influenced by the individual's personal characteristics (e.g., impairment, age, race, gender), their resources, and their environment (physical, social, economic, political).

These arguments around capability are supported by the findings from the studies reported earlier. Furthermore, the need for educational opportunities and training, to differentiate between choice and capability, was demonstrated during a conference discussion panel undertaken as part of Study Two. During this dialogue, an audience member sought to clarify what people chose to purchase with their individualised funding package; the logic here was that if this was known, service providers could add these items to their ‘menu’ of services. In short, it is not about what a person possesses or the services on offer, but the kind of self-determined life that a person with a disability can build, given the appropriate resources and supports.

6.2.3 Self-determination

Self-determination is also directly linked to choice and capability. According to Deci and Ryan (2008), the theory of self-determination 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. When considering service provision, people with a disability have traditionally been motivated by what Deci and Ryan describe as ‘controlled motivation’. While this certainly can lead to improvements, it is generally driven by a desire to gain approval, or avoid shame. Controlled motivation, in this sense, was highlighted in Study Two (A4.4) as a potential implementation challenge whereby people did not have the skills to make choices, relying instead on guidance from providers. This practice was also consistently highlighted in the international literature as ‘learned passivity’ (Study Three) which, if left unchecked or worse still enabled, limited any changes in outcomes (Studies Two and Three).

‘Autonomous motivation’, on the other hand, relates to self-motivation. As the ‘porridge’ quote above highlights, this type of motivation sometimes needs to be facilitated at first, but very soon it can lead to a host of positive outcomes, such as improved self-esteem, confidence, belief, independence, reliance, amongst other aspects that enhance self-image and behaviour (Studies Two and Three). These in turn can impact a range of other domains, including relationships, work, education and health care (Deci & Ryan, 2008; Ng et al., 2012), particularly for people with a disability (Perreault & Vallerand, 2007; Saebu et al., 2013).

6.3 SUPPORTING POLICY IMPLEMENTATION FOR INDIVIDUALISED FUNDING IN IRELAND

The discussion thus far, has revisited: (1) the national and international policy landscape as well as the historical context of service provision in Ireland (Study One); (2) the evaluation of individualised funding pilot initiatives in Ireland (Study Two); and (3) the international evidence around effectiveness of individualised funding and the associated context and mechanisms that facilitate or inhibit successful implementation and, ultimately, the improvement of the various health and social care outcomes of interest (Study Three). The next section draws upon a key research output (Appendix 3.7) which was developed in conjunction with the research funders (Genio) in order to provide guidance on various options that might help to promote and support the implementation of individualised funding in Ireland; this is particularly timely and important given the plans that are currently underway for national roll-out. In addition an implementation assessment tool, called INFINITE - based on policy, research evidence, and framed within an implementation science framework - was developed as part of this research to support decisions makers in Ireland when assessing the best implementation option (Appendix 3.7).

Before summarising these implementation options, the process of political engagement and examples of early implementation are described in more detail in order to contextualise the material that follows.

6.3.1 Political engagement

Progress in implementing individualised funding in Ireland has been slow despite repeated policy recommendations and ongoing, albeit small-scale, research that further supports these policy recommendations. Political prioritisations are arguably most evident in annual budget allocations. Therefore, the HSE Service Plans were examined in order to reveal these priorities and imminent plans for reform. In December 2015, the HSE Service Plan earmarked €38.5 million for ‘new initiatives’, representing just 0.3% of the overall €12,928.5m budget. Of this, a total of €7.5m, (0.06%) from the overall HSE budget was allocated for new initiatives within the disability sector (HSE, 2015), a nominal figure given the scale and ambition of the aforementioned national policies. Surprisingly however, and contrary to policy recommendations and plans for individualised funding (Department of Health, 2016), the 2016 service plan specifically recommended the use of this 'new initiative' budget for 1,500 day centre places. Thus, instead of directing all new funding towards the implementation of innovative supports as recommended in *New Directions (2012b)*, the bulk of the funding was directed towards day centres, which may be considered tangential to policy aspirations for self-direction and individualised supports (Fleming, McGilloway, et al., 2016a; HSE, 2012b). Furthermore, prior to the most recent HSE service plan (2017), the Minister of State for Disability reinforced this decision, when he tweeted about the need for what could be described as, more traditional services (Figure 6.2).

Tough going finalising HSE Disability Service plan for 2017. I need more respite & day places, + more personal asst hrs

6:00 PM · 22 Nov 16

Figure 6.2 - Tweet from Minister of State for Disability

(McGrath, 2016)

Despite the ongoing ambiguities between policy and practice, there would now appear to be a window of opportunity in Ireland whereby evidence-based policy can be implemented successfully, as described in 'Kingdon's policy window'. This window of opportunity occurs when three elements (or streams) converge including: 1) the recognition of a problem; 2) the identification of a solution; and 3) political will (Kingdon, 2002). Such a convergence is arguably occurring within the disability sector in Ireland today, as described in Box 6.1.

Box 6.1 - Kingdon's policy window in Ireland 2017

1) **problem recognition -** a growing discontent with the traditional provision of support services for people with a disability (Inclusion Ireland, 2013) and an evidence and policy base recommending change (Department of Health, 2012; HSE, 2011b, 2012b);
2) **solution -** 'individualised funding', a funding mechanism/initiative, and an approach which values the abilities and life aspirations of people with a disability by facilitating independent, autonomous, self-determined, community-based support; and
3) **political will** – in this case, the establishment of a National Taskforce on Personalised Budgets, by the Minister of State for Disability, Finian McGrath.

In line with policy recommendations, and despite limited political support, exemplars of individualised funding have been set up, a number of which formed the basis of the evaluation reported in Study Two.

6.3.2.1 Implementation to date

The current individualised funding model in Ireland involves a relatively small number of individuals who have managed to obtain an amount of money de-bundled from the current 'block grant system'. As outlined earlier in section 6.1 – and as reported in more detail in Chapter Four (Study Two) - the process for securing individualised funding when released from the block grant, was described as the single most significant barrier to implementing individualised and self-directed supports. Nonetheless, a number of people with disabilities have managed to secure access to individualised funding. Many of these were part of the Genio-funded pilots, but there is evidence to indicate from further work, that other individuals (exact number unknown), along with their support network, have been able to negotiate individualised funding (Flynn, Angus, & Cassen, 2015). The nature of this allocation (e.g. a once-off or ongoing) has depended on context-specific factors such as: a disability manager who was willing to challenge the status quo; whether the individual was a participant in one of the pilot initiatives; or whether they had a particularly proactive and influential support network. In these exceptional circumstances, positive stories have already begun to emerge from those who have availed of self-directed supports in Ireland (Fleming, 2016b; Fleming, McGilloway, & Barry, 2016d; Flynn et al., 2015).

6.3.3 Implementation Options

Although the implementation of individualised funding in Ireland is limited, plans are afoot to roll out individualised funding on a national basis, with the Taskforce on Personalised Budgets expected to provide recommendations by the end of 2017. Based on the extensive results relating to national and international implementation evidence presented here, an exercise was undertaken to identify and describe a number of possible implementation options based on these results, framed around policy, international best practice, available resources and implementation science (Appendix 3.7). The two options will be briefly summarised below.

6.3.3.1 Option One: No change to the status quo (the ‘do nothing’ option)

All existing disability services - in line with current HSE service plans - will continue to be funded, including an increase in day centre places as well as the respite and personal assistant services envisioned by the Minister of State for Disability (Figure 6.2). Alongside the traditional services, the current individualised funding option in operation in Ireland today, albeit not routinely available, will continue to be available alongside traditional service provision.

Arguably, this ‘do nothing’ option may not be economically viable in the long term, particularly if the current level of traditional services is maintained in conjunction with the roll-out of individualised funding. Furthermore, it may not be considered particularly progressive in terms of meeting international best practice and attendant policy recommendations. Notably, Ireland is the last nation in the European Union to ratify the UNCRPD (Lennon, 2016), whilst it has also been suggested that the disability services in Ireland are not meeting the recommendations of the Committee on the Rights of Persons with Disabilities (Inclusion Ireland, 2013), and especially in view of continuing delays in its process of de-institutionalisation (Study One – Chapter Three).

6.3.3.2 Option Two: Incremental implementation

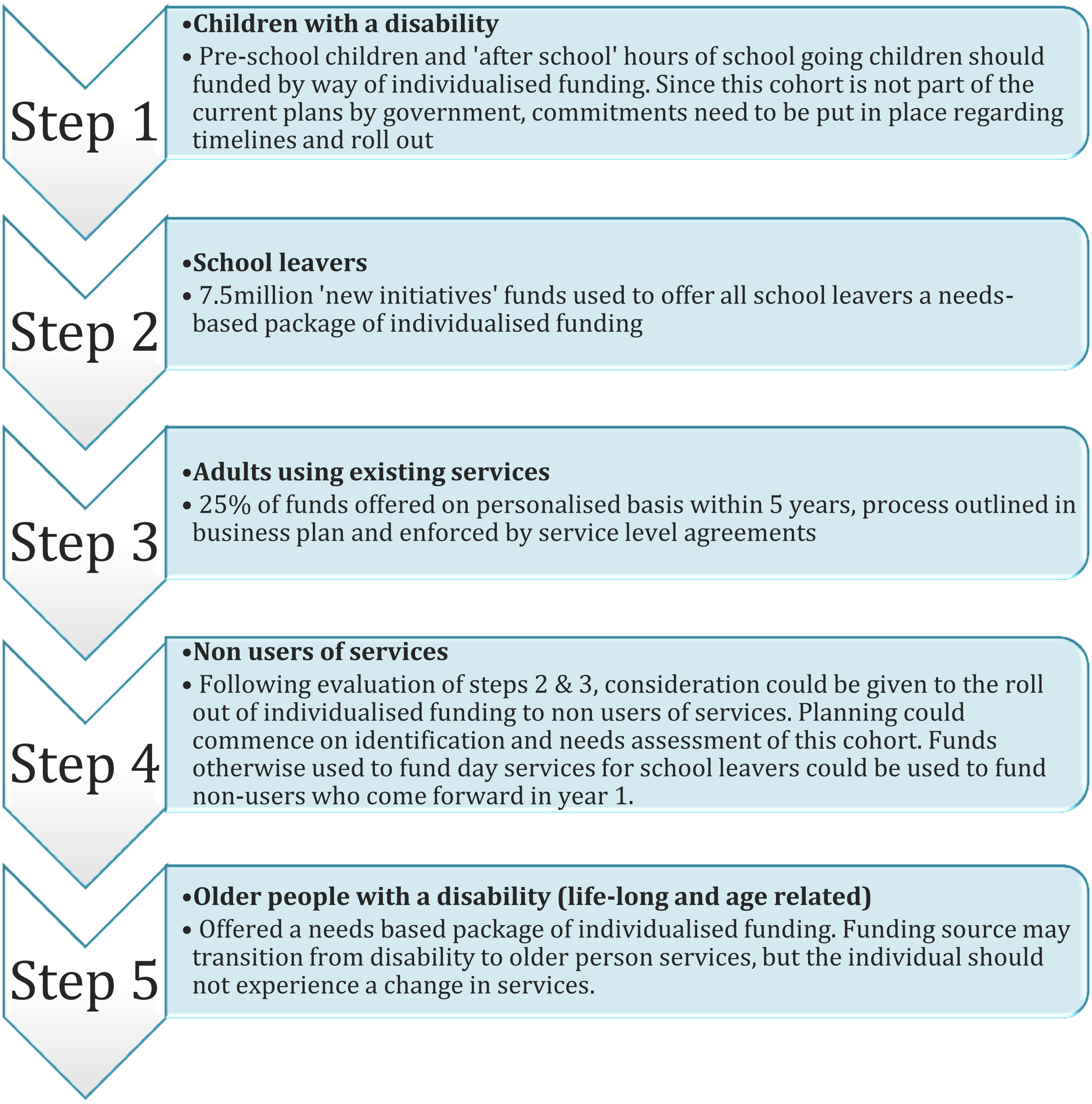
An incremental approach is one potential mechanism for rolling out individualised funding on a gradual basis, thereby allowing sufficient time for people, systems, organisations, cultures and budgets to adapt to the new service mode. This would avoid a feeling of being overwhelmed, which as indicated in the systematic review, had a demotivating effect. One way to achieve incremental implementation is by adopting what might be called a 'cohort approach'. This focuses on specific groups of people at different stages including:

- Cohort 1 - School leavers
- Cohort 2 - Those currently availing of traditional services
    - *Cohort 2a – Adults availing of services*
    - *Cohort 2b – Children availing of services*
- Cohort 3 – People with severe or profound impairments
- Cohort 4 – Older people with age related disability

This incremental approach, described in detail in Appendix 3.7 and summarised in Figure 6.3, would commence with a prospective cohort approach for all school-leavers, with a supplementary retrospective process based on a case-by-case, individualised, needs-based assessment utilising a standardised resource allocation assessment tool. Following such an assessment, people's options should be clearly explained - including individualised funding and self-directed options. Information dissemination therefore needs be carefully considered and should be incorporated into the business plans of new and existing service providers, ensuring that a similar implementation approach is adopted nationally. A transparent and consistent national approach will ensure that people are not restricted by lack of / shifting or conflicting information that is geography-specific, a concern highlighted in the evaluative research of the pilot initiatives and the international evidence (Studies Two and Three).

Should people decide, at this stage, that they would like to avail of individualised funding, then training should commence as soon as possible for the person with a disability, in terms of 'choice making' and developing the necessary independent life skills. Families and the person's wider support network must also receive training to facilitate and support the transition of their family or friend. Such training activities will require additional resources, as will the organisational restructuring of existing service providers and the development of new brokerage/intermediary services. However, whilst such transitionary / implementation costs are unavoidable, the potential benefits in the longer term are many.

Ultimately, this incremental approach would lead to a situation where individualised funding is a real option for people with a disability throughout the life course, from childhood to old age (Figure 6.3). This whole-sector approach is also in line with policy recommendations regarding integrated and person-centred approaches to implementation of health services more generally (Houses of the Oireachtas, 2017; WHO, 2017).



Step 1

- **Children with a disability**
  - Pre-school children and 'after school' hours of school going children should funded by way of individualised funding. Since this cohort is not part of the current plans by government, commitments need to be put in place regarding timelines and roll out

Step 2

- **School leavers**
  - 7.5million 'new initiatives' funds used to offer all school leavers a needs-based package of individualised funding

Step 3

- **Adults using existing services**
  - 25% of funds offered on personalised basis within 5 years, process outlined in business plan and enforced by service level agreements

Step 4

- **Non users of services**
  - Following evaluation of steps 2 & 3, consideration could be given to the roll out of individualised funding to non users of services. Planning could commence on identification and needs assessment of this cohort. Funds otherwise used to fund day services for school leavers could be used to fund non-users who come forward in year 1.

Step 5

- **Older people with a disability (life-long and age related)**
  - Offered a needs based package of individualised funding. Funding source may transition from disability to older person services, but the individual should not experience a change in services.

Figure 6.3 - Individualised funding throughout the life-cycle

6.4 EVALUATION OF THE STUDY

6.4.1 Strengths of the study

The mixed methods approach used in this study involved a combination of primary and secondary data as well as the triangulation of national data (Studies One and Two) with international evidence (Study Three). The use of existing national data was a particular strength of Study One given that research fatigue is a major factor for vulnerable and often over-researched populations. This approach was also less expensive and labour intensive, allowing space for the more ambitious Studies Two and Three.

Study Two, the first of its kind in Ireland, evaluated the implementation of individualised funding across a wide geographical spectrum (urban/rural and national spread), range of disability types (physical, sensory, intellectual, developmental and mental health) and modes of delivery (direct payments, community connector, brokerage). The participatory approach generated support and buy-in from various stakeholders, which led to a greater exposure of the research and dissemination of the findings; this led to, amongst other things, an invitation to give an opening address at a national workshop on individualised funding (Fleming, 2016a) and a subsequent invitation to produce an article for people with a disability, family members and allied staff within the disability sector in Ireland (Fleming, McGilloway, et al., 2016d). The participatory workshop which was conducted as part of this study also provided an invaluable opportunity to validate the preliminary emergent findings, thereby ensuring that the key messages were representative of the multiple study informants and key stakeholders in the implementation process.

The timing of Study Two was also a major strength, as highlighted earlier when discussing 'Kingdon's Policy Window'. As a result, the study findings are unique within an Irish context and are extremely valuable to decision makers and those developing policy in this field. A number of unique policy dialogue opportunities for the researcher also materialised as a result, including an invitation to join the National Taskforce On Personalised Budgets, involvement in direct consultation with the Health Research Board and the Department of Health in Ireland, and opportunities to present (in various media formats) to national and international audiences (see full list of research outputs in Appendix 3). The significance of these opportunities will be discussed later in relation to policy and practice (section 6.5.2).

As outlined earlier, there is much debate within the literature as to the effectiveness of individualised funding. For this reason, Study Three was undertaken to comprehensively collate, critically appraise and synthesise the international evidence available on individualised funding with regard to, not only its reported effectiveness on health and social care outcomes, but also in identifying implementation challenges and successes. This review was registered with the prestigious Campbell Collaboration and the review process involved/involves a number of international experts in various fields, including content experts, information retrieval specialists and methods specialists. Thus, Study Three provides a comprehensive, in-depth and freely available repository for those seeking to access the best available international evidence on individualised funding as it relates to health and social care in countries across the world.

6.4.2 Limitations of the study

The research reported here was conducted in order to fill an important knowledge/evidence gap and particularly – at least in the first instance - for policy drivers within Ireland. As indicated in Section 6.4.2.2 below, the timing of the evaluation was not ideal, but this was outside the control of the researcher. With this in mind, the pragmatic approach adopted, within a realist evaluation framework, lent itself well to such a dynamic, complex and rapidly evolving social intervention. Nonetheless, there were a number of limitations to each of the three studies which are examined below.

6.4.2.1 Study one

As highlighted in Chapter Three, one potential limitation of this study - but one outside the researcher's control - related to the completeness of the National Intellectual Disability Database, which was based on voluntary registration. Therefore, the database may not capture *all* people with intellectual disabilities living in Ireland, and especially the extreme cohorts (i.e. those with a mild intellectual disability) since they tend to use more mainstream services and activities, and those with profound intellectual disabilities, for whom day services are inaccessible / inappropriate. Nonetheless, the database contains the most accurate data available for people with an intellectual disability in Ireland.

Another potential limitation relates to the fact that over half of the data pertaining to 'future demand for residential services' was found to be inaccurate on the national database (Dodd et al., 2010). Although Dodd et al. did not focus on day services in their audit, which was the focus of Study One, it must be acknowledged that similar inaccuracies regarding 'future demand for day services' data, may exist within the dataset that was used in the current study. However, these limitations are not unusual when utilising secondary data. Ultimately, the highest quality national data available were used to provide the best picture possible on a nationwide basis.

6.4.2.2 Study two

Study Two was conducted in the most systematic and robust manner available but there were a number of insurmountable issues which may limit the generalisability of the findings. The first pertained to the fact that the national pilot initiatives had commenced before research design and ethical approval for the current study had been finalised. This, in turn, limited the design of the evaluation. For example, baseline outcome data could not be collected prior to the commencement of the pilots. In addition, the researchers did not have any oversight of the allocation of participants to the pilot initiatives. Therefore, it was unclear whether the sample was representative of the more general population of people with disabilities, although those implementing the pilots had reportedly taken such matters into consideration.

Another potential limitation relates to accessing the pool of potential participants for one of the four pilots, when the gatekeeper (after organisational consent had been provided) decided not to extend an invitation of participation to their end users because he felt they were an over-researched group. This in itself was an interesting observation, since the pilot was intended to promote choice, control and mainstream participation and yet this cohort was not being provided with the option to participate in the research. Fortunately, relevant secondary qualitative data pertaining to this group, in the form of video footage from a national conference, was freely available online. As described in Chapter Two, these data were transcribed and used as part of the qualitative dataset.

6.4.2.3 Study three

As discussed in Chapter Five, there were several changes made to the study protocol for the systematic review based on: (a) the resource-intensive nature of the review; and (b) the complex nature of the study designs. Many of these changes did not limit the study as such but led to changes in, for example, the planned screening process. However, a number of changes did present a potential study limitation. Data extraction for qualitative data was conducted by only one review member, but since the vast majority of qualitative data reported was included (verbatim) in the analysis, this did not pose a major limitation. Only data pertaining to ineligible participants (minors and older people without a life-long disability) were excluded, and such data were indicated in the screening tool utilised by the second independent reviewers.

The planned quality assessment was conducted in a detailed manner by one reviewer, although the screening tool (for double full text screening) was adapted to highlight any major methodological limitations, which were taken into consideration during the in-depth quality assessment.

Finally where there was no evidence of a life-long disability, older people were excluded from the eligible sample. While this may have inadvertently excluded some people with a life-long disability, it was deemed more appropriate to make such an exclusion rather than report findings which did not pertain to a disabled population.

6.5 IMPLICATIONS OF THE STUDY FINDINGS

This multi-faceted research provides useful historical and political context, followed by a critical analysis of implementation and outcomes data, thereby offering a review of wide-ranging evidence for governments, service providers and end-users who are considering individualised funding. While the specific findings from each of the three studies have been examined, the discussion will now turn to more general recommendations for future research, policy and practice.

6.5.1 Directions for further research

Evaluative research on complex social interventions is inherently difficult and particularly when working with a vulnerable population where buy-in (and perhaps consent) is required from multiple stakeholders (e.g. person with a disability, family member, provider of services). These difficulties are perhaps exemplified by the lack of robust effectiveness data in the systematic review, despite spanning a period of more than 25 years. As a result, only seven quantitative studies containing robust effectiveness data were deemed eligible for inclusion in the review.

One possible reason for this, as indicated throughout this research, is the propensity to compare what are perceived to be ‘old’, ‘traditional’ services with ‘new’ and promising individualised funding. Indeed, it is clearly not an ‘either / or’ situation as indicated, for example, by fears of losing access to traditional services for people with a disability, or the potential for privatisation of service provision, with the perceived impact of devaluing the role and quality of service provision. With this in mind, there are two suggested key areas for future research. The first of these focuses on practical research design, while the second, perhaps more important recommendation, suggests examining the delicate relationships between context and mechanisms and how these impact outcomes - rather than focusing on individualised funding versus traditional services per se.

6.5.1.2 Practical research recommendations

In terms of research recommendations, it is crucial that the introduction of individualised funding is accompanied by a detailed, robust evaluation plan which is initiated during the planning phase. The challenges to implementation, described in Studies Two and Three, should help to inform the design of such an evaluation by, for example, attempting to address changing political, economic and environmental factors which can have a serious negative impact on participation and buy-in to the research. As such, several contingency plans should be in place and incorporated into study design and ethical approval phases. Without such plans, the integrity of the findings could be compromised if, for example, there are fidelity issues in terms of how the intervention is implemented, any substantial delays in implementation, and/or participant drop out.

Furthermore, as recommended in Study Three, any evaluative research study should attempt to incorporate a minimum follow-up period of 9 months, but ideally include multiple time-points over a longer period of time. Finally, buy-in from all stakeholders is very important in terms of recognising the value of evaluative research. The evidence from Studies Two and Three indicates that overly bureaucratic processes were a major challenge for research respondents with many indicating a sense of feeling overwhelmed with the amount of paperwork and data collection, which often seemed duplicative. Therefore, it is important to pre-empt and carefully manage these challenges through collaborative relationships and participatory approaches in order to ensure the collection of robust data. By involving end-users during the research design stage, the researcher will, for example, gain important insights and potentially gain access to existing sources of data rather than duplicating data collection.

The pragmatic realist evaluation and mixed methods approach adopted in this study allowed sufficient flexibility to adapt to changing parameters (e.g. sometimes moving back and forth between data collection and analysis) and the use of inductive methods (Studies One and Two) or a mix of both inductive and deductive approaches (Study Three). Furthermore, the focus of the research was not simply on trying to determine whether individualised funding improves a person's life in terms of measurable outcomes, but to point to why and how these outcomes are achieved, for whom and in what circumstances. The data generated from this research were rich and insightful, offering a valuable resource and source of guidance for researchers planning further work in this area.

6.5.1.3 Outcome focused – behaviour change

Future research might focus on context and mechanisms rather than the difference between traditional vs. individualised service provision. For instance, a theme that emerged in both Studies Two and Three related to the need for more behaviour change research amongst all stakeholders in terms of, for example, addressing learned passivity for people with a disability and also the paternalistic, over-protective behaviours observed amongst both paid and unpaid supporters.

When national rollout commences, a behaviour change intervention could be utilised/designed for those receiving individualised funding. One group could continue implementing individualised funding without any behaviour change intervention, at least in the first instance, whilst another group could receive a behaviour change intervention. 'Social role valorisation' is one such model which has been successfully utilised during the implementation of individualised funding in Australia and the UK (Duffy, 2015; Greer, 2015; Peipman & Vermeij-Irvin, 2015); this is designed to improve social roles by enhancing people's social images and personal competencies (Wolfensberger, 2011). The ultimate goal would be to observe any differences in outcomes between the groups over time. This might involve several designs involving, for example, a Randomised Controlled Trial involving an intervention and a services-as-usual or wait list control group, or a design where family members receive the intervention, but not the end user's paid support (or where both groups receive the intervention). These designs, of course, would be dependent on having sufficient numbers to observe significant differences, but with national implementation, this should be possible.

A behaviour change intervention is just one example of the many types of interventions that could be incorporated into a national implementation plan, but the evidence from the current research indicates an imminent need for such an intervention in a national and international context. The evidence also points to other interventions that could be developed such as an 'educational programme around the ethos of individualised funding', 'choice making' and developing ‘independent life skills’. These too could be outcome focused in relation to various stakeholders. Other potential, outcome focused, interventions will be outlined below.

6.5.1.4 Outcome focused – timing of individualised funding

Study One indicated that the younger cohort of people (i.e. those making the transition to adulthood) should be the focus of future research. This type of research could be conducted by jurisdictions which are adopting individualised funding for the first time. Not only does this younger cohort appear to be falling through the gaps in the system (as indicated in Study One), but the natural period of transition presents a timely opportunity to introduce individualised funding before, for example, any allocation of funding becomes tied up into block grants. Whilst this cohort may still choose ‘traditional’ forms of service provision, a national, standardised allocation and assessment procedure (integral to the individualised funding route) offers the flexibility for them to change their mind, should things not work out. Most importantly, the systems and processes that facilitate these must be monitored through ongoing evaluative research, to ensure realisation of the core goals of person-centeredness, independence, self-determination, choice and control.

A comparison of implementation at this transitionary period could be compared with cohorts accessing individualised funding at a later stage, such as, adults already within the traditional system. However, the focus here is not on individualised vs. traditional service provision, but rather the best time in a person’s life to introduce individualised funding, and the factors that lead to differences in personal, health and social care outcomes.

6.5.1.5 Outcome focused – economic evaluation

Another area in need of future research relates to the economic appraisal of individualised funding. Existing costs data within the literature are limited due to, amongst other things, the lack of robust and comparative data. However, most studies within the literature (as seen in Study Three) involve comparing traditional services with individualised service provision, with the underlying goal of determining which mode of delivery is more expensive. However, cost-effectiveness analyses should consider the full range of costs alongside a wide range of outcomes including personal, health and social care outcomes. The availability of robust cost-effectiveness data would allow the prioritisation of resource investment in modes of service delivery that result in the greatest health and social care gains, as recommended in both national and international guidelines (HIQA, 2014; Tan-Torres, Baltussen, Hutubessy, D.B., & C.J.L, 2003). Health-services researchers should work with health economists, in particular, to identify the best outcomes to measure. Practitioners and policy makers also need to be actively engaged to ensure that data collection is prioritised and that front-line staff members understand the value and importance of robust data.

One final element, highlighted in the discussion, and of particular importance when sourcing data, is identifying and categorising the types of supports provided through different sectors, such as education, health and social-care. As highlighted in Study Three, the separation of these funding streams during implementation led to an overly complex and bureaucratic system. Therefore, any changes or recommendations based on economic evaluations need to be considered in terms knock-on effects for practice.

6.5.2 Implications for policy and practice

6.5.2.1 Increasing Dialogue

As outlined previously, this research was conducted in a very timely manner, in the lead up to the formation of a National Taskforce on Personalised Budgets. As such, much interest was being generated through the participatory approach taken to the study, but also in terms of outputs, such as peer reviewed papers, publications of professional interest, media interviews, and national and international presentations. As a member of the advisory and consultative arm of National Taskforce on Personalised Funding, the lead researcher was ideally placed to feed research findings into the early implementation process, by attending and actively contributing to the taskforce meetings since September 2016 (to the present).

Furthermore, the participatory approach adopted in Study Two, meant that the findings were directly informed and verified by the individuals participating in the pilots, their family and friends and the organisations implementing individualised funding. According to Walmsley and Johnson (2003), these stakeholders are the experts in the field. As such, the co-construction of research and evidence through collaborative partnerships between researchers and those impacted by the findings can potentially augment the pertinence, quality, outcome, sustainability, uptake, and transferability of the research (Jagosh et al., 2012; Macaulay et al., 2011). With this in mind, the research participants reportedly gained useful insights by participating in the initial data collection, but also the participatory workshop where they had the opportunity to network and share key lessons learned with others implementing and receiving individualised funding. This was a unique opportunity that would not have otherwise taken place, had the research project not brought these key stakeholders together. This 'casting of the net' meant that research findings were being disseminated, not only by the researcher (as is the convention), but also by the various stakeholder groups, thereby having a potentially more tangible and lasting effect.

The dissemination of the research findings through informal channels has also extended beyond the disability sector. For instance, other sectors, such as older people services looking for new and innovative ways of facilitating needs-led, person-centred services, extended an invitation to the researcher to present findings at the Irish Gerontological Society conference in 2017. This relatively new concept for the older persons services (in Ireland), led to considerable interest during the panel discussion at the conference in question (Fleming, 2017a).

Another example of the practical application of study findings relates to Study One; a key recommendation from this study was to re-examine and re-develop the national database. Interestingly, such a redevelopment is currently underway and being conducted by the HRB in Ireland. Following a presentation of the study findings (Fleming, McGilloway, & Barry, 2017), the lead researcher was invited, by a staff member within the host body (the HRB) to contribute to the ongoing process, which involved consultation based on study findings and insights from the wider evaluative research.

Similarly, a team of economists from the strategic arm of the National Personalised Budgets Taskforce within the Department of Health, sought consultation and advice based on the collective research findings. Following this consultation, feedback was solicited from the Assistant Principal Economist in the Department of Health, which indicated the value of the research findings across all three studies. This is illustrated well in the quote below (Box 6.2).

Box 6.2 – Feedback from consultation with Department of Health

> *We're currently at the point of evidence gathering, and developing a framework for understanding how moving to, or operating under a system of personalised budgets may impact on the financial sustainability of the system. With that, we found the paper outlining day service trends particularly useful for identifying and understanding data sources and relevance. More broadly, your work has provided us with reflected consideration of the wider space in which we're operating, and will likely provide further insights as the policy development progresses. In particular, the greatest value of your papers may be if pilot schemes are developed as your research brings key insights for design and implementation for service providers and users.* *(Ní Chobhthaigh, 2017)*

6.5.2.2 Contributions to the international literature

The findings from this research have been cited nationally and internationally by a number of authors including: (McConkey, Kelly, Craig, & Keogh, 2017; Occupational Therapy MSc Student, 2016) Study One; (Mulkeen, 2016; Raudeliunaite & Gudžinskienė, 2017) Study Two; and (Dickson, Sutcliffe, Rees, & Thomas, 2015; Pike et al., 2016) Study Three. Even during the early stages of research dissemination, the contribution of the research evidence was considerable, indicating the timeliness and importance of the research. For example, the protocol for the systematic review (Study Three) has already been cited twice and recommended by Professor Pilar Munuera Gómez, of the Compultense University of Madrid (www.researchgate.net). These citations and recommendations – which pre-date the publication of the final review report - suggest that the review findings will be of considerable value to the international community of researchers, policy makers and practitioners.

Furthermore, the interest from non-academic audiences has also been considerable; with each of the Frontline Magazine publications viewed 1,782 and 1,293[15] times respectively (Appendix A3.5 and A3.6). The SPHeRE programme also selected the policy brief, prepared as part of results dissemination, as the first of its kind to be circulated among the extensive multi-disciplinary 'SPHeRE Network', in a move to integrate research findings generated through PhD scholarships, into real world policy and practice (Fleming, 2017b - Appendix 3.8). This again demonstrates the value of this research, its timeliness and scope.

6.5.2.3 Practical implications

Study one provides a contextual basis within which to interpret and understand national datasets (as highlighted in Box 6.2). Study Two and Three describe the successes and challenges associated with the implementation of individualised funding, with an implementation framework having been developed to guide policy makers in their decision making process (Appendix 3.7). Furthermore, the evidence-based implementation options, presented earlier in Section 6.3.3 and Appendix 3.7, provide a basis for the National Taskforce on Personalised Funding to conceptualise, and plan for, national implementation. The framework and implementation options described in this chapter were also shared with the Genio Trust for use in their ongoing policy dialogue (Fleming, McGilloway, Keogh, Barry, & Healy, 2017 (Draft)). They were also shared with health economists in the Department of Health, who reportedly found the paper insightful:

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[15] As of September 26th 2017. Data sourced from www.frontline-ireland.com

> *"The paper highlighted issues which could support policy implementation and planning, highlighting issues such as over burdensome governance mechanisms … The paper is a good source of review and identifying implementation issues and potential pitfalls" (Ní Chobhthaigh, 2017).*

6.6 CONCLUSION

The multi-faceted and mixed method research reported in this thesis involved three separate but related studies designed to assess the development and implementation of individualised funding in Ireland and internationally. The first two studies focused on individualised funding in an Irish context. This involved a description, in the first instance, of traditional service provision (including historical development) with a particular focus on the most commonly utilised services for the largest user-group (i.e. people with intellectual disabilities). Study Two then described, against this backdrop, the first national evaluation of four individualised funding initiatives. Using exploratory and participatory methods, this study highlighted the feasibility and acceptability of individualised funding within an Irish context, in addition to capturing implementation successes and challenges. Finally, the international evidence was extensively reviewed and critically appraised with regard to the effectiveness of individualised funding in improving a range of health and social care outcomes. Collectively, the findings of all three studies provide important insights into the context and mechanisms under which improved outcomes associated with individualised funding can be achieved. The results may be used to inform policy and practice and future research, in a number of ways, as indicated below (Section 6.6.1 and 6.6.2 respectively).

6.6.1 Recommendations for Policy and Practice

- National databases, such as the NIDD, should conduct regular reviews and updating of data capture forms to ensure that their remit is sufficiently broad to include new and innovative models of service delivery.

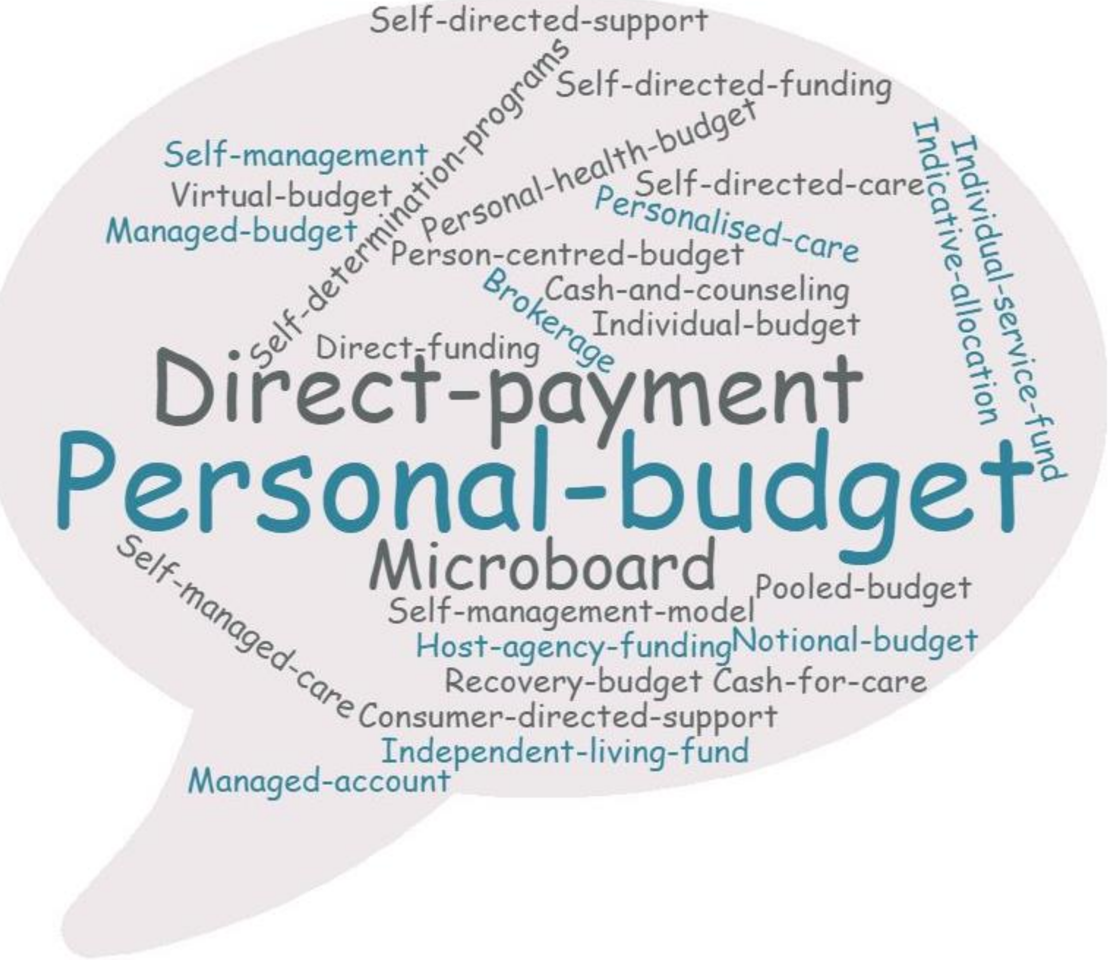
- Service developments in Ireland and in other developed countries must be responsive to national trends within their individual jurisdictions and not become overly focused on, for example, urban centres.
- Individualised funding could be introduced on an incremental basis, starting with school leavers and, in time, moving to a whole society approach including disabled children and (where appropriate) adults and older people receiving supports within traditional services.
- Individualised funding should not be shoehorned into existing systems, processes and procedures that have been developed for a time when societal perspectives and understanding of disability were very different from those that are in evidence today. These initiatives should, instead, be facilitated by a needs-led, person-focused, aspirational resource allocation system that is flexible and capable of adapting to various, dynamic and changing contexts.
- Information dissemination is integral and needs to be carefully considered. Dissemination strategies should be incorporated into the business plans of new and existing services, thereby ensuring that a similar implementation approach is adopted nationally. A transparent and consistent national approach will ensure that people are not restricted by lack of / shifting or conflicting information that is geography-specific.
- The necessary resources, (human, time and financial) should be provided to facilitate the transition from a paternalistic mode of service provision to one that is truly person-focused, needs led and focused on full community integration.
- All stakeholders (i.e. organisations, practitioners, formal and informal supporters and individuals with a disability) should be offered educational and training opportunities to develop the theoretical and practical skills to deliver meaningful person-centred support.

- Educational and training activities will require additional resources, as will the organisational restructuring of existing service providers and the development of new facilitative / intermediary services.

6.6.2 Future Research

- It is critical that the introduction of individualised funding is accompanied by a detailed, robust evaluation plan initiated during the implementation planning phase.
- Any evaluations of individualised funding interventions should be outcome-focused. Such interventions should have a minimum time frame of 9 months, but ideally data should be gathered at multiple time-points over a longer period of time.
- The context and mechanisms that facilitate or inhibit successful implementation and attendant outcomes should be focus for future research rather than examining differences between traditional vs. individualised service provision.
- Economic evaluations should be based on robust approaches (e.g. cost-effectiveness analysis or cost benefit analyses) whereby changes in personal, health and social care outcomes are considered in the context of comprehensive costs data and the use of appropriate methods therein.
- Researchers should work collaboratively with practitioners and policy makers to ensure that outcome data collection is prioritised and that front-line staff members understand the value and importance of robust data.
- Future research should consider the use of mixed methods approaches to properly evaluate such complex social interventions and preferably involving (resources permitting) evaluations of impact (or outcomes), process evaluations and rigorous economic appraisals.

Overall, the findings from this study represent an important and useful addition to the literature while also providing comprehensive evidence on the effectiveness and implementation of individualised funding in countries across the world including Australia, Belgium, Canada, England, Germany, Ireland, Northern Ireland, Scotland, Wales, and the USA. As such, the findings provide an important resource for those implementing individualised funding both in Ireland and elsewhere, whilst also providing an important ‘toolkit’ for policy and practice more generally. Individualised funding has been shown to have considerable benefits over traditional models of service delivery but any national roll-out must be accompanied by robust, participatory, collaborative and evaluative research to provide much needed quantitative data and especially in the view of the dearth of outcomes data when compared to the length of time individualised funding has been in existence. Lastly, the collective findings presented as part of this multi-strand research, suggest that government, policy makers, practitioners and end-users alike, should advocate for, and support, implementation in their respective jurisdictions, providing opportunities for improved outcomes and a progressive and shared reconceptualisation of disability supports throughout the world.


Self-directed-support
Self-determination-programs
Self-directed-funding
Self-management
Personal-health-budget
Individual-service-fund
Indicative-allocation
Virtual-budget
Self-directed-care
Managed-budget
Personalised-care
Person-centred-budget
Brokerage
Cash-and-counseling
Individual-budget
Direct-funding
Direct-payment
Personal-budget
Microboard
Self-managed-care
Pooled-budget
Self-management-model
Host-agency-funding
Notional-budget
Recovery-budget
Cash-for-care
Consumer-directed-support
Independent-living-fund
Managed-account

Appendices

APPENDIX 1 – SUPPORTING DOCUMENTATION FOR STUDY 2

A1.1 - TEXT FROM LETTER OF INVITATION TO ORGANISATIONS

Dear (Name)

Re: EVALUATION OF THE DEVELOPMENT AND IMPLEMENTATION OF PERSONAL BUDGETS FOR PEOPLE WITH A DISABILITY IN IRELAND.

Further to our correspondence earlier this year, I am now writing to you to formally invite your organisation to participate in the research I am conducting around personal budgets for people with a disability in Ireland. You might recall that this research is being funded by Genio as part of the HRB-funded SPHeRE PhD programme (www.sphereprogramme.ie).

As indicated in our initial discussion, it would be much appreciated if you facilitate and support this important project in the following ways:

1. Provide access to internal documents produced in the lead up to and running of the new service. Documents of interest include meeting minutes; implementation / roll out plan; internal and external communications (e.g. memos and pamphlets); funding applications; monitoring reports for funders; and financial reports. These documents will only be accessible to myself and will be either stored on an encrypted laptop or in a locked cabinet.
2. Help to negotiate access to a sample of people who avail of your service. It is important that participants should freely agree to participate and should not be pressurised in any way.
3. Encourage the participation of two members of staff in one-to-one interviews. This will likely be the CEO and a project manager/coordinator. Another member of staff may be invited to take part at a later date. It is anticipated that this meeting will last no longer than one hour and can take place in a private space in your offices, or at another location of your choosing.

I am attaching an information sheet and consent form, for your reference. This does not have to be completed at this stage but we would appreciate if you would circulate to any staff members who may be invited to take part, asking them to jot down any questions they might have for me in advance of the research commencing.

I hope that your organisation is still willing and able to participate in this valuable piece of research. If so, please complete and sign the attached (yellow) reply slip and return to me in the stamped addressed envelope provided. Once you have provided staff names, I will contact them separately to invite them to participate.

Many thanks for your help and support.

Kind regards

Padraic Fleming

PHD SPHeRE scholar

083 1803165 Project Mobile Number purchased specifically for project cc Dr Sinéad McGilloway

Note: This letter scored 51.6 (easily understood by 10th and 12th grade students) on the Flesch Readability Ease' index

A1.2 - TEXT FROM ORGANISATION INITIAL CONSENT FORM

Researcher: Padraic Fleming 01 – 708 6725
Supervisor: Dr. Sinead McGilloway 01 – 708 6311
Maynooth University Department of Psychology
Maynooth University, Maynooth, Co. Kildare

I hereby confirm that (organisation) is willing to participate in this research and to provide help and support with the following:

1. Provide access to internal documents produced in the lead up to and running of the new service. Documents of interest include meeting minutes; implementation / roll out plan; internal and external communications (e.g. memos and pamphlets); funding applications; monitoring reports for funders; and financial reports. Nominate a main contact point for access to documents.
2. Help to negotiate access to a sample of people who avail of your service.
3. Encourage the participation of two members of staff in one-to-one interviews. This will likely be the CEO and a project manager/coordinator. Another member of staff may be invited to take part at a later date. It is anticipated that this meeting will last no longer than one hour and can take place in a private space in your offices, or at another location of your choosing.

(CEO NAME)

______________________________ (BLOCK PRINT)

______________________________ (Signature)

Contact details for **ALL** staff members:

Name (BLOCK)	**Job Title**	**Email**

Initially two of these staff members will be invited to participate.

A1.3 - TEXT FROM INTERVIEW SCHEDULE FOR STAFF MEMBERS

Introduction

Hi [name]. Before we get started, I want to give you some information about how this meeting will go. It will last approximately 1 hour, and I'll let you know when we're coming to the end. First of all, I want to assure you that there are no right or wrong answers. As you know, I have recently reviewed documents produced during the development of the initiative and I just want to hear from you about that time. There are particular areas that I want to explore, but this is not like filling in a survey, more of a free flowing conversation, so feel free to add anything or diverge at any time.

Basically I am looking to find out a bit more about the development and roll-out of the [brokerage / direct payment] programme. Firstly I will get you to tell me a little about the organisation and a bit about your own history within the organisation. I will be asking you questions around certain themes such as the decisions to develop such a programme, the recruitment process, the impact the programme is having on the organisation, participants and their families/circle of support. Again it's very much your personal perspective on the various themes.

As you know our conversation will be recorded but this is simply for my use, so that I can recall our conversation. That way, I won't have to take notes and we can just have a chat! The recording will be stored safely on an encrypted laptop and nobody except myself or a trusted colleague will hear it. It will be deleted within five years of the study being completed. Your name and any other identifiable information will be removed from the transcription. This is subject to the Data Protection Act (2003).

You are free to end the interview at any time, if you don't feel comfortable with the way it's going and you can decline to answer any questions if you don't want to answer them. If you want a break during it, that is no problem, we can stop the recorder and take as much time as you need! Have you any questions?

So, [name], tell me about your job here at [name of service]

- Job title/post
- How long have you worked for this organisation?
- What did you work at before joining this organisation?
- What was your motivation for applying for this particular role?
- What are your day to day duties?
- What is your contact with clients?

Themes

Brokerage / Direct Payment model
What are your views of the brokerage / direct payments model?
How does it work? Functions / Processes
How is it different to more traditional service provision?
As you see it, what are the strengths?
What are the weaknesses?
Is it sustainable?

Services Users
How does a service user go about availing of the service?
What is the process?
What does this model provide to the service user?
How does the service user benefit from this model?
What are the advantages?
Are there disadvantages?

Service Providers
What is the role of the service provider?
What is your role?
How does that differ to traditional models of service provision?

Policy makers
Policy seems to be moving towards individualised supports through a resource allocation system.
Do you agree?
Do you think this is the right way to go?

A1.4 - TEXT FROM INTERVIEW SCHEDULE FOR INITIATIVE PARTICIPANT

Introduction

Hi [name]. Before we get started, I want to give you some information about how this meeting will go. It will last approximately 1 hour, and I'll let you know when we're coming to the end. First of all, I want to assure you that there are no right or wrong answers. I have already spoken to some of the people working in (organisation) so I have an idea of how the service works, but I would like to hear what it's like from your perspective. There are particular areas that I want to explore, but this is not like filling in a survey, more of a free flowing conversation, so feel free to add anything or diverge at any time.

Basically I am looking to find out a bit more about your life before getting involved with (programme name), and since you became involved. I'm interested in what motivated you to try this new programme, what your expectations were and whether they have been met. Firstly I will get you to tell me a little about yourself, your family, friends, past times, things like that. I will then be asking you questions around certain themes such as the aspects of the service that seem to be working, those that may need tweaking, the impact this programme is having on your life and your hopes for the future.

As you know our conversation will be recorded but this is simply for my use, so that I can recall our conversation. That way, I won't have to take notes and we can just have a chat! The recording will be stored safely on an encrypted laptop and nobody except myself or a trusted colleague will hear it. It will be deleted within five years of the study being completed. Your name and any other identifiable information will be removed from the transcription. This is subject to the Data Protection Act (2003).

You are free to end the interview at any time, if you don't feel comfortable with the way it's going and you can decline to answer any questions if you don't want to answer them. If you want a break during it, that is no problem; we can stop the recorder and take as much time as you need! Have you any questions?

So, [name], tell me about your job here at [name of service]

- *Where are you from/do you live? / Age / Family / Education / Work*
- *Past-times Do you live in urban or rural area?*
- *When you were young, how did you see your life progressing? What were your dreams?*
- *Disability – In your words tell me about your disability. What is it and how does it affect your daily life?*

A typical day

Can you tell me about a typical day in your life? From getting up in the morning to going to bed at night and everything in-between. You might also tell me what your needs are and how these are met?

Prompts: So what time does you're alarm go off at?
Getting up – morning routine – showering – using the facilities – dressing – food
Daily activities – transport – working – socialising
Role of assistive technologies

Themes

History of your disability

- Impact on living arrangements
- Impact on education
- Impact on social life
- Health needs
    - What are they / Access / Cost / State assistance

People in your life

Who are the people you meet in a typical week?

Explore each role

Funds

Before availing of services through (programme name) how did you get the supports you need? How did it work? How were things decided? How much input did you have? Were you satisfied? Strengths? Limitations?

Direct Payments vs Brokerage

Self-management – why?
How demanding?
Did someone assist you plan services/supports/activities

Personal Outcomes

Satisfied with the new arrangements?
What has changed in your life? Positive & Negative

Family	Social	Past-times
Work	Financial	Health & Well-being
Education	Living arrangements	

To what extent do you feel in control of decisions?
Are you involved with new services/activities/supports not previously available?
What are your goals for the future?

Organisation and Staff

What support do you get to self-manage?
Satisfied with access to information
What contact do you have with the various staff members?
Are there restrictions in accessing services/activities/supports?
Do you employ support staff directly?
How does it make you feel?

Programmatic

Are there areas of the programme that you would like to change?

Prompts (if necessary)
Leadership / Staffing / Choice / Your involvement / Others involvement / Outcomes

Note: This information sheet scored scored 71.1 (easily understood by 7th grade students) on the Flesch Readability Ease' index

A1.5 - TEXT FROM LETTER OF INVITATION TO INITIATIVE PARTICIPANT

Dear (Name)

Re: EVALUATION OF THE DEVELOPMENT AND IMPLEMENTATION OF PERSONAL BUDGETS FOR PEOPLE WITH A DISABILITY IN IRELAND.

Your name was provided to me by (name) in (organisation). I believe (name) has told you about the work that I am doing at the moment. This involves meeting with staff and participants from brokerage or direct payment pilot projects around Ireland to discuss progress to date. I was hoping that you would be willing and available to take part in this valuable piece of research.

Attached to this letter is a detailed information sheet and consent form. You do not have to complete it at this time, but it is there for you to read and jot down any questions you might have for me.

If you agree to take part in this research, it will involve meeting with me to discuss your experience of participating in (service name). I will come to a location which best suits you. The meeting will involve talking about, for example, what your life was like before using (service name) and what it's been like since. It will be very relaxed and informal and you will not have to answer any questions if you do not wish to do so. You will be able to take breaks throughout the meeting, whenever you wish. Most importantly, there are no right or wrong answers!

I would be most grateful if you would consider participating in this piece of research. If you are happy to do so, please complete the attached participation form and return to me as soon as possible.

I look forward to hearing from you.

Many thanks in advance for your help.

Kind regards

Padraic Fleming

PHD SPHeRE scholar

083 1803165 Project Mobile Number purchased specifically for project

cc Dr Sinéad McGilloway

Note: This cover letter scored 67.4 (easily understood by 8th and 9th grade students)

A1.6 - TEXT FROM PARTICIPANT INFORMATION AND CONSENT FORM

We would like to invite you to take part in an important research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information. Also, please ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?

This research is being carried out by Padraic Fleming, who is completing a PhD in Maynooth University Department of Psychology. The research is funded by Genio as part of the Health Research Board (HRB)-funded SPHeRE programme. Further information about these can be found on the following websites: www.sphereprogramme.ie - www.genio.ie - www.hrb.ie

The aim of this research is to evaluate the implementation of Personal Budgets to ascertain if they are feasible within an Irish context, and if so, if they are appropriate mechanisms for supporting people with disabilities to gain independent and self-determined lives within their local community. This in turn will provide data for evidence-based decisions by policy drivers around utilisation of funds from individually allocated resources.

As part of the research, meetings are being held with staff to understand the decisions which led them to develop a brokerage or direct payments programme. These meetings will also assess the implementation of the programmes to date. Meetings will also be held with programme participants and a nominated advocate to assess the perceived impact that the personal budget has had on their lives to date.

Who has approved this study?

The study has received ethical approval from the Maynooth University Social Research Ethics Sub-Committee.

Do I have to take part?

No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us some of your time to meet and talk about your experiences. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form.

If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as the analysis is completed. If you withdraw from the research, it will have no impact with your involvement with (organisation name) and you will not be treated any differently.

What will happen if I take part?

Padraic will visit you at home (or at another location which suits you best) sometime during the next few weeks. You will be given an opportunity to ask any questions you might have and if you are happy to proceed, Padraic will ask you questions, for example, about your life, family, friends and your involvement with (organisation) and the impact the Personal Budget has had on all of these things. The meetings will be recorded with your consent to help Padraic remember the details correctly. Nobody will have access to the recording except Padraic or possibly a trusted colleague who may be helping him to type up the notes.

All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. When the findings of this study are reported, information from individuals will be reported using fictitious names so nobody will be able to identify you.

How long will the whole process take?
After you have had a chance to meet Padraic and ask any questions you might have, the meeting should last about 45 minutes in total. If this seems too long then we can stop after 10 or 20 minutes and start again after a break or on another day. You can take as many breaks as you wish and Padraic has no problem returning on another day if necessary.

Will my taking part in this research be kept confidential?
All information which is collected about you during the course of the research will be kept strictly anonymous by removing any personally identifiable information from the transcripts (typed notes), such as names, addresses, and locally identifiable information. All information will be held on an encrypted laptop or in a locked cabinet at Padraic's place of work and will be accessed only by the research team; no information will be distributed to any other unauthorised individual. The recording and documents with identifiable information will be deleted 5 years after study completion.

The research team will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent. However, it must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by legal and ethical concerns. For example, if the research team has any concerns about your safety, or the safety of others, a healthcare professional will be informed and will contact you to ensure that appropriate supports are put in place.

What will happen to the results of the research?
The research will be written up in report format and may be published in journals and presented at conferences or other public fora. Any publications arising from this research will not contain any personally identifiable information. A copy of the research results will be available upon completion.

What if I want to gain access to my information?
Any information that you provide to the researcher will be made available to you, on request. You should contact Padraic Fleming, the lead researcher, by emailing Padraic.fleming@nuim.ie or by phoning him to request access to your information (Tel: 083 1803165).

Who do I contact if I experience any discomfort or stress as a result of the study?

In the first instance, you should speak to a health professional at (organisation name). If you would like to speak to somebody else confidentially we have provided some useful numbers on a separate sheet, should you feel upset or distressed.

Who do I contact if I have a question?
Please feel free to address any questions to Padraic Fleming, the lead researcher, who is also available on the telephone to discuss the study with you (Tel: 083 1803165).

Alternatively, you may contact Padraic's supervisor, and Senior Lecturer at Maynooth University, Dr Sinéad McGilloway, at (01) 708 6052/4765 or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland.

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

THANK YOU FOR TAKING THE TIME TO READ THIS

Participant Consent Form

Title of Project: EVALUATION OF THE DEVELOPMENT AND IMPLEMENTATION OF PERSONAL BUDGETS FOR PEOPLE WITH A DISABILITY IN IRELAND.

Please initial box

If I am not in a position to provide written consent, I agree to the use of audio or video recording for consent

I have had the opportunity to ask questions and that any questions have been satisfactorily answered.

I understand that my participation is voluntary and that I am free to withdraw from the research at any time (and withdraw my data up to the point of data analysis), without giving any reason and in the knowledge that my legal rights and my access to, or use of, services will not be affected.

I understand that all information will be stored anonymously. All information will be held on an encrypted laptop or kept in a locked cabinet which will be accessed solely by the research team and will not be distributed to any other unauthorised individual. These data may be accessed by me at my discretion.

I understand that all information will be treated with the strictest confidence, except in cases where the research team is legally or ethically bound to disclose information (e.g. in the interests of participants' safety and wellbeing).

I agree that this meeting can be recorded and I understand that the audio recording will be transcribed and that I will be permitted to edit this transcript, should I so wish. Once the transcript is edited, I understand that the audio recording will be destroyed and the transcript will be stored securely for five years in the premises of the Maynooth University Department of Psychology, after which time it will be destroyed.

I understand that my data will be analysed along with data of other participants and may be used in a report or other publications, but that all care will be taken to ensure that the analysis or quotations do not include any personally identifying details and that I will not be personally named in any reports or publications.

I agree to take part in the above study.

_______________________ _______________________

Name of participant *Signature*

Date:

No__________.

For Office Use Only

Useful contact numbers

If at any point after this meeting you feel upset or distressed about any of the issues which arose, you can talk to somebody from one of the organisations below:

Samaritans is a confidential emotional support service for anyone in Ireland. You can call this number day or night, 24 hours a day. FREE PHONE 116 123.

GROW is a Mental Health Organisation which helps people who have suffered, or are suffering, from mental health problems. PHONE: 1890 474 474

Aware supports those who are directly affected by depression. Aware operates a helpline from 10am to 10pm (Mon to Wed) and 10am to 1am (Thurs to Sun). PHONE: 1890 303302

Note: This information sheet scored scored 67.1 (easily understood by 8th and 9th grade students) on the Flesch Readability Ease' index

A1.7 - TEXT FROM LETTER OF INVITATION TO STAFF MEMBER

Dear (Name)

Re: EVALUATION OF THE DEVELOPMENT AND IMPLEMENTATION OF PERSONAL BUDGETS FOR PEOPLE WITH A DISABILITY IN IRELAND.

Your name was provided to me by (name) in (organisation). I may have spoken to you previously but if not I believe (name) has told you about the work that I am doing at the moment. This involves meeting with staff and participants from brokerage or direct payment pilot projects around Ireland to discuss progress to date. I was hoping that you would be willing and available to take part in this valuable piece of research.

Attached to this letter is a detailed information sheet and consent form. You do not have to complete it at this time, but it is there for you to read and jot down any questions you might have for me.

If you agree to take part in this research, it will involve meeting with me to discuss your experience of working in (service name). I can come along to your offices in (organisation) if this is convenient for you? The meeting will involve talking about, for example, the development and roll-out of (service name), any challenges you faced and how these were overcome, and what has/has not worked well. It will be very relaxed and informal and you will not have to answer any questions if you do not wish to do so. Most importantly, there are no right or wrong answers!

I would be most grateful if you would consider participating in this piece of research. If you are happy to do so, please complete the attached participation form and return to me as soon as possible.

I look forward to hearing from you.

Many thanks in advance for your help.

Kind regards

Padraic Fleming

PHD SPHeRE scholar

083 1803165 Project Mobile Number purchased specifically for project

cc Dr Sinéad McGilloway

Note: This information sheet scored 64.4 (easily understood by 8th and 9th grade students) on the Flesch Readability Ease' index

A1.8 - TEXT FROM STAFF MEMBER INFORMATION AND CONSENT FORM

We would like to invite you to take part in an important research study. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take a few minutes to read carefully through the following information. Also, please ask us if there is anything that is not clear, or if you would like more information.

What is the purpose of this study?
This research is being carried out by Padraic Fleming, who is completing a PhD in Maynooth University Department of Psychology. The research is funded by Genio as part of the Health Research Board (HRB)-funded SPHeRE programme. Further information about these can be found on the following websites: www.sphereprogramme.ie - www.genio.ie - www.hrb.ie

The aim of this research is to evaluate the implementation of Personal Budgets to ascertain if they are feasible within an Irish context, and if so, if they are appropriate mechanisms for supporting people with disabilities to gain independent and self-determined lives within their local community. This in turn will provide data for evidence-based decisions by policy drivers around utilisation of funds from individually allocated resources.

As part of the research, meetings are being held with staff to understand the decisions which led them to develop a brokerage or direct payments programme. These meetings will also assess the implementation of the programmes to date. Meetings will also be held with programme participants and a nominated advocate to assess the perceived impact that the personal budget has had on their lives to date.

Who has approved this study?
The study has received ethical approval from the Maynooth University Social Research Ethics Sub-Committee.

Do I have to take part?
No, you are under no obligation whatsoever to take part in the research. However, we hope that you will agree to take part and give us some of your time to meet and talk about your experiences. It is entirely up to you to decide whether or not you would like to take part. If you decide to do so, you will be asked to sign a consent form.

If you decide to take part, you are still free to withdraw at any time without giving a reason and/or to withdraw your information up until such time as the analysis is completed. If you withdraw from the research, it will have no impact with your involvement with (organisation name) and you will not be treated any differently.

What will happen if I take part?
Padraic will visit you at your office (or at another location which suits you best) sometime during the next few weeks. You will be given an opportunity to ask any questions you might have and if you are happy to proceed, Padraic will ask you questions, for example, about your job and the successes and challenges of implementing the new programme. The meetings will be recorded with your consent to help Padraic remember the details correctly. Nobody will have access to the recording except Padraic or possibly a trusted colleague who may be helping him to type up the notes.

All the information you provide will be kept at Maynooth University in such a way that it will not be possible to identify you. When the findings of this study are reported, information from individuals will be reported using fictitious names so nobody will be able to identify you.

How long will the whole process take?
The meeting should last about one hour in total.

Will my taking part in this research be kept confidential?
All information which is collected about you during the course of the research will be kept strictly anonymous by removing any personally identifiable information from the transcripts (typed notes), such as names, addresses, and locally identifiable information. All information will be held on an encrypted laptop or in a locked cabinet at Padraic's place of work and will be accessed only by the research team; no information will be distributed to any other unauthorised individual. The recording and documents with identifiable information will be deleted 5 years after study completion.

The research team will take all reasonable steps within law to ensure that confidentiality is maintained to the greatest possible extent. However, it must be recognised that, in some circumstances, confidentiality of research data and records may be overridden by courts in the event of litigation or in the course of investigation by lawful authority

What will happen to the results of the research?
The research will be written up in report format and may be published in journals and presented at conferences or other public fora. Any publications arising from this research will not contain any personally identifiable information. A copy of the research results will be available upon completion.

What if I want to gain access to my information?
Any information that you provide to the researcher will be made available to you, on request. You should contact Padraic Fleming, the lead researcher, by emailing Padraic.fleming@nuim.ie or by phoning him to request access to your information (Tel: 083 1803165).

Who do I contact if I experience any discomfort or stress as a result of the study?
We have provided some useful numbers on a separate sheet, should you feel upset or distressed and wish to speak to somebody confidentially.

Who do I contact if I have a question?
Please feel free to address any questions to Padraic Fleming, the lead researcher, who is also available on the telephone to discuss the study with you (Tel: 083 1803165).

Alternatively, you may contact Padraic's supervisor, and Senior Lecturer at Maynooth University, Dr Sinéad McGilloway, at (01) 708 6052/4765 or write to her at the Department of Psychology, John Hume Building, Maynooth University, Maynooth, Co. Kildare, Ireland.

If during your participation in this study you feel the information and guidelines that you were given have been neglected or disregarded in any way, or if you are unhappy about the process, please contact the Secretary of the Maynooth University Ethics Committee at research.ethics@nuim.ie or +353 (0)1 708 6019. Please be assured that your concerns will be dealt with in a sensitive manner.

THANK YOU FOR TAKING THE TIME TO READ THIS

Participant Consent Form

Title of Project: EVALUATION OF THE DEVELOPMENT AND IMPLEMENTATION OF PERSONAL BUDGETS FOR PEOPLE WITH A DISABILITY IN IRELAND.

Please initial box

I have had the opportunity to ask questions and that any questions have been satisfactorily answered.

I understand that my participation is voluntary and that I am free to withdraw from the research at any time (and withdraw my data up to the point of data analysis), without giving any reason and in the knowledge that my legal rights and my access to, or use of, services will not be affected.

I understand that all information will be stored anonymously. All information will be held on an encrypted laptop or kept in a locked cabinet which will be accessed solely by the research team and will not be distributed to any other unauthorised individual. These data may be accessed by me at my discretion.

I understand that all information will be treated with the strictest confidence, except in cases where the research team is legally or ethically bound to disclose information (e.g. in the interests of participants' safety and wellbeing).

I agree that this meeting can be recorded and I understand that the audio recording will be transcribed and that I will be permitted to edit this transcript, should I so wish. Once the transcript is edited, I understand that the audio recording will be destroyed and the transcript will be stored securely for five years in the premises of the Maynooth University Department of Psychology, after which time it will be destroyed.

I understand that my data will be analysed along with data of other participants and may be used in a report or other publications, but that all care will be taken to ensure that the analysis or quotations do not include any personally identifying details and that I will not be personally named in any reports or publications.

I agree to take part in the above study.

______________________ ______________________

Name of participant *Signature*

Date:

No. _________

For Office Use Only

A1.9 - TEXT FROM PARTICIPATION FORM

PLEASE TYPE or PRINT IN BLOCK CAPITALS

NAME					
ADDRESS					
PHONE NUMBER					
EMAIL ADDRESS					
TIMES WHICH SUIT ME	Please insert a suitable time that you could meet with me over the coming weeks:				
	Mon	Tues	Weds	Thurs	Fri
Dec x – Dec x					
Dec x – Dec x					
Jan x – Jan x					
Jan x – Jan x					
Below please suggest a place where is most suitable for you to meet. This should be a quiet and private space. It can be in your offices or elsewhere.					

Please return by email to Padraic.fleming@nuim.ie

or post to:

Padraic Fleming
Maynooth University Department of Psychology
Maynooth University
Maynooth
Co. Kildare

A1.10 – PLAN FOR PARTICIPATORY WORKSHOP

Timing	Exercise/Task	Rationale	Description	Who	Resources Needed
10.30 – 10.40	Welcome and Introductions	Let everyone know who is in the room, put people at their ease etc.	Sinead McGilloway to welcome everyone, introduce the purpose of the session and then round the room introductions	Sinead McGilloway	Workshop Pack with slides for 5 presentations. Camera
10.40 – 10.50	Managing expectations for the workshop	Clarify the purpose of the workshop, identify people's expectations and goals	Padraic to present the preamble to the workshop (interview stages etc.)	Padraic to lead	Laptop, projector, pedestal
10.50 – 11.00	Áiseanna Tacaiochta presentation	Inter-agency communication emerged from phase one data as requiring improvement. Therefore this exercise will raise awareness. It will allow others in the room know how the pilot was organised and structured	Representative to introduce the project, background, processes and procedures, people involved	Representative	Laptop, projector, pedestal
11.00 - 11.10	Bridging the Gap presentation	Inter-agency communication emerged from phase one data as requiring improvement. Therefore this exercise will raise awareness. It will allow others in the room know how the pilot was organised and structured	Representative to introduce the project, background, processes and procedures, people involved	Representative	Laptop, projector, pedestal
11.10 – 11.20	Connect-Ability presentation	Inter-agency communication emerged from phase one data as requiring improvement.	Representative to introduce the project, background, processes and procedures, people	Representative	Laptop, projector, pedestal

		Therefore this exercise will raise awareness. It will allow others in the room know how the pilot was organised and structured	involved		
11.20 – 11.30	Possibilities Plus presentation	Inter-agency communication emerged from phase one data as requiring improvement. Therefore this exercise will raise awareness. It will allow others in the room know how the pilot was organised and structured	Representative to introduce the project, background, processes and Laptop, projector, pedestal procedures, people involved	Representative	Laptop, projector, pedestal
11.30 – 11.50	Tea / coffee	Tea / coffee	Tea / coffee	O'Briens Order	O'Briens Order
11.50 – 12.20	Present Qualitative Findings	Present the main findings from Phase 1 (qualitative exploratory interviews)	Padraic to present the main findings from the research to date	Padraic to present. Sinead / Sarah time keeping	Laptop, projector, pedestal
12.20 – 12.30	Questions & Answers	Opened to the floor to take some questions regarding the results	Padraic to answer any questions that the audience might have relating to the presentation or the findings in general	Padraic to answer. Sinead to facilitate / time keeping. Sarah to take notes.	Notepad. Dictaphone
12.30 – 13.00	Group work	In groups – Brain storm and write down main points on the flipchart.	4 groups. 5 sheet with 1 question / theme on each sheet. 5 Minutes per sheet to jot down.	Padraic / Sarah / Sinead to float / assist / remind people to move onto next sheet	4 flipchart stands / 4 flip charts / markers
13.00 – 13.20	Discussion	Feedback the general discussion which emerged within the exercise.	Each group have 5 mins to present back 1 main point from each page	Sarah to facilitate. Padraic to take notes.	Notepad. Dictaphone.
13.20 – 14.00	Lunch	Lunch	Lunch	O'Briens Order	O'Briens Order

A1.11 – AGENDA FROM PARTICIPATORY WORKSHOP

Maynooth University
National University of Ireland Maynooth

SPHeRE
Structured Population and Health-services Research Education

Agenda – Individualised Budgets

'Stakeholder Sharing and Learning' Workshop

Date: Friday 4th September

10.30 – 10.50

Introductions – Dr. Sinead McGilloway

What to expect today (Learning Objectives) – Padraic Fleming

10.50 – 11.30

Presentations from Organisations

1 – Áiseanna Tacaiochta

2- Bridging the Gap

3- ConnectAbility

4- PossibilitiesPlus

11.30 – 11.50
Tea / Coffee Break

11.50 – 12.20

Presentation and Discussion of findings from interviews

12.20 – 13.20

Group Work and Discussion

13.20 – 14.00

Lunch

GENIO

HRB
Health Research Board

A1.12 – TRANSCRIPTION OF GENERAL DISCUSSION AT END OF WORKSHOP

PF: Thanks everyone in the room. Asks participants as experts if any important questions that still need to be answered.

Staff CS2: I just think, if we can come together as a body of people and start to do some kind of direct funding Facebook page and that every organisation could link in, because there's power in numbers and it's, you know, you see protests all the time that are happening and it's not a protest, it's just an informative thing, be it Down Syndrome Ireland, whoever it is, there are so many organisations in Ireland. I never even knew that you guys existed (Organisation) and I'm down in (county), it isn't down there obviously, but there are so many around Ireland that people don't know about that might benefit from direct funding and if we could do some kind of blog, some kind of Facebook page, whatever it is to get the word out, I think would be hugely beneficial for going as a campaign forum to the government eventually or the HSE.

PF: I think that's a great idea. *(Agreement around the room)* And you have the power.. to make that happen. You are the people that would form that group and through word of mouth, all the other people that you know, it could grow and grow and grow.

Staff CS2: You may have to form it and we all join. *(Laughs around room)*

Researcher: You need somebody to take a lead because these things tend to unwind...

Parent CS4: I just think if you are trying to advocate or or lobby or whatever the word is, to the HSE or the government or the politicians, I think you need something that's clear. Is what Padraic was able to provide today. You know sometimes the information is too loose and the questions asked are too loose. You know, you need to pick out, what's the exact question we need to ask of that politician. And even with the election coming up. If, if a page could be formulated to give all people with disabilities, their families and widen out the circle so that every politician coming to the door, someone will ask the question, OK, what's the story with individualised budgeting, how's it going, where's it at. And so at least, he says oh jays, I better, as well as filling the potholes, and whatever else he's going to be asked about. This would be a question, you know, because for the parents of small children with a disability, this is a perfect question for the future. And if you can get them on board... but you need somebody with a clear question to ask them...

(Discusses example)... allocation of funds cut.... why.... gives them a power

Parent (CS 3): You need the information that there is individual budgeting out there, that... and we need, you're right, we need a leader, em we need somebody to really push, so that (organisation) is not doing it or (organisation)...or whatever, but a good few weeks, just before the summer holidays. I'm part of a working group with the carers association. We were invited in to have a conversation with Minister Kathleen Lynch and the head of HSE for disability services. And I asked them a question, I said I'm a member of (organisation), you know, getting individualised funding, it's been amazing, life changing experience for us and our family. Is it there to stay or how long is it going to be a pilot project and both of their answers to me was, that each organisation, charity, whatever, they're all being told that they have to give 3% of their allocated budget to families who want to get individualised funding. That was their answer to me.

(CONVERSATION ensues about 3%) An advocate from CS4 also heard 3%. People not singing off same hymn sheet.... They're saying nationally 3%, all organisations for the individual families that want that. But you're still going to have to fight for it. *(CONVERSATION continues)* CS4 parent heard this 2 years ago but hasn't arrived. Staff CS4 also questions whether this is a real figure since they met with Kathleen Lynch a year ago. No deadlines. No timescales. We found it frustrating. Now maybe it has progressed since then. (CS1 takes about policy and how only 5% of any policy is actually implemented. "The policy is there, the law is there, it's just not being enacted. And is it a case that when it comes to people with disability, there's not enough of a force there to go up and shut the Dail down with a protest...)

Advocate CS4. We don't have a la stating that disabled people are entitled to anything. It’s always "If we have resources".

Staff CS4: There's no accountability, so you can produce a document like value for money or any other type of document you like, as a policy document, but there is nothing to say, like this doesn't have any key performance indicators or whatever, you know, we'll charge, whatever. There's no consequences. *(General conversation...)*

Advocate CS4: The law needs to fundamentally change, (?) do have a right to quality of life, because we don't at the moment

Staff CS1: But I mean if they are going to give you 11,000 to attend a service, surely you should be able to pick and choose what can buy that with, so every service...

Advocate CS4: Yeah but that's only a day service. That's from 9 to 3 or 4 o'clock. What do you do with the rest of *(General consensus from another person with disability).*

Parent CS3: Its people, unfortunately there are some people that will fight the fight to get what they need and there there are some that just get so bogged down that they just give up and let go and that's no criticism and we wonder why there's no protest and we wonder why...

Advocate CS4: But you can see why because...

Staff CS3: It's not just the person with disability that's vulnerable. It’s the family... They don't want to push the system because they are fearful that they will lose (**Advocate CS4:** They will lose what they have) They're very fearful...

Parent CS4: You wouldn't mind fighting the fight if you thought that fight you fought made it easier for somebody coming behind you... that’s what I find very frustrating because there's some of us that did fight the fight and get what we needed and very delighted to have done that and see the benefits of that. But I, I know of people now that are ten months still waiting to try and unbundle money that, that the HSE gave to a service provider. And continue to pay to it this year, even though they went down a different road. And that's what's really frustrating because, those sort of stories about that struggle put people off. And I know one of the things that the HSE has been saying, and I know (Name) has said it. There's no demand for this. Would there be a demand for it?

Parent CS3: If they knew about it. **Parent CS4**: One if they knew about it but if they didn't make it such a monumental struggle to get it. Like that would break the heart of anybody. **Parent CS3**: But sure the documents now, if you, if your child is being assessed and the documents, if you're applying for the DCA, mean it's like a 50 page document. I have families that are coming in and actually some of them just find it so difficult just to sit down and and sign those forms and I've gone to the Citizens Information Bureau and I said some of the families are really struggling, even signing the form. And they said, send them down to us, we'll help them sign the form. Sometimes it's even signing, it's getting those forms ... but it's like the hurdle... hurdle hurdle hurdle, it's constant

Parent CS4: It has to be made, as I said, it's not for everybody but it should be on the list of options that you can choose. That's all we're looking for. We're not looking that everybody has to go individualised funding or anything else. People are very happy with traditional day service, why shouldn't they stay in it, of course they should. But it should be an option the same as the other option and it should not be that option that they attempt to break you before you get it. If you're stronger than them is the only way you're going to get it.

Staff CS1: Well there's power in numbers. (?) If you keep knocking on the door, eventually it will have to open. But if you have enough of people, so you know, going back to the Facebook page. If you have enough of people singing the same hymn, continuously banging on the door. They'll soon have to open that door and deal with that issue

Staff CS3: I think that struggle as well that you're talking about is something that really should be illustrated in the research. Because it's a big part of it. Cos like, yes people are getting individualised funding, the journey towards that, em, like as you say is hurdle after hurdle, and that needs to be highlighted as much as all the benefits. (**Staff CS4**: When you actually do get in, if you're one of the lucky ones) Yeah, exactly and that, that brings with it, kind of a guilt as well, like I know that (name) says that

Staff CS1: Whereabouts in Ireland is individualised funding actually happening now? (**Staff CS4:** Dublin, East Coast Dublin) (**Parent CS4:** Collectively, could anyone put a figure on the amount of people that are being supported by an individualised fund in the country, You know, a broad point figure between something and something) (**Staff CS4:** We're working with 15 people who have funding at the moment...) (**Staff CS3:** We have 20, maybe 10 more coming on) (**Advocate CS4:** But there's other people) So the East coast basically Dublin are rolling it out. (**PF:** Well it's less than 50...) *(Everyone talks together)*

Staff CS4: ... but (organisation) have an agreement for 50 people, don't you? (**Staff CS3:** Yeah well... for 100 people) (**PF:** A target) (CS3: Yeah a target) Yeah, so there's an agreement by the HSE that you can support 100 people in this way (**Staff CS3:** Yeah, until... yeah, until 2017) (**Staff CS4:** So the process for those people you know, they go and request their individual budget no matter what disability manager they're in and they come to you or how, how is that working?) (**Staff CS3:** Yeah, they usually come to us first and then we help them in approaching their disability manager, but our membership is scattered throughout the country. It would be more so in Dublin and in Galway but we are scattered, we're trying to continue to scatter people around the country, because if it is to be representative and fair, it should be nationwide

Staff CS1: So as a suggestion, if we did create an individualised funding Facebook page and all services link in and like it and say look, you know, this is how it helps, that, that's our forum, that's our voice. Because I did not know it was being rolled out anywhere. Even if it was only for a year. Or two years, even if it was only for 5 people or 10 people. I mean, and I'm running that through Genio now on my, second and a half year, so we don't know what all of us are doing. So we don't know what all of us are doing and we're a group of 20 people singing off the one hymn sheet. How's the rest of Ireland supposed to know.

Staff CS4: Well just explain what is happening with us is I suppose, our immediate catchment area is, Wicklow, Kildare, Meath and Dublin. And that's just very pragmatic, we're going to be supporting eh, to our support workers, you know we don't want to spend 3 hours getting to see them and 3 hours driving back again. Em, what we have done in a couple of situations where we're able to do it, we have more local supports, so we're supporting somebody in Waterford and somebody in Sligo at the moment. Em, but what we would like to see is other, eh I suppose brokerages develop around the country, that would take on that role. Now, the rollout is probably the wrong word, I mentioned (CS3) cos they have that agreement. We, I mean, we have been in talking to (Name), you know, wasn't keen on it. She was saying to me, look, we're piloting (organisation) kind of that's enough and we're trying to point out this is a different one. So what they have agreed, kind of, informally is that in Kildare, west Wicklow, school leavers can have the option of coming to us. Em, what has happened then, is other individuals where their money is floating have come looking for us and we'll, the money is available, in other words they've left a service and the funding has come away from the service and the HSE are still holding it, then it's relatively straight forward, if the family push it that they want (CS4), then that funding does become available.

There a very small number of cases and in other cases where HSE has a problem, they want solved and they think we can solve it, their willing to put funding our way in relation to that. So it's very ad hoc for the rest. Now ad hoc in the sense that once we start we're presuming, that's it, it's going. And I think they're presuming it as well. So, it's not that it's year to year but it is for new people coming in, it is very difficult to get it, and sometimes because parents and (parent) would be a good example, if you push hard enough, they'll want to find some solution.

Advocate CS4: (Name) what happens to a person, goes to a day service and then goes to a residential service. So they have two pots of money. (**Staff CS4:** Yeah. Well if we are providing the full 24 hour supports for the person, we would look for both pots of money. Yeah. Now in some cases people are doing a course so they could finish em, so that funding needed for that course would be provided. Some of those courses are two days a week, three days a week. That we would... and that that’s funding for that and we would look at supporting them through the rest of the week. That's kind of how it might work but we have three incidences where a service has released funding, right. Now, one of them was quoted actually in one of the slides, eh, it's a very small amount of money and through negotiation that improved a bit. OK. So the service released a little bit more. And the HSE agreed to add a little bit to it. And it's still relatively speaking fairly small funding. But we have three cases where one of the three different agencies agreed for one person. They don't see us as too threatening. It's just one person. Three, four or five people might be looking for this in their agency, they would probably be a little bit, more of a challenge.

Staff CS4: I think there are some disability managers that are very progressively thinking, you know (**Staff CS4:** Would like to support it) would like to to support it, but they're choked in their system. And then you have disability managers that actually, they're aware of (CS3) but that's all they're aware of and they don't want to hear anything else. But yet families don't want what (CS3) have which is the company set up, some families don't, some families are happy with the company based and equally are good as one another, it's just different way of doing it. But it’s educating the disability managers from our point of view and the difference and what it is. It's the same thing but in a different way. And it's individualised. There's, within the individualised, there's a slight difference and that led to confusion...

PF: There is a slight difference, and I mentioned this a couple of times, but I would argue that you're a lot closer, you're a lot more similar than ye think ye are, (**Staff CS4**: we are very similar, yeah yeah) Even in (CS4) and (CS3) are a lot more similar than you might think. Em, because I would say the (CS3) is kind of merging into brokerage a bit and equally you guys are merging into direct payments a bit. And just because they have certain labels doesn't mean that they don't branch outside of those boxes.

Staff CS4: I think the aims are the same, the values are the same and what you do. (talk together) (PF: For everybody, it's finding the mechanism to get there and sometimes that looks the same regardless of what organisation you're working with. (**PwD:** Yeah that's right)

Advocate CS4: It's all built on circle of support. But there are a lot of people that do not have family support. And it's a crucial element, you know, like where do the half of the other people wanting to have more choice and control. Who's going to fight for them because they, they really don't have the support of their family.

PF: I suppose that's one of the things that I saw as being quite innovative, is that, it's building that circle of support and it doesn't necessarily always have to be somebody that is very passionate about... (**Advocate CS4:** I get that, but like I'm connected to about 20 people. And out of them, they all have, well it's half and half. Like half wouldn't have family, or don't want the connection of family. But they equally wouldn't be able to say and go to (CS3) or (CS4) and say, I want more choice. (**PF:** yeah, it's that initial step) You know what I mean. where are they going... they're getting lost. (**PF:** Well I suppose, I think that that kind of comes back a little bit to, I think you were saying, that people don't know what's available to them. People don't...) (**Advocate CS4:** But they... well, ok, I think they do to a point, they just don't know how to (**PwD:** To get around it) or like, they might say it to somebody and it's like, OK, fine. Like I'm listening to a girl for 3 / 4 years telling me she wants to live on her, not on her own, but with different people. 4 years and she's still saying the same thing, you know. And in 4 years time she could be sayin the same. And there's many of them saying

Parent CS3: So almost like you nearly need a company that could help that person to plan and to... If they can't come around with a circle of support. You need somebody to help them to get a circle of support. (**Advocate CS4:** And the only thing, the only thing that they're coming to me is because I listen, do you know what I mean...) (**PA of advocate:** Yet they go to a service, and nobodies listening to them)

Staff CS1: Advocates have to be out there for whatever circle that you're on, on a localised basis, (**Advocate CS4:** And they have to be objective and they have to work for that person and not for the system, you know and I think that's a real flaw)

PF: I agree. I whole heartedly agree with what you're saying, but I think, I think what we're doing in this room could be the turning point and maybe not for everybody that's currently here, but going forward (**Parent:** going forward for the younger) And I don't, like and that's not to say that we forget about the people who don't have natural supports, of course we don't but (**Advocate CS4:** And I appreciate, you know, you can only do what you can do and stuff like that)

Parent CS3: Here's a little, I don't know, a little small of bulb. But for the younger generation that are coming behind you guys, we are really being told and very much it's being embedded from a very early stage of the circle of support, of connection, of friendships.. so they have learnt from the past and it is changing, not changing quick enough (**Advocate CS4:** Oh yeah, I see it with the young people but there are many many other people that, like we have a very high percentage of 50 and 60 and 70 year old people, that have a disability and all them people....)

Staff CS3: But it is moving. I mean, and ever so slow as it is, it is progressing. It's just to keep it flowing, to keep it being pushed.

PF: I'm just conscious that we're nearly half an hour now over our schedule. Was there any final comments before we wrap up.

Researcher: Just briefly. Just from a, you know the Facebook idea, interesting exercise, I'm not sure who could take it on but one simple and very interesting exercise might be to do a kind of a profile of the various different, even yourselves, even starting with that. You could use something like a tree, metaphor, same goal, similar vision, you know of what the end game is but then you're obviously branching out into different kind of nuanced models or whatever. But even for, like to communicate to a politician or something or for the public at large em, you know, just to have something like even in a graphic presentation that gathers together that information. It could be put together and maybe that exists already, but I get a sense that it mightn't and it just might help for some of that communication because even for me today, I'm learning about the various different, the models and learning the language and that kind of thing and just something like that, that helps could be useful.

Staff CS3: And could I also say that em, in response to your question as well, (CS3) is running a like a pre-budget and an election campaign (etc etc and potential opportunity for organisations to work together on a shared goal to share statistics and experiences)

Parent CS4: *(talking about incinerator campaign as example of how to organise and run a campaign, making it easy for people to engage)*

Parent CS3: *(Queries if university has IT section to take on the role?)*

Staff CS3: *(Suggests sharing everyone's contact details)*

Staff CS4: Just to say, the two organisations that have been very supportive of this are Down syndrome Ireland and Inclusion Ireland (etc etc try and link in with them and their customers)

Researcher: What about parsing the media in a creative way, is that something that could be done to raise awareness. Because that has been a recurring theme today.

Staff CS3: I think telling peoples stories because people read papers and they want to know the person, they want to know (**Researcher:** Correct) You know who is (name), where does she live, what was she doing, what is she doing now. How has life changed? Again simple. And they like headlines and they like, they usually like bad news but if you can put in some bad news, but here's the answer and this is how it's worked. You see it in the Daily Mail all the time. They've got a campaign on everything every other week. Just because its headlines and it sells papers (etc etc.... Needs coordination... Suggestions for an investigative journalist piece... Hold politician up on their word... somebody to take it on. Human interest only human interest... Migrant council of Ireland have series of podcasts... follow families.... draws you in, telling whole story... Photo of Syrian child on beach etc etc...Frustrations expressed... Do we have to set ourselves on fire... that's a disgrace)

PF: (PwD) did you want to say something?

PwD: Yeah I do actually. I was listening on your opinion, everyone of your opinions. They're kind of good opinions. If you were a disability person standing in the middle (indicates to middle of the room) and the HSE is talking to you, you're not going to get much (?) out of them. You're not going to get anything from them. They want to get bad words about them, about disability. If you guys had all disability like me and your standing in the middle and talking to the HSE. I'd say their not going to give you anything. Their aiming for us. ... They're trying to drag us out of here.

A1.13 – ANONYMISED CODING PLAN

Metadata	Case Study Number	Service Type	Type of data collection	Study population sample	Particpant real name	Particpant
Code	CS1	B	I	P1	Example	Example
CS1_B_I_P1	Case study 1	Brokerage	Interview	Participant 1	John	Steve
CS1_B_I_P2	Case study 1	Brokerage	Interview	Participant 2		
CS1_B_I_P3	Case study 1	Brokerage	Interview	Participant 3		
CS1_B_I_A1	Case study 1	Brokerage	Interview	Advocate 1		
CS1_B_I_A2	Case study 1	Brokerage	Interview	Advocate 2		
CS1_B_I_A3	Case study 1	Brokerage	Interview	Advocate 3		
CS1_B_I_S1	Case study 1	Brokerage	Interview	Staff Member 1		
CS1_B_I_S2	Case study 1	Brokerage	Interview	Staff Member 2		
CS1_B_FG_P1	Case study 1	Brokerage	Focus Group	Participant 1		
CS1_B_FG_P2	Case study 1	Brokerage	Focus Group	Participant 2		
CS1_B_FG_P3	Case study 1	Brokerage	Focus Group	Participant 3		
CS1_B_FG_P4	Case study 1	Brokerage	Focus Group	Participant 4		
CS1_B_FG_P5	Case study 1	Brokerage	Focus Group	Participant 5		
CS1_B_FG_P6	Case study 1	Brokerage	Focus Group	Participant 6		
CS1_B_FG_P7	Case study 1	Brokerage	Focus Group	Participant 7		
CS1_B_FG_P8	Case study 1	Brokerage	Focus Group	Participant 8		
CS1_B_DA	Case study 1	Brokerage	Document Analysis	Codes from above will be used when names arise in documents		
CS2_DP_P1	Case study 2	Direct Payment	Interview	Participant 1		
CS2_DP_P2	Case study 2	Direct Payment	Interview	Participant 2		
CS2_DP_P3	Case study 2	Direct Payment	Interview	Participant 3		
CS2_DP_A1	Case study 2	Direct Payment	Interview	Advocate 1		
CS2_DP_A2	Case study 2	Direct Payment	Interview	Advocate 2		
CS2_DP_A3	Case study 2	Direct Payment	Interview	Advocate 3		
CS2_DP_S1	Case study 2	Direct Payment	Interview	Staff Member 1		
CS2_DP_S2	Case study 2	Direct Payment	Interview	Staff Member 2		
CS2_DP_FG_P1	Case study 2	Direct Payment	Focus Group	Participant 1		
CS2_DP_FG_P2	Case study 2	Direct Payment	Focus Group	Participant 2		
CS2_DP_FG_P3	Case study 2	Direct Payment	Focus Group	Participant 3		
CS2_DP_FG_P4	Case study 2	Direct Payment	Focus Group	Participant 4		
CS2_DP_FG_P5	Case study 2	Direct Payment	Focus Group	Participant 5		
CS2_DP_FG_P6	Case study 2	Direct Payment	Focus Group	Participant 6		
CS2_DP_FG_P7	Case study 2	Direct Payment	Focus Group	Participant 7		
CS2_DP_FG_P8	Case study 2	Direct Payment	Focus Group	Participant 8		
CS1_B_DA	Case study 1	Brokerage	Document Analysis	Codes from above will be used when names arise in documents		
CS3_B_P1	Case study 3	Brokerage	Interview	Participant 1		
CS3_B_P2	Case study 3	Brokerage	Interview	Participant 2		
CS3_B_P3	Case study 3	Brokerage	Interview	Participant 3		
CS3_B_A1	Case study 3	Brokerage	Interview	Advocate 1		
CS3_B_A2	Case study 3	Brokerage	Interview	Advocate 2		
CS3_B_A3	Case study 3	Brokerage	Interview	Advocate 3		
CS3_B_S1	Case study 3	Brokerage	Interview	Staff Member 1		
CS3_B_S2	Case study 3	Brokerage	Interview	Staff Member 2		
CS3_B_FG_P1	Case study 3	Brokerage	Focus Group	Participant 1		
CS3_B_FG_P2	Case study 3	Brokerage	Focus Group	Participant 2		
CS3_B_FG_P3	Case study 3	Brokerage	Focus Group	Participant 3		
CS3_B_FG_P4	Case study 3	Brokerage	Focus Group	Participant 4		
CS3_B_FG_P5	Case study 3	Brokerage	Focus Group	Participant 5		
CS3_B_FG_P6	Case study 3	Brokerage	Focus Group	Participant 6		
CS3_B_FG_P7	Case study 3	Brokerage	Focus Group	Participant 7		
CS3_B_FG_P8	Case study 3	Brokerage	Focus Group	Participant 8		
CS1_B_DA	Case study 1	Brokerage	Document Analysis	Codes from above will be used when names arise in documents		
CS4_B_P1	Case study 4	Brokerage	Interview	Participant 1		
CS4_B_P2	Case study 3	Brokerage	Interview	Participant 2		
CS4_B_P3	Case study 3	Brokerage	Interview	Participant 3		
CS4_B_A1	Case study 3	Brokerage	Interview	Advocate 1		
CS4_B_A2	Case study 3	Brokerage	Interview	Advocate 2		
CS4_B_A3	Case study 3	Brokerage	Interview	Advocate 3		
CS4_B_S1	Case study 3	Brokerage	Interview	Staff Member 1		
CS4_B_S2	Case study 3	Brokerage	Interview	Staff Member 2		
CS4_B_FG_P1	Case study 3	Brokerage	Focus Group	Participant 1		
CS4_B_FG_P2	Case study 3	Brokerage	Focus Group	Participant 2		
CS4_B_FG_P3	Case study 3	Brokerage	Focus Group	Participant 3		
CS4_B_FG_P4	Case study 3	Brokerage	Focus Group	Participant 4		
CS4_B_FG_P5	Case study 3	Brokerage	Focus Group	Participant 5		
CS4_B_FG_P6	Case study 3	Brokerage	Focus Group	Participant 6		
CS4_B_FG_P7	Case study 3	Brokerage	Focus Group	Participant 7		
CS4_B_FG_P8	Case study 3	Brokerage	Focus Group	Participant 8		
CS1_B_DA	Case study 1	Brokerage	Document Analysis	Codes from above will be used when names arise in documents		

A1.14 – CONTENT ANALYSIS FROM DOCUMENTARY ANALYSIS

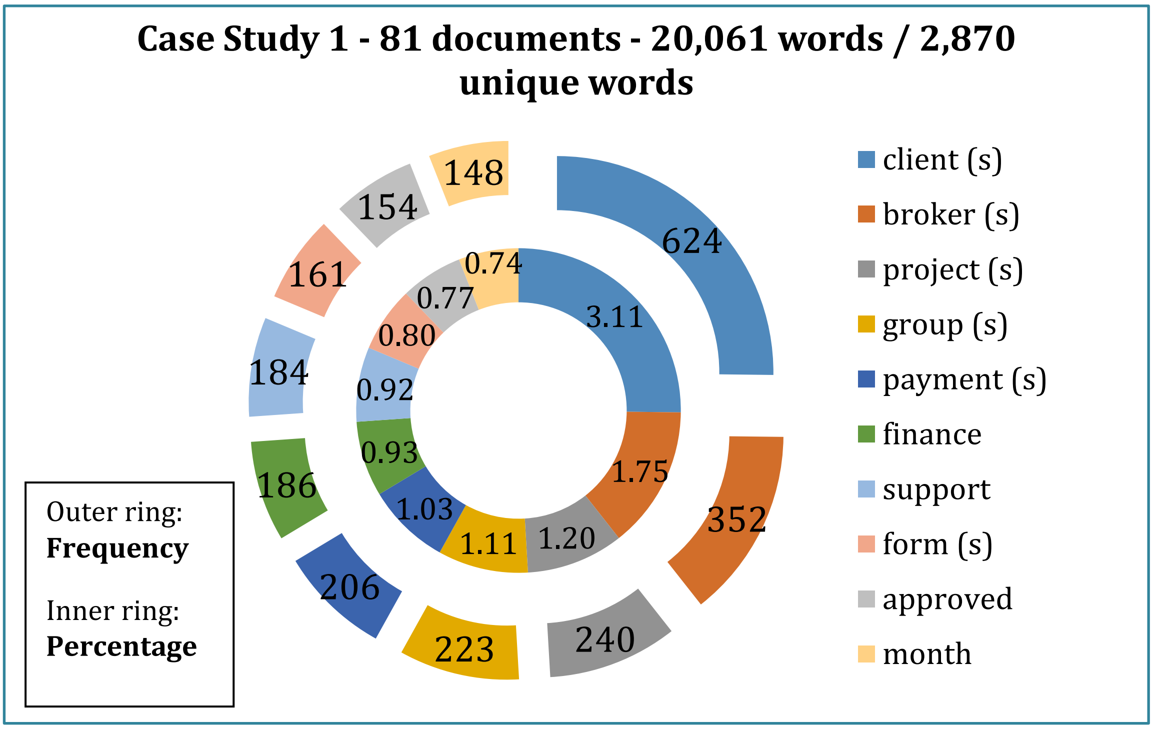


Figure A1.14.1 - Content analysis for case study 1

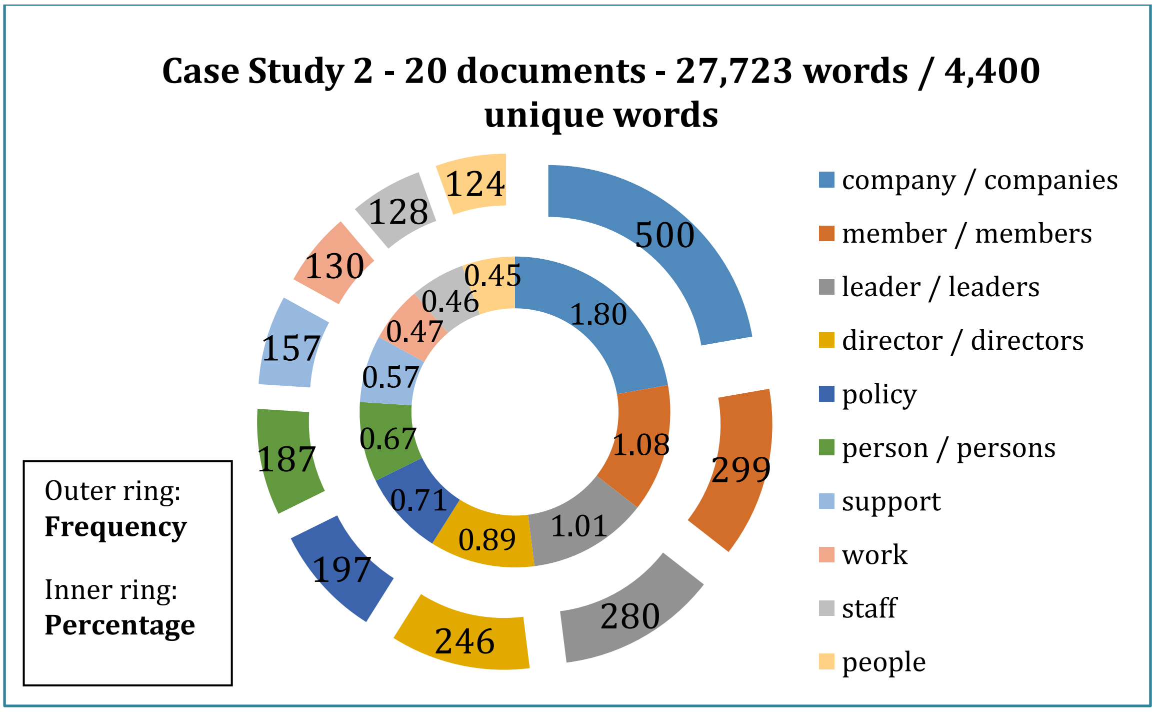


Figure A1.14.2 - Content analysis for case study 2

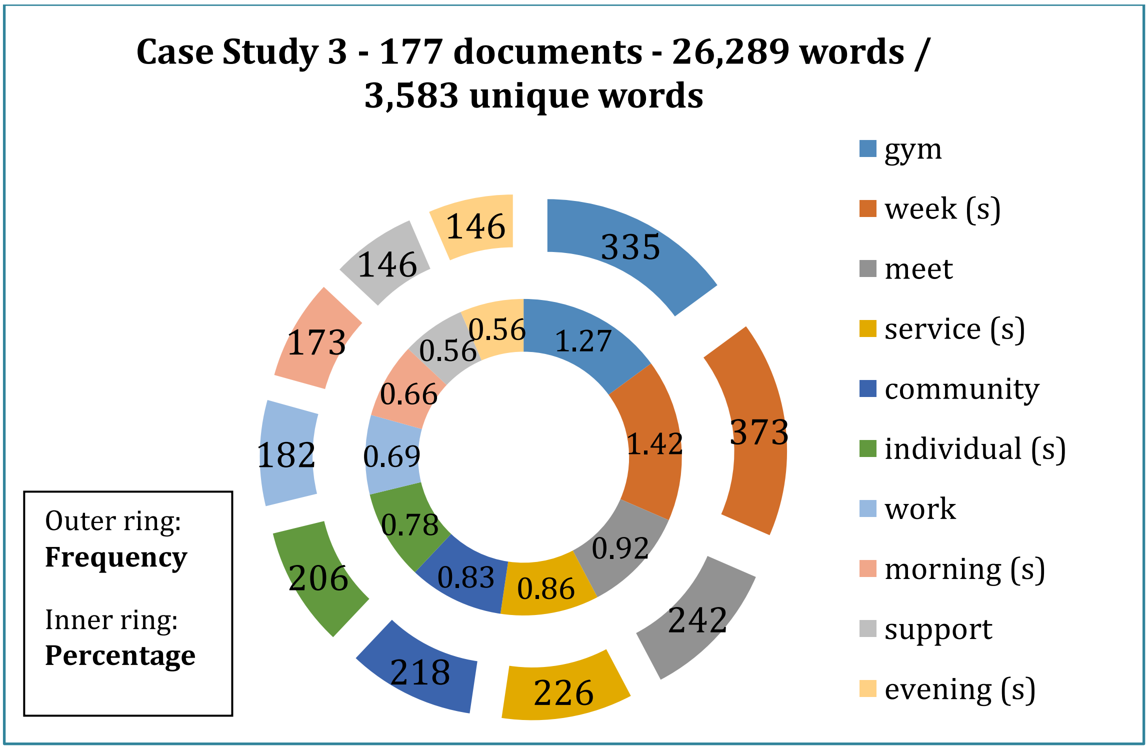


Figure A1.14.3 - Content analysis for case study 3

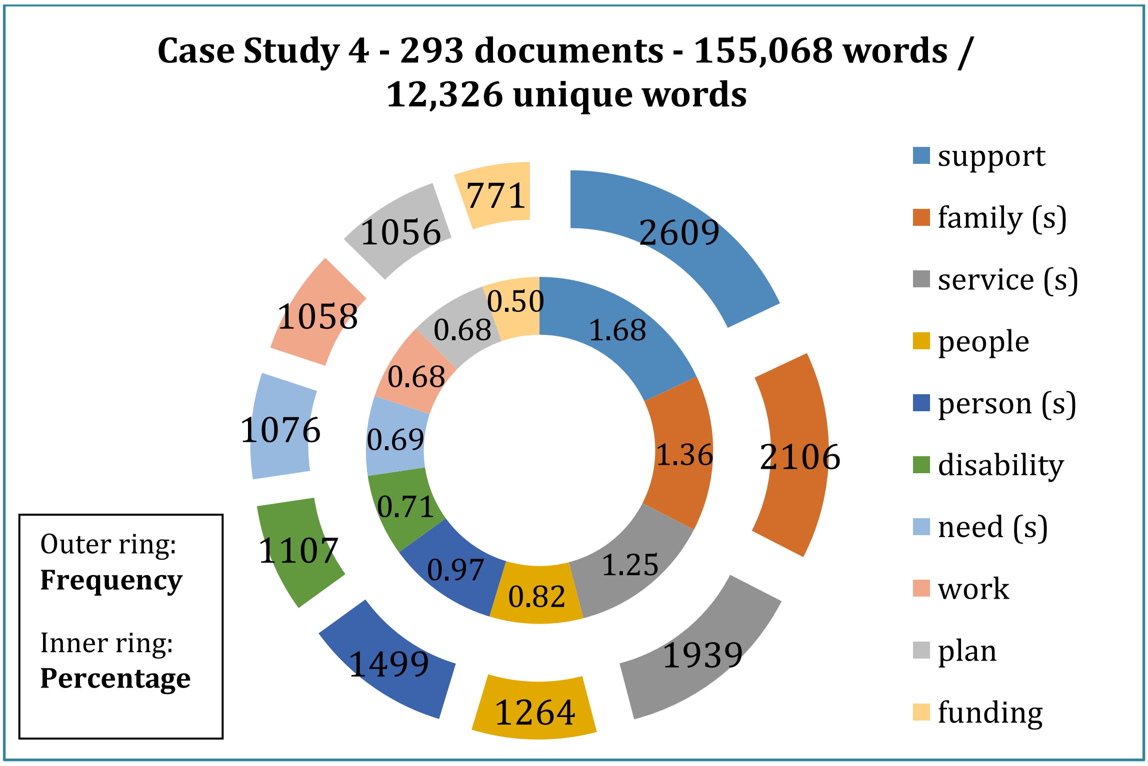


Figure A1.14.4 - Content analysis for case study 4

A1.15: COMPLETE LIST OF QUALITATIVE THEMES, SUBTHEMES AND LEVELS OF CODING

	MACRO	MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	
1	Stakeholders					0
2		Advocates				0
3			Perceived barriers			6
4			Natural Supports			146
5				Pet		5
6				GF / BF		3
7				Essential to process		31
8				Family		169
9					ADL	20
10					Trust the profs	6
11					Family fight TM	22
12					Fam. Reaction	50
13					Fam. Worries	41
14			Client treatment			0
15				Child		6
16				Enable-Disabling		47
17				Family home		7
18				Too close		6
19				Protective		32
20				Questioning choice		16
21		Paid support				45
22			CP-Broker attributes			9
23				Broker skills		17
24				SP_Broker Attributes		14
25			Broker rate			4
26			Staff duties			29
27				Fundraising		17
28				Research		19
29			Role. Broker			96
30				Encourage		30
31				Broker limitation		16
32			Use of PA/KeyWorker/Mentor			75
33				Key worker experience		4
34		PwD attributes				0
35			Self-image			62
36				Successful		7
37				Confident		12
38				Dependent		6
39				Activist		9
40				Care-giver		4
41				Adaptive		9
42				Skilled		13
43				Naming disability		16
44				Disablist		6
45				Apathetic		18
46				Lack confidence		18
47				Questioning diagnoses		3
48			Drop out			15
49			Defensive			8
50			C-Isolated			13
51			Client enthusiasm			9
52			Lean to group			24
53				Adversary behaviour		18
54			Anxious			34

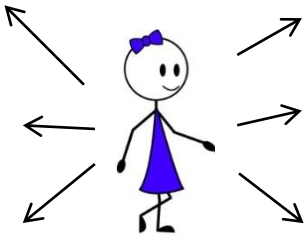
	MACRO	MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	
55				Wanting to please		2
56			Passion for			13
57			Leading the way			9
58			Not in service			6
59			St/AD-Acknow. limitation			31
60				Demotivated		4
61				Vulnerable group		4
62			St/Ad-acknow. strengths			18
63	Process					0
64		P - 3rd party input				20
65		P-Organic / Informal				23
66		P - Staff Recruit.				61
67			Advert			8
68			Innovative			14
69		Tool Developed				29
70		P - Admin				67
71		SP - Process Fears				20
72		P-Disengaged				33
73			Source of fund??			8
74			C/Ad-Uninformed			7
75			Told what to do			10
76		Monitoring				46
77		Client recruitment				49
78			SP - Eligibility crit.			43
79			Info. 4 clients			60
80				C- Became aware IF		16
81		Meeting broker				56
82			P - Get 2 know			36
83			P - ID needs/goals			100
84				Client activities		148
85					Hobby	44
86					Educ / Classes	76
87					Exercise / Gym / Sport	25
88					C: Work/Job	73
89				Needs led		44
90				P - ID&Org acts.		64
91		P - Exist. resources				27
92		P - Staff Handover				11
93		P - Time mngt				29
94		P - Lessons Learnd				64
95			Assistive item			26
96			Practical learning			26
97				Online resources		8
98			Fidelity/Integrity			3
99			Expectations mngt			27
100		P-Next steps				18
101			Uncertainty Future			26
102			Future planning			70
103			SP-Future Direction			31
104				SP- Hopes		7
105			SP-Sustainability			48
106			Impact - pilot end			20
107			Area 4 improvement			28

	MACRO	MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	
108				Inter-agency comm.		11
109				Training		41
110					Family Education	19
111					Comm. Education	7
112					SP - Educ. needs	13
113		Trial and Error				17
114		P - Money mngt				120
115			P - Money allocation			81
116			De-Bundle Money			26
117			Uncertain $ control			8
118			Petty cash			14
119	Outcomes					11
120		SP/AD: + outcome				83
121		Empower client				46
122			Given voice			9
123		Independence				63
124		Client + outcome				64
125			Indo. Skills Dev't			79
126			Health +			7
127			Sense of control			26
128			Social Support			48
129			Financial Support			8
130			Life Purpose			10
131			Indo. Travel			82
132				Holiday		11
133				Car/Dependent		17
134				Pedestrian training		3
135				Taxi		2
136				Drive		15
137				Bicycle/Scooter		7
138				Public Transport		37
139		New Opps				7
140			Unexpected activity			5
141			New experiences			27
142		ID challenges				102
143			Difficult ID acts			10
144			Practical			7
145			Deterrent			33
146			Client struggle			16
147			Need guidance			25
148		Client Adverse effect				36
149			Pulling away social			5
150		Ltd. comm engag't				9
151	System					0
152		Pre I.F.				0
153			Motivation I.F.			46
154				lifelong struggle		12
155		SP- + HSE Collab.				24
156			HSE driven			29
157			Governance			8
158		SP-Systemic issues				22
159			Slaves2system			22
160			Lack of trust			30
161			SP - Int. frustrations			8
162			System weakness			33
163		Support Model				3
164			Trad. model			120

	MACRO	MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	
165				Keep connection / security		13
166				SP-Demotivated		7
167				Institutionalised friendships		22
168				Group home		20
169				Aware TM unfit		48
170			Direct Payments			36
171			Brokerage			33
172				partnership		13
173			TM vs. I.F.			62
174		SP-Gov't agenda				13
175			SP - RAS system			19
176			Policy			23
177			VfM			46
178	Organisational					3
179		Following BP				11
180		Power abuse				15
181		Org. Challenges				66
182			Demand / Ltd resources			6
183			People Mngt			9
184		Org Process Fund				27
185		Org Structure				14
186		SP - Org Change				28
187		Recyc. old models				17
188		SP_ Org Success Story				21
189		Org resist I.F.				14
190			Org. fears			32
191			Org. disengagement			17
192			Org. Resistance			16
193		Org. Confusion				9
194			Mgt / Staff. uninformed			15
195	Community					0
196		Tailor exist. comm. resources				17
197		Community Spirit				21
198			Peer support			20
199		Comm. resources				43
200		Comm. engag't				76
201			Devlping friendships			10
202			CP-Sociable			26
				TOTAL CODED SECTIONS OF TEXT		**5540**

A1.16 – TRANSCRIPTION OF FLIPCHARTS FROM PARTICIPATORY WORKSHOP

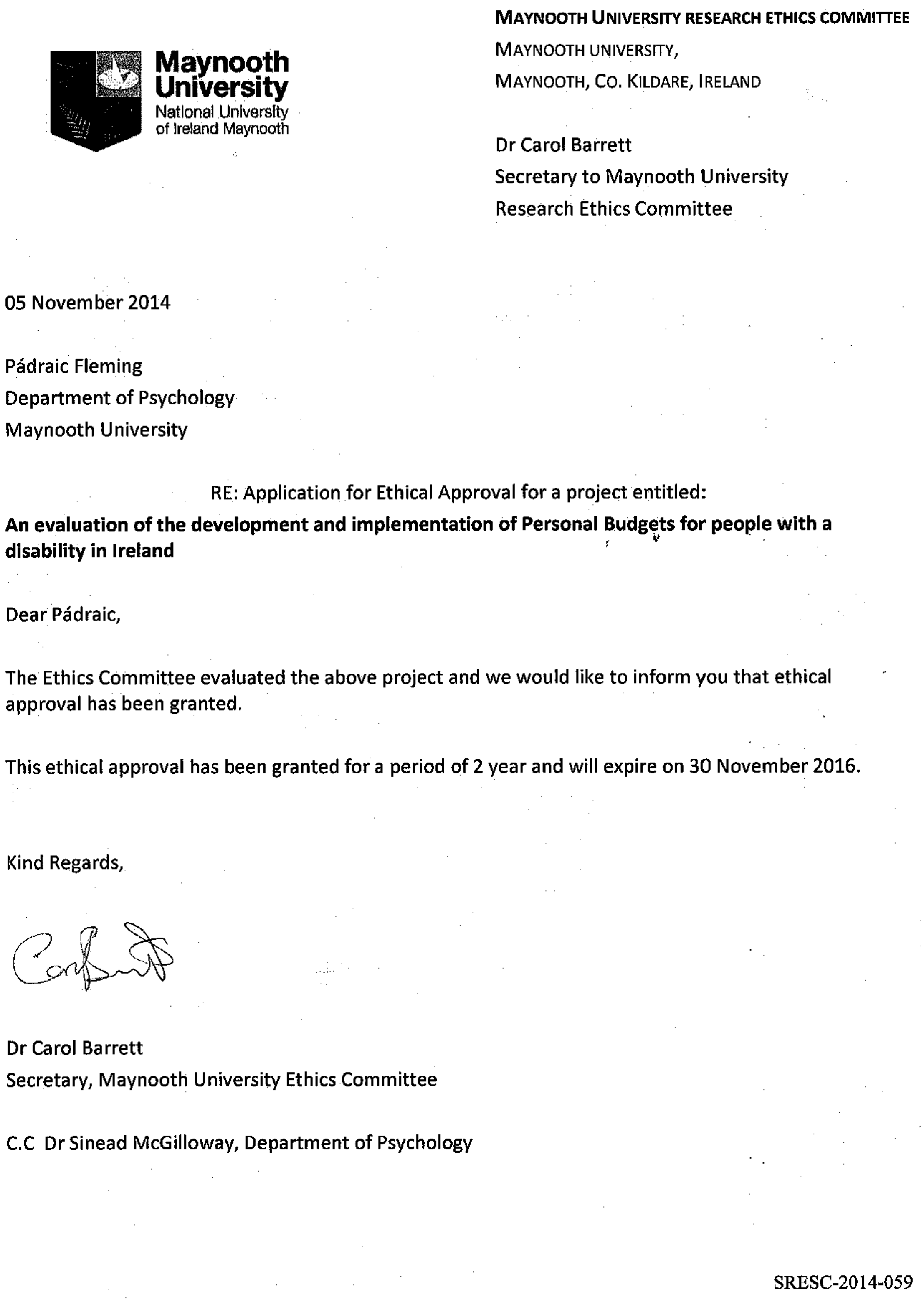
Questions	Group 1	Group 2	Group 3	Group 4
Given the importance of "natural supports", how can we ensure that supports will not have a disabling effect?	Do more things Try it! Learn Challenge yourself Introduce me Give me confidence I want my opinion heard Ask me, don't assume! Letting go Talk & plan – Decide pluses and minuses	Natural supports not disabling if… Parents reassured – risks managed - *taking it a step at a time - Acknowledging parents fears - Acknowledging persons needs/wishes Workplace co-workers: - Talk to management first - Explain to co-workers what persons abilities and challenges are - Same rights as other staff - Value someone for trying	Talk to other families already using service Regular feedback – Is the process working? Open minded and personal relationship P.A. <–> Person	Leader training – Advocacy training for themselves Giving guidance so they can direct themselves Circle of support – build a good network Right support to go in the right direction Family need support and training around empowering and supporting a person with a disability and understanding & achieving that balance Families need outside facilitator to keep an objective view
How can we collaborate together to strengthen the case for HSE systematically de-bundling money?	Working as a team Communicate with each other - Meetings like today	DSI/Inclusion Ireland projects: - Give families questions / context	4 HSE regions meet with the services here today (& Padraic) to synchronise services	More family meetings and presentations of what is available People with disabilities would

	- Social Media (Facebook page to post news, comments, give/get advice, share) Getting our success story out there Stories context = meaning	to put to politicians - Including parents of young children - All over the country e.g., reduction in day funding - Direct to senior HSE also Get Vol. bodies to support individualised funding Let people know where their money is Target politicians at election time! Use emails to politicians; meet them if possible	nationally Get the government to enact the policy that is supposedly in place! Get a social media (funding individuals) to get the message to Government, HSE etc.	be more involved in the presentation to HSE / politicising Awareness of different models of individualised budgets & how funding is used – managed by setting up their own company or the broker system Show proof of concept of what is happening Use main national lobbying organisations (Inclusions, National Federation, National platform)
How can we ensure that individuals remain the leading force, especially as numbers increase?	Communication Individual leads (Upward arrow) Natural supports + Circle stays focussed and action orientated Circle and natural supports grow more empowerment to the person Support worker also advocates (oncowages?)	Ensure there is enough support for person Good “discovery” process – ongoing Independent monitoring: Do you want to continue? Create a <u>culture</u> of listening to the person. <u>Person</u> at centre of circle of	Maintaining person-centeredness Create a circle of support plus communication with family and client very important Match the changing needs of clients interests with Pas	 Person at centre remains at centre of their own support plan - As the numbers increase to make sure that each individual is involved from the start

		support Is there a tool to evaluate the lived experience of the person Develop persons confidence and empower them.	Regular meetings with client (1:1 service agreement) Flexibility	Peer support Open to input from stakeholders Flexibility adapting to the changes experience by individuals Continuous reviews & evaluation of the plan led by individuals
Should we be pushing for Resource Allocation Systems as the mechanism for allocating money to individuals? If yes, how do we go about that? If no, what are the alternatives?	Quicker access to individualised funds Efficient, fair, consistent Uncomfortable process? See the person – not the score Where is person's voice?	Yes How to get it? - Get NDA report? - Look for HSE & Dept. position - Get national organisations to support introduction of RAS – DSI, Inclusion Ireland, NAS	Yes ↕ Pursue HSE Depending on needs of client No 1 person happy with the package of care (Pas)	Needs are holistic, cross departmental approach needed Supports should be provided by mainstream systems (housing) Evaluate health & wellbeing Wellbeing is individual to each person (emotional needs and independent living needs)
How do we ensure that all possible options / activities are made available to individuals, especially those who are unsure what they want to pursue?	Know the person first - Their interests - What they are into One size doesn't fit all Find out what might be of interest / exciting – Try it –	Sampling – trying things for short periods <u>Explore</u> what the person wants – tease it out e.g. what they really want from job (Gossip, news, contact	Open communication Between provider/client/family & circle of support Group effort to find out	Revisiting the discovery process regularly Actively engaging in listening Letting people really sample

	Try something else Practical? - Locality - Travel - Realistic The right people and introduction	with people) Tease out: the location, the people there, the skill… “Is that your final answer?” (TV) Revisit occasionally (not initially ready?) Shared learning from others	what’s on where Sampling / taster (new 2/3 classes) (Avoid porridge) Research / Plan in advance Link in via media with all resources: Email / FB	different things and engaging more in different activities
Are there any other important questions that we should seek to answer?	Come together – use technology FB / Blog – Someone needs to take the lead Advocate to the HSE – clear feedback – clear questions to ask politicians on the door, such as, why was the individual allocation cut from 14k to 10K? Why did nobody hear about this? Leader to connect organisations 3% of budgets to go to people who want individualised funding (Inclusion Ireland were talking about this in 2011) HSE – Not singing off the same hymn sheet Policy around for so long – no progress Law needs to change – no law stating PwD have entitlements: always stated “if resources are available” What do you do outside of the 9-5 service? How many people are receiving I.F. Minority of disability managers are progressive Build a profile – Tree – branching out to create a network Inclusion Ireland and Down Syndrome Ireland are two organisations which are supportive of I.F.			

A1.17 – LETTER OF APPROVAL FROM RESEARCH ETHICS COMMITTEE



Maynooth University
National University of Ireland Maynooth

MAYNOOTH UNIVERSITY RESEARCH ETHICS COMMITTEE
MAYNOOTH UNIVERSITY,
MAYNOOTH, CO. KILDARE, IRELAND

Dr Carol Barrett
Secretary to Maynooth University
Research Ethics Committee

05 November 2014

Pádraic Fleming
Department of Psychology
Maynooth University

RE: Application for Ethical Approval for a project entitled:

An evaluation of the development and implementation of Personal Budgets for people with a disability in Ireland

Dear Pádraic,

The Ethics Committee evaluated the above project and we would like to inform you that ethical approval has been granted.

This ethical approval has been granted for a period of 2 year and will expire on 30 November 2016.

Kind Regards,

Dr Carol Barrett
Secretary, Maynooth University Ethics Committee

C.C Dr Sinead McGilloway, Department of Psychology

SRESC-2014-059

A1.18 – SCRIPT FOR WORKSHOP

Welcome everyone and thank you for taking the time to come here today to hear the results of the research undertaken around personal budgets for people with a disability in Ireland. I would like to take this opportunity to explain what you should expect from today's workshop, and I will take a few minutes to answer any questions at the end, before commencing the first part of today's workshop.

First of all, I will present the findings from the recent research undertaken with service providers and service users participating in personal budgeting initiatives in Ireland. At the end of that presentation, I will take questions related to the presentation, or any thoughts or feedback which you might have.

It is important to note that we are audio recording today's session, so you should be aware that any feedback you provide will be recorded. After today's workshop, I will transcribe all the feedback received and this will be analysed as part of the broader research project that I am undertaking. You do not have to identify yourself when providing feedback, but you should also feel free to do so, since any identifiable information about yourself and any other person or service will be anonymised, meaning that names or other identifiable information will be changed, so that an individual cannot be identified. The anonymised feedback may be used as part of a published report, or presented with other findings at a conference.

The audio recordings will be stored securely on an encrypted laptop or in a locked cabinet in Maynooth University. Only the research team will have access to them and the recordings will be permanently deleted once they have been transcribed and anonymised. If you have identified yourself during the feedback and therefore possible to identify your feedback you can request that your feedback is removed up until the point where the feedback is analysed. After data is analysed it will no longer be possible to remove your feedback. My contact details are available in your information pack if you would like to withdraw your feedback. Please let me know at the end of the workshop or as soon as possible afterwards by email or phone call

When we have completed the questions and answers session after the presentation, we will move onto a group activity. We will randomly split you into small groups of five or six. Obviously personal assistants or other advocates should remain with your client. As a group you will be asked to discuss a specific topic and one person should provide feedback at the end. You will have a flipchart to help capture the group feedback. This feedback will then be opened up to the floor for discussion. The feedback will be recorded and flipcharts will be collected at the end.

Today's workshop is very informal and we are all aware that the discussions here today are sensitive and therefore should be treated confidentially. Other than anonymised research findings, the feedback should not and will not be publicly discussed, so please don't be afraid to contribute to the questions and answers sessions or to the group work. Equally however, if you do not want to participate, you can simply listen in. Ultimately, I can remove your contribution from the transcripts, as explained earlier, so feel free to engage with today's workshop, so that we can all benefit from the knowledge and experience in the room.

Are there any questions at this point?

APPENDIX 2 – SUPPORTING DOCUMENTATION FOR STUDY THREE

APPENDIX 2.1 - SEARCH STRINGS FOR VARIOUS ELECTRONIC DATABASES / SEARCH ENGINES

Database	EMBASE (13,216 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' OR **'self-determin*':ab,ti** AND [1985-2015]/py **AND [humans]/lim**
Database	PsychInfo (12,560 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-directed assessment" OR "self-directed care" OR "self-directed support" OR "support plan" OR "virtual budget" OR “disability living allowance” OR **"self-determin*"**) 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” **OR "self-determin*")**)
Database	ASSIA (8,622) – subject heading, title, abstract
Syntax	**(((SU.EXACT("Benefits" OR "Compensation" OR "Minimum Wage" OR "Pensions" OR "Restitution (Corrections)" OR "Salaries" OR "Wages") OR SU.EXACT("Costs" OR "Health Care Costs" OR "Housing Costs" OR "Rents") OR SU.EXACT("Capital") OR SU.EXACT("Foreign Investment" OR "Human Capital" OR "Investment") OR SU.EXACT("Fund Raising") OR SU.EXACT("Income" OR "Profits") OR SU.EXACT("Resource Allocation") OR SU.EXACT("Child Support" OR "Contributions (Donations)" OR "Financial Support" OR "Food Stamps" OR "Grants" OR "Subsidies") OR SU.EXACT("Money") OR SU.EXACT("Finance" OR "Public Finance")) AND (SU.EXACT("Blind" OR "Congenitally Handicapped" OR "Deaf" OR "Handicapped" OR "Mentally Retarded" OR "Physically Handicapped") OR SU.EXACT("Senility") OR SU.EXACT("Alzheimer's Disease") OR SU.EXACT("Community Mental Health" OR "Mental Health") OR SU.EXACT("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("Affective Illness" OR "Depression (Psychology)") OR SU.EXACT("Autism") OR SU.EXACT("Developmental Disabilities") OR SU.EXACT("Learning Disabilities") OR SU.EXACT("Disability Recipients"))) OR (ab(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 individual?ed fund OR individuali?ed**

	OR personali?ation OR personali?ed care 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 self-determin*) OR ti(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 individual?ed fund OR individuali?ed OR personali?ation OR personali?ed care 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 self-determin*))) AND pd(19850101-20161231)
Database	Medline First Search (8,800) – mesh heading, title, abstract
Syntax	yr: 1985-2016 and ((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: 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 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 ti: self-determin*)** 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* **OR ab: self-determin*))**
Database	SCOPUS (10,994) – title, abstract, keyword
Syntax	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 **(EXCLUDE(SUBJAREA,"ENGI") OR EXCLUDE(SUBJAREA,"COMP") OR EXCLUDE(SUBJAREA,"PHAR") OR EXCLUDE(SUBJAREA,"AGRI") OR EXCLUDE(SUBJAREA,"IMMU") OR EXCLUDE(SUBJAREA,"PHYS") OR EXCLUDE(SUBJAREA,"ENER") OR EXCLUDE(SUBJAREA,"DENT") OR EXCLUDE(SUBJAREA,"EART") OR EXCLUDE(SUBJAREA,"CENG") OR EXCLUDE(SUBJAREA,"VETE")) AND (**

	EXCLUDE(SUBJAREA,"BIOC") OR EXCLUDE(SUBJAREA,"CHEM")) AND (EXCLUDE(PUBYEAR,1984) OR EXCLUDE(PUBYEAR,1983) OR EXCLUDE(PUBYEAR,1982) OR EXCLUDE(PUBYEAR,1981) OR EXCLUDE(PUBYEAR,1980) OR EXCLUDE(PUBYEAR,1979) OR EXCLUDE(PUBYEAR,1978) OR EXCLUDE(PUBYEAR,1977)) AND (EXCLUDE(PUBYEAR,1976) OR EXCLUDE(PUBYEAR,1975) OR EXCLUDE(PUBYEAR,1974) OR EXCLUDE(PUBYEAR,1973) OR EXCLUDE(PUBYEAR,1972) OR EXCLUDE(PUBYEAR,1971) OR EXCLUDE(PUBYEAR,1970) OR EXCLUDE(PUBYEAR,1969)) AND (EXCLUDE(PUBYEAR,1968) OR EXCLUDE(PUBYEAR,1967) OR EXCLUDE(PUBYEAR,1966) OR EXCLUDE(PUBYEAR,1965) OR EXCLUDE(PUBYEAR,1964) OR EXCLUDE(PUBYEAR,1963) OR EXCLUDE(PUBYEAR,1962) OR EXCLUDE(PUBYEAR,1958) OR EXCLUDE(PUBYEAR,1957) OR EXCLUDE(PUBYEAR,1956) OR EXCLUDE(PUBYEAR,1955) OR EXCLUDE(PUBYEAR,1954) OR EXCLUDE(PUBYEAR,1953) OR EXCLUDE(PUBYEAR,1952) OR EXCLUDE(PUBYEAR,1951) OR EXCLUDE(PUBYEAR,1950) OR EXCLUDE(PUBYEAR,1949) OR EXCLUDE(PUBYEAR,1947) OR EXCLUDE(PUBYEAR,1946) OR EXCLUDE(PUBYEAR,1943) OR EXCLUDE(PUBYEAR,1942) OR EXCLUDE(PUBYEAR,1941) OR EXCLUDE(PUBYEAR,1940) OR EXCLUDE(PUBYEAR,1939) OR EXCLUDE(PUBYEAR,1938) OR EXCLUDE(PUBYEAR,1934) OR EXCLUDE(PUBYEAR,1933) OR EXCLUDE(PUBYEAR,1932) OR EXCLUDE(PUBYEAR,1926) OR EXCLUDE(PUBYEAR,1925) OR EXCLUDE(PUBYEAR,1924) OR EXCLUDE(PUBYEAR,1923) OR EXCLUDE(PUBYEAR,1922) OR EXCLUDE(PUBYEAR,1915) OR EXCLUDE(PUBYEAR,1914) OR EXCLUDE(PUBYEAR,1912) OR EXCLUDE(PUBYEAR,1909) OR EXCLUDE(PUBYEAR,1906))
Database	Sociological Abstracts (9,839) -subject heading, title, abstract
Syntax	**(((SU.EXACT("Benefits" OR "Compensation" OR "Minimum Wage" OR "Pensions" OR "Restitution (Corrections)" OR "Salaries" OR "Wages") OR SU.EXACT("Costs" OR "Health Care Costs" OR "Housing Costs" OR "Rents") OR SU.EXACT("Capital") OR SU.EXACT("Foreign Investment" OR "Human Capital" OR "Investment") OR SU.EXACT("Fund Raising") OR SU.EXACT("Income" OR "Profits") OR SU.EXACT("Resource Allocation") OR SU.EXACT("Child Support" OR "Contributions (Donations)" OR "Financial Support" OR "Food Stamps" OR "Grants" OR "Subsidies") OR SU.EXACT("Money") OR SU.EXACT("Finance" OR "Public Finance")) AND (SU.EXACT("Blind" OR "Congenitally Handicapped" OR "Deaf" OR "Handicapped" OR "Mentally Retarded" OR "Physically Handicapped") OR SU.EXACT("Senility") OR SU.EXACT("Alzheimer's Disease") OR SU.EXACT("Community Mental Health" OR "Mental Health") OR SU.EXACT("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("Affective Illness" OR "Depression (Psychology)") OR SU.EXACT("Autism") OR SU.EXACT("Developmental Disabilities") OR SU.EXACT("Learning Disabilities") OR SU.EXACT("Disability Recipients"))) OR (ab(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 individual?ed fund OR individuali?ed OR personali?ation OR personali?ed care 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 self-determin*) OR ti(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 individual?ed fund OR individuali?ed OR personali?ation OR personali?ed care 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 self-determin*))) AND pd(19850101-20161231)
Database	Worldwide Political Science Abstracts (6,450) – subject headings, title, abstract
Syntax	**(((SU.EXACT("Benefits" OR "Compensation" OR "Minimum Wage" OR "Pensions" OR "Restitution (Corrections)" OR "Salaries" OR "Wages") OR SU.EXACT("Costs" OR "Health Care Costs" OR "Housing Costs" OR "Rents") OR SU.EXACT("Capital") OR SU.EXACT("Foreign Investment" OR "Human Capital" OR "Investment") OR SU.EXACT("Fund Raising") OR SU.EXACT("Income" OR "Profits") OR SU.EXACT("Resource Allocation") OR SU.EXACT("Child Support" OR "Contributions (Donations)" OR "Financial Support" OR "Food Stamps" OR "Grants" OR "Subsidies") OR SU.EXACT("Money") OR SU.EXACT("Finance" OR "Public Finance")) AND (SU.EXACT("Blind" OR "Congenitally Handicapped" OR "Deaf" OR "Handicapped" OR "Mentally Retarded" OR "Physically Handicapped") OR SU.EXACT("Senility") OR SU.EXACT("Alzheimer's Disease") OR SU.EXACT("Community Mental Health" OR "Mental Health") OR SU.EXACT("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("Affective Illness" OR "Depression (Psychology)") OR SU.EXACT("Autism") OR SU.EXACT("Developmental Disabilities") OR SU.EXACT("Learning Disabilities") OR SU.EXACT("Disability Recipients"))) OR (ab(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 individual?ed fund OR individuali?ed OR personali?ation OR personali?ed care 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 self-determin*) OR ti(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 individual?ed fund OR individuali?ed OR personali?ation OR personali?ed care 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 self-determin*))) AND pd(19850101-20161231)
Database	CINAHL (12,903) – 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 "self-determin*"**))) 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*" **OR "self-determin*"**)))

Database	EconLit with Full text (2,111) - 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 (AB (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 "self-determin*"))**) 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*" **OR "self-determin*"))**)
Search Engine	Google Scholar – 5,960 (of which 432 imported into Endnote)
Syntax	disability disabled mental disorder budget fund cash allocation personalized
Database	OpenGrey.eu – 412 (of which 6 were imported into Endnote)
Syntax	Personal Budget – 0/17 Individualised funding – 0/17 Individualized funding – 0/1 individual budget – 0/74 cash and counselling - 0 “consumer directed care” – 0 "direct-payment" OR “direct payment” 1/6 (2 others not available by link or through google) "personal health budget" – 0 individualized AND disability – 0/2 individualized AND disorder – 0/1 individualized AND mental – 0/2 individualized AND dementia – 0/2 individualised AND disability – 0/5 individualised AND disorder – 0/6 individualised AND mental – 0/4 individualised AND dementia – 0/3 personalised AND disability – 0/4 personalised AND disorder – 0/7

	“Person centred” - 0/71 Broker 0/87 Money AND disability 1/2 Money AND disorder 0/1 Money AND mental 0/9 Money AND dementia 0/2 Cash for care - 4/19 Personalisation AND disability – 0/4 AND disorder – 0/1 AND mental - 0/1 AND dementia – 0/1 personalised care AND disability – 0/2 personalised care AND disorder / mental / dementia – 0/1 person centered – 0/13 "self-directed" AND DDMD – 0/5	personalised AND mental – 0/8 personalised AND dementia – 0 personalized AND disability – 0 personalized AND disorder – 0/1 personalized AND mental – 0/1 personalized AND dementia – 0/1 budget AND disability – 0 budget AND mental – 0/1 budget AND disorder – 0/1 budget AND dementia – 0 "support plan" - 0/7 Self-determined – 0/22
Database	GreyLit – 873 (of which 31 were imported in Endnote)	
Syntax	Handicap – 0/2 Retard – 0/7 Blind – 0/14 Deaf – 0/3 Impairment – 0/35 Autism – 0/9 Autistic – 0/3 Personalisation – 0 / 6 Personalization AND disability – 4 / 265 "personalised care" – 0 / 1 "personalized care" – 2 / 27 "self-directed" – 0/3 broker – 0/5 Cash for care - 2/16 Pooled budget 0/3 self-directed support – 0 indicative allocation – 0/5 recovery budget – 0/18 disability living allowance – 0/1 virtual budget – 0/1 notional budget – 0 individualized funding AND disability – 1/33 individualized funding AND disorder - 0/8 individualized funding AND mental – 0/8 individualized funding AND dementia – 0 cash for care – 0/16	Personal budget AND disability – 1/14 Personal budget AND mental – 0/3 Personal budget AND disorder – 0/1 Personal budget AND dementia – 0/0 individual budget AND disability – 0 individual budget AND mental – 0 individual budget AND disorder – 0 individual budget AND dementia – 0 budget AND disability – 0/39 budget AND mental – 0/20 budget AND disorder – 0/15 budget AND dementia - 0 "cash and counselling" – 4/10 “consumer directed care” – 10/38 "direct-payment" OR “direct payment” – 3/22 "personal health budget" – 0/45 support plan AND disability – 1/31 support plan AND disorder – 0/23 support plan AND mental – 0/23 support plan AND dementia – 0/3 “Self determination” - 0/11 resource allocation system – 0/22 Direct payment 0/22 (many repeated) individual service fund AND disability - 2/23 individual service fund AND disorder - 0/4 individual service fund AND mental - 0/4 individual service fund AND dementia – 0 managed budget AND disability - 0/5 managed budget AND disorder – 0 managed budget AND mental – 1/6 managed budget AND dementia – 0

Database	Proquest dissertation and Thesis – 7,975	
Syntax	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*) OR 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*)	
Database	VHL Regional Portal - Latin America database - 549 (of which 1 was imported into Endnote) http://search.bvsalud.org/portal/ (Excluded Medline from search results – All other databses searched)	
Syntax	**Individualized funding – 0/4** **Direct Payment – 0/21** **Cash for care – 0/6** **Cash and counseling – 0/0** **Personal budget – 0/71** **consumer directed care – 0/3** **person centred – 0/21** **money AND disability – 0/5** **Money AND mental 1/82** **Money AND dementia 0/6** **disability AND payment 0/8** **mental AND payment 0/19** **dementia AND payment -0/1** **personalised care – 0/25**	**"self-directed" – 0/65** **broker – 0/13** **Pooled budget 0/0** **indicative allocation – 0/0** **recovery budget – 0/7** **disability living allowance – 0/0** **virtual budget – 0/6** **notional budget – 0/0** **personalisation – 0/6** **Self-determined – 0/58** **Support plan AND disability – 0/6** **Support plan AND mental – 0/104** **Support plan AND dementia – 0/12**
Database	**NORART - (Norwegian and Nordic index to periodical articles)** **601 (zero imported into Endnote)**	
Syntax	**Disability – 0/126** **Dementia - 0/51**	**Mental – 0/424**
Database	**Australian Policy Online – 985 (of which 16 were imported into Endnote)**	
Syntax	**Searched “Individualised funding” – 6/21** **Direct Payment – 2/125** **Cash for care – 0/36** **Cash and counselling – 0/3** **Personal budget – 1/110** **consumer directed care – 0/54** **money AND disability – 0/47** **Money AND mental 0/33** **disability AND payment 0/78** **personalised care – 1/13** **"self-directed" – 2/32** **broker – 0/55**	**Pooled budget 0/11** **indicative allocation – 0/49** **recovery budget – 0/20** **disability living allowance – 3/38** **virtual budget – 0/20** **notional budget – 0/16** **personalisation – 0/60 (Some already captured)** **Self-determined – 0/73 (some already captured)** **Support plan – 1/91 (many already captured)**

Search engine	Google – 1,000 (of which 25 were added to Endnote)	
	Google will be searched to identify any relevant conference proceedings in addition to relevant NGOs that may have relevant research unpublished elsewhere. The following terms will be searched: disability disabled mental disorder budget fund cash allocation personalized individualised 200 results were searched, since the latter 100 did not produce any relevant results. 21 relevant results were added to Endnote. The following specific searches were then conducted searching the first 100 results for each: **Direct payment disability mental dementia** – 3 (many information leaflets etc but not research, however publications were checked for many organisations) **Personal budget disability mental dementia** – 0 (Most already reviewed in previous searches) **Individualised funding disability mental dementia** – 1 (Most already reviewed in previous searches) **Cash for care disability mental dementia** – 0 (Results were more about paying carers) **Cash and counselling disability mental dementia** – 1 **Consumer directed care disability mental dementia** – 2 **Brokerage disability mental dementia** – 0 **Individual service fund disability mental dementia** – 0	
Post screen	103 additional titles included in full-text screen	
	Forward citation searching (40) and hand-searching based on conference papers and other sources that guided the search (63)	
Key Journals	Seven journals were searched using key terms at the end of the screening process (February 2017) - 259 (of which 2 additional titles were screened)	
Syntax	Cash and counseling - 2/5 Cash for care – 0/5 Personal Budget – 0/36 Individual Budget – 0/22 Indicative allocation – 0/8 Notional budget – 0/8 Pooled budget – 0/8 Recovery budget - 0/6 Virtual budget – 1/2	Personal Health Budget – 0/16 Direct-Payment OR direct payment – 0/73 Individual service fund – 0/0 micro board OR microboard OR micro-board – 0/10 Disability living allowance – 0/8 Supplemental Security Income – 1/1 individualised fund OR individualized fund - 0/22 consumer-directed care OR consumer directed care – 0/32

APPENDIX 2.2 - PAPER OUTLINING RESULTS REFINEMENT PROCESS

IDENTIFYING AND TACKLING CHALLENGES IN UNDERTAKING MIXED-METHODS SYSTEMATIC REVIEWS: AN EXEMPLAR FROM THE FIELD OF DISABILITY

Padraic Fleming, Sinead McGilloway

Introduction

There are many well documented challenges in undertaking robust systematic reviews (Francis, Baker, & Soares, 2012; Mahood, Eerd, & Irvin, 2014; Runnels, Tudiver, Doull, & Boscoe, 2014) and not least the fact that researchers strive to answer often narrow questions by locating / identifying studies that use precise tools and rigorous methods to measure effect. This is to be expected and endorsed in terms of improving the quality and robustness of such reviews. However, this approach can often lead to 'empty reviews', with relatively few studies that meet the very stringent inclusion/eligibility criteria and/or specific search strategy terms; arguably, these may be considered to be of only questionable utility for service providers and policy makers. Very often, the recommendations from an 'empty review', is the call for more, and improved research. Such conclusions have drawn criticism, and lead commentators to question the value of systematic reviews (Lang, Edwards, & Fleiszer, 2007). These kinds of challenges may be exacerbated when conducting reviews that involve the use of mixed methods and which require a deeper understanding, perhaps, of contextual factors. For example, the importance of context was a recurring theme at the recent 'What Works Global Summit 2016', held in London last November. In terms of context, for example, the 'Contextualized Health Research Synthesis Program' (CHRSP), in Canada, argue that the key question to ask when providing evidence-based support for decision makers, policy makers and clinicians is not 'What works?' but 'What will work here? (WWGS, 2016, p. 47).

The current short article arose from an oral presentation at the 'What Works' conference which was very well received (in line with the emerging conference theme) and which, as a result, it was felt should be shared with a larger audience. The principal aim of the ongoing review that provided the context for this presentation and the current paper, is to determine whether or not individualised funding is an effective mechanism for improving the health and social care outcomes of people with a disability. A second aim is to critically appraise and synthesise the qualitative evidence relating to stakeholder perspectives and experiences of individualised funding with a particular focus on the stage of 'initial implementation' (Fleming et al., 2016).

The specific objective of this current paper is to suggest and highlight strategies for dealing with challenges associated with: (1) addressing a broad research question; (2) using both quantitative and qualitative methods to measure effect; and (3) the need to highlight the importance of context during the implementation of a complex intervention with internationally diverse terminology and a broad range of outcomes. We outline how we addressed these challenges when undertaking a mixed methods systematic review - in the field of disability - which generated initial search results totalling an unmanageable number of 105,329 potentially relevant references/studies.

Background

Individualised funding is an umbrella term that encapsulates a growing range of descriptors for a mechanism of allocating disability-sector state funds directly towards the individual with a disabling impairment or their support network. Designating the funds in such a manner aims to place the individual at the centre of the decision making process in order to provide a self-determined life, whereby making day-to-day decisions about personal, health and social care needs empowers the individual to choose what supports they require, how this support is provided, when and by whom (Carr, 2010; Jon Glasby & Littlechild, 2009; United Nations, 2006). This is a paradigm shift away from the traditional agency-directed, group-based provision of services. It is not new however, with (cumulatively) decades of experience in the US, Canada, the UK, Australia and the Netherlands. The emerging language used to describe this new funding model has varied widely including: 'Cash and Counseling' in the US; 'Self-managed Care' in Canada; 'Direct Payments' in the UK; 'Self-Directed Funding' in Australia; and 'Person-centered Budget' in the Netherlands, to name but a few (Fleming, 2016b). This variation in terminology relates to the broader health and social care systems that are in place. The interventions have evolved in these country-specific contexts in different ways but ultimately all strive for personalised services resulting in improved outcomes while using existing state funds.

International policy has been promoting independent, self-directed supports for people with a disability for several decades. On foot of the first independent living movements in the US and Canada during the late 1960s / early 1970s, the UK reached a critical legislative milestone during the 1990s when the National Health Service and Community Care Act was established, emphasising the importance of people with a disability living in their own homes. This was closely followed by the Direct Payments Act 1996, which saw UK national implementation of Direct Payments commence in 1997. The 'United Nations Convention on the Right of Persons with Disabilities' (UNCRPD) subsequently endorsed individualised funding as one way to achieve self-determination (United Nations, 2006), leading to smaller countries, such as Ireland, to adapt international best practice within its national policy (Department of Health, 2012; Inclusion Ireland, 2016).

Method

The search strategy for the review was purposely broad, in order to identify all relevant quantitative and qualitative studies. Thus, it focused on: 1) the population of interest, itself expansive, including adults (18 and over) with any form of disability, mental health issue or dementia; and 2) the intervention which endeavoured to capture any financial intervention using state funds. Study design, comparator groups or outcomes of interest were not included at search stage. A wide range of academic databases (including general, psychological, medical, social, economic, business and policy), regional specific databases, sources of grey literature and search engines were employed. . Where thesauri existed, relevant subject terms were exploded in order to capture all narrower terms. Known terms, identified in existing literature were also included in the search strings. Further detail of the search strategy is available in the protocol (Fleming, Furlong, et al., 2016).

Results

This broad search strategy resulted in 105,329 references, 90% of which (95,245) were automatically imported into Endnote. The remaining 10% (9,562) were screened at search stage since automatic import into Endnote was not possible or would have required reference import on an individual basis, which was not feasible. The latter approach was only required for sources of grey literature, such as 'Australia Policy Online' (a grey literature database), where 985 titles were screened online, after the search was conducted, but only 16 were imported in Endnote (top right quadrant of Figure A2.2.1). In total, 522 grey literature references were manually imported into Endnote, giving a total of 95,767 references, which were saved in a 'master file'. Of these references, 13,493 duplicates were removed from a 'working file'. Only 9,265 were automatically found by Endnote when matching titles against the standard 'author, year and title'. This was due to discrepancies in author name or order, in year or slight variations in title. After adjusting the criteria for matching 'title only' or 'author only', a further 4,228 duplicates were identified. The latter was only reached after manual verification that the titles found were in fact duplicates and not, for example, separate publications from same study. In this way, a total of 13,493 duplicates were successfully identified and removed, leaving a total of 82,274 potentially eligible studies for the next 'refinement' stage described below.

[INSERT FIGURE A2.2.1 HERE]

There were limited resources for conducting the systematic review in terms of budget and manpower (as is often the case). Consequently, practicalities dictated the need for a new systematic approach to further reduce the remaining 82,274 titles before double screening of titles and abstracts could commence. This new approach was a departure from the published protocol (Fleming, Furlong, et al., 2016), but provided a robust, transparent and replicable process. This refinement strategy consisted of the three following steps:

1. Text mining

This involved scanning the titles, as displayed in Endnote, to identify irrelevant terms such as 'embryo, stem cell or biobank'. Using Endnote's search function, these terms were used to locate titles which included these irrelevant terms. Results were manually scanned to see if there were in fact potentially relevant studies included. If not, all search results were copied to a new Endnote file (named 'irrelevant titles') and removed from the 'working file'. This process was repeated across several hundred terms. All terms identified in the titles and variations or related terms were recorded including the number of titles removed based on each set of terms (Appendix 2.2.1).

2. Failsafe check

In order to check if any potentially relevant titles had inadvertently been removed, the 'irrelevant titles' endnote file was used to conduct a failsafe check. This involved searching the titles and abstracts for any of the 'known terms'. This amounted to 149 titles being returned to the working file. In addition, as new terms emerged during the review, the 'irrelevant titles' file was searched for these new terms, although no further titles were located based on these searches. After steps one and two had been completed, almost two-thirds of the titles (64%, 52,770) had been successfully removed, taking approximately one month's work (March 2016).

3. Manual title screen

A manual title screen was then carried out in line with our protocol. This involved reading each title to identify clearly irrelevant studies. Despite the previous two steps in the refinement process, many irrelevant studies remained. For example, there were many studies discussing the stock market and in particular brokers within the stock market. However, brokers and brokerage is a commonly used term within the individualised funding literature and therefore any such terms could not be automatically removed. Any ambiguous titles were not removed, since there were no grounds for doing so. In total, a further 22,346 titles, or 27% of the total titles were removed. Once again, step two was repeated as a failsafe check. Figure A2.2.2 below demonstrates the percentage of titles removed per database. Unsurprisingly 'Business Source Complete' and 'EconLit' saw almost all titles removed (99.2% and 97.6% respectively). Applied Social Science Indexes and Abstracts (ASSIA), on the other hand, had the least removed, although 49.7% were still deemed irrelevant. Step three took another month to complete (April 2016).

[Insert Figure A2.2.2 here]

Following the search refinement process, the double screening of titles and abstracts commenced with a much more manageable 7,158 references (Figure A2.2.1), or 8.7% of the original number. This process took approximately five months with one full time screener and two part-time (second) screeners (May – September 2016). A total of 6,934 titles were removed during this process with an overall inter-rater reliability score of 0.6, which reflects 'good agreement' (Higgins & Green, 2011). The inter-rater reliability moved from 'fair agreement' (0.4 – 0.59) in earlier batches of reviewed references to an 'excellent agreement' score of 0.8 on batches of references reviewed towards the end of the process. This was due to the complexity and variation within the interventions in question, and the need for ongoing clarification, discussion and refinement of the screening process. During the title/abstract screening process, 134 articles, 19 books and several conference proceedings were identified, which did not meet the eligibility criteria, but which may have contained additional relevant references. These documents were used to conduct 'forward citation chasing', during the hand-searching process, which led to almost 3,700 titles scanned and an additional 104 references added to the full-text eligibility screen. These additional texts were generally grey literature consisting of organisational and governmental reports which would not be contained within the academic databases searched and often did not contain keywords that would have made them clearly identifiable in the grey literature search. The final number of titles included in the full text review was 328.

Discussion and conclusion

There is much work being undertaken to enhance aspects of the systematic review process, with such papers and guidance featured in the Campbell Collaboration Methods Group, for example. However, while innovative methods continue to emerge, researchers are hesitant to negate the proven and often extensive methods undertaken in traditional reviews. Indeed for the current review, one of the two (anonymous) information retrieval specialists who reviewed the protocol, recommended the inclusion of additional databases such as Business Source Complete and EconLit. However, as shown earlier, these databases were totally unsuitable for this particular review. In fact, no references retrieved from these two databases were included in the 286 articles selected for full text eligibility screen. This is useful information because it strongly suggests that these databases should be excluded when updating the review, thereby immediately reducing the number of titles by 3,886 (4%). While this process can only be conducted post hoc, the above example strengthens the argument to present summary tables based on the relevance of databases searched. While only possible post-hoc, presenting statistics on the appropriateness of databases utilised strengthens the argument made by Alison Bethel, data retrieval specialist from University of Exeter Medical School, to generate and report a summary table for systematic review searches. Such summaries show: 1) the databases from which the included references are drawn 2) the databases from which unique references versus duplicates were identified; and 3) those databases which were searched and which contained a relevant reference that was not detected in the search strategy adopted (Bethel, 2016). Furthermore presenting such summary information provides useful information for future search strategy development and filter design by highlighting the unsuitability of some databases in certain subject areas.

The search refinement strategy presented in this paper offers a systematic, robust, transparent, cost and time efficient method of reducing a large number of search results to a more manageable number. As this review demonstrates, it is sometimes necessary to have a very broad and inclusive search strategy but this can lead to inordinately large and cumbersome files when using the traditional, reliable and validated method of systematic review searching. Indeed there are other methods of searching which may also offer a useful alternative, such as the 'Pearl Harvesting Search Strategy' (Keenan, Connolly, & Stevenson, 2016). Similar to 'cluster searching', this method is particularly useful for reviews of complex interventions that rely on an understanding of context (Booth et al., 2013). Whilst these kinds of search strategies may be more time-efficient, they require a finite list of terms and in the case of our review, this was not deemed feasible in view of the still evolving terminology around individualised funding initiatives within the disability sector.

Further research is recommended to test the sensitivity and specificity of alternative search and/or refinement methods when compared with those that are currently used in practice. The final review report is due to be published in the Campbell Library in 2018.

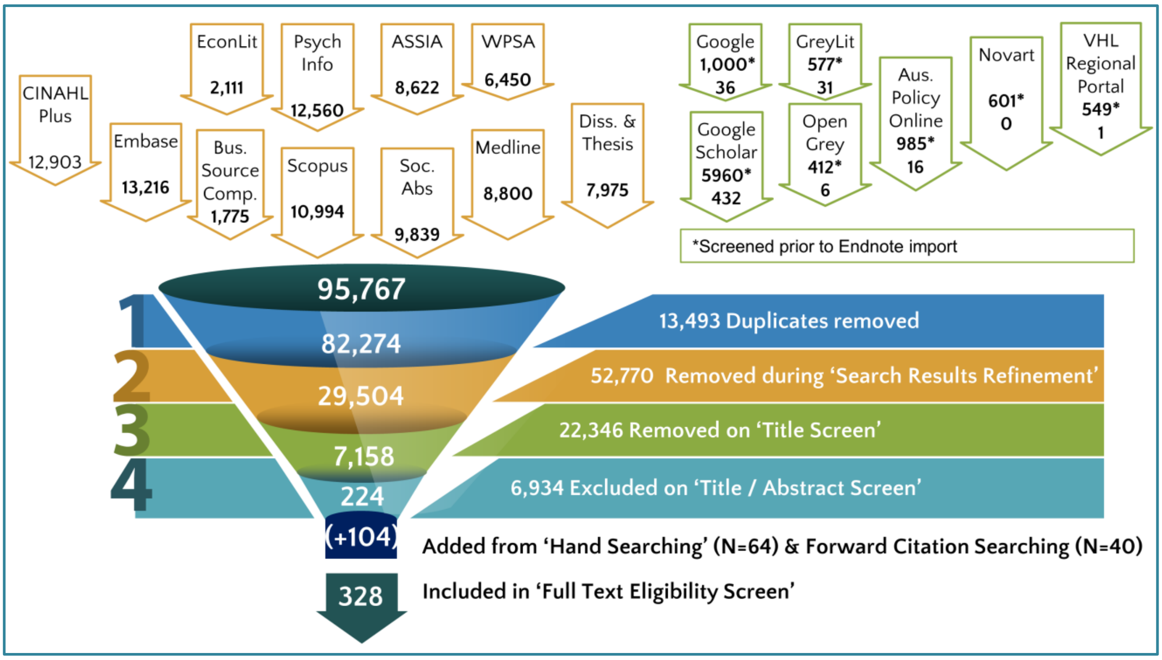


Figure A2.2.1 – Search results refinement process

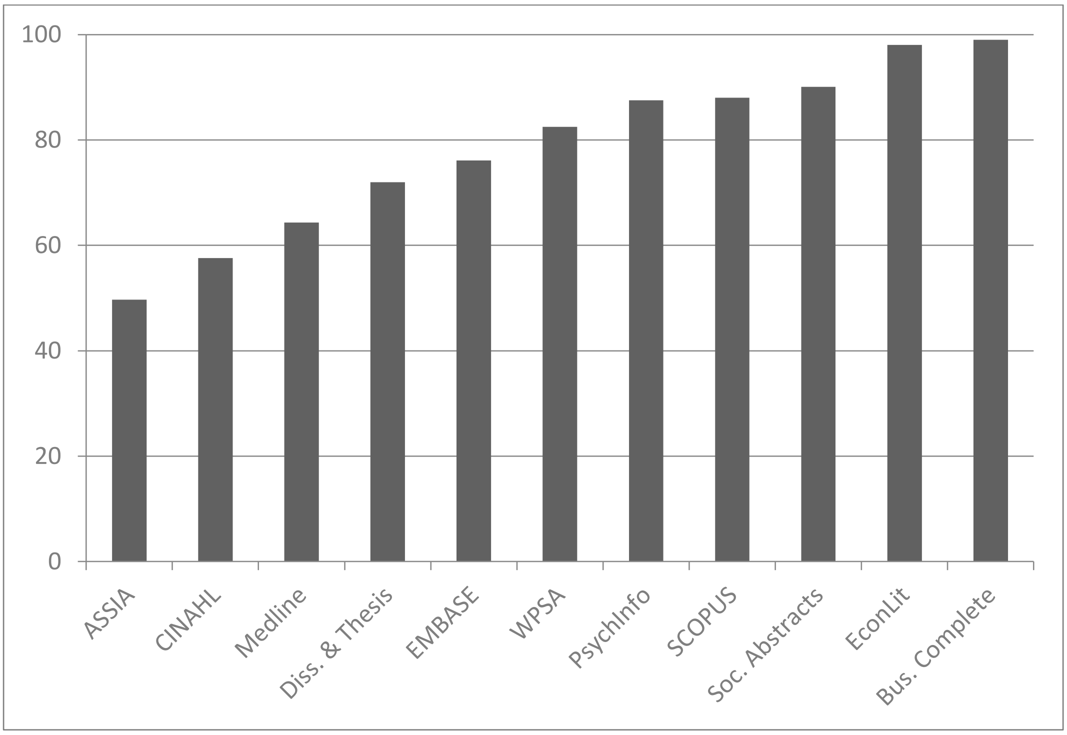


Figure A2.2.2 – Percentage of titles removed by type of database during step three of the refinement process

Appendix 2.2.1

Selection of illustrative terms used for text minding	Number removed
addict OR nicotine OR substance	258
back pain OR yoga	195
computer AND technology	558
divorce OR marriage	168
environmental OR climate change OR climate OR weather OR hurricane	439
food OR nutrient OR nutrit OR farm OR agricultur OR ranch	475
genetic	341
HIV	1087
industr	247
lifestyle OR migration OR migrant OR oversea OR disaspora	342
military OR veteran	338
oxygen OR oxide OR water OR gas OR carbon OR pollut OR tropical OR irrigat OR sanitat	198
prison OR inmate OR incarner OR offender OR juvenile	248
school OR kinder OR montessori OR arithmetic OR elementary	1247
toxic OR chemical OR placebo OR polar	283
verbal OR blog OR social media OR online OR game	213

APPENDIX 2.3 - QUALITATIVE STUDY CHARACTERISTICS

The references pertaining to the 69 studies, with eligible qualitative data, included in the systematic review are listed within this Appendix (including linked titles). The table below demonstrates the study characteristics for the first and last study included in the review, however the complete table will be provided as an online supplement for the Campbell Collaboration publication.

First Author (year) (linked)	**Pub Status (linked)**	**Program Name**	**Intervention Description**	**Country (Language)**	**Design**	**N**	**Type of disability**	**Sample Characteristics**	**Funding Source**	**Type of data presented**
Oliver (1992)	NP Not Linked	Personal Assistance Scheme with Personal Assistance Advisor	PwD employed and managed PAs directly. Advisors provide advocacy work, advice and information about PA schemes and about managing workers and/or employment law. Nearly a quarter required some kind of practical assistance (e.g. help with applying to Independent Living Fund).	England English	Mixed methods including a qualitative study and uncontrolled cross-sectional survey. Face-t0-face interviews were conducted	48 RR: 33% (16) PwD only	Not specified	Age: Range: 32-70 Mean: 45 Female: n = 9 (56%) Ethnic/racial minority: Unknown	Independent Living Fund and the Local Authority.	The majority of data reported was raw data using direct quotes. RWC: 1,865

First Author (year) (linked)	**Pub Status (linked)**	**Program Name**	**Intervention Description**	**Country (Language)**	**Design**	**N**	**Type of disability**	**Sample Characteristics**	**Funding Source**	**Type of data presented**
McGuigan (2016)	P Not Linked	Direct Payment (DP)	A DP is a means tested cash payment made to individuals who have been assessed as needing services, in lieu of social service provision. DP allow PwD to avail of care, which they can tailor to their needs, and to source that care themselves rather than depend upon existing statutory or traditional providers.	Northern Ireland English	Mixed methods including Qualitative interviews and Cross-sectional survey	317 Proposed sample 10% N = 30 (2 DP users and 28 informal carers implementing PB on behalf of family member)	Learning 40% (n=12), physical 27% (n=8), mental health 7%(n=2), 5 older (n=5) (65+) and 3 <18	Of PwD: Age Range: <18-65+ Female: 37% (n = 11) Ethnic/racial minority: Not reported	Local Authority	Data were summarised using free text with extensive use of direct quotes. RWC: 1,851

C – Control / I – Intervention
P – Published in peer reviewed journal / NP – Not published in peer reviewed journal
Linked – Linked to other identified titles / Not Linked – Not linked to other identified titles
PA – Personal Assistant
PwD - Person(s) with a lifelong Disability /Dementia
RR – Response Rate
RWC: Results Word Count
*Data for the minors and the older cohort [65+ (2 sites) / 3-17 years and 60+ (1 site)] were excluded. Older cohort was excluded as there was no way to determine who had a life-long disability and who was receiving age-related home support.
** Uncontrolled pre-post longitudinal study not included. Control only used at time 3.

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APPENDIX 2.4 - QUANTITATIVE STUDY CHARACTERISTICS

References pertaining to the 7 studies, with eligible qualitative data, included in the systematic review are listed within this Appendix (including linked titles). The table below demonstrates the study characteristics for the first and last study included in the review (chronologically), however the complete table will be provided as an online supplement for the Campbell Collaboration publication.

First Author (year)	Pub Status (linked)	Program Name	Intervention Description	Country	Design	N	Type of disability	Sample Characteristics	Funding Source	Control Condition
Beatty (1998)	P Not Linked	Consumer directed personal assistant services (PAS)	The personal assistant is accountable to the consumer, not to a supervising nurse or agency with the intended purpose of providing the PwD control and independence while achieving full integration within the community.	USA	Quasi-experimental non-randomised controlled longitudinal survey. Surveys were conducted by mail and telephone.	92 60 (1) 32 (C) RR: 100% (secondary use of existing data)	Physical	Average age: 42 (I) 44 (C) Female: 47% (I) 42% (C) Ethnic/racial minority: 20% (I) 15% (C)	Virginia's PAS program (I) Medicaid Waivers and usually (fully or in part) self-funded (C)	In receipt of personal assistance services that were not consumer directed.
Woolham (2013)	P Not Linked	Personal Budget (PB)	Based on a self-assessment, an ‘indicative budget’ is given to PwD at an early stage in the process to create a support plan (with support from others if needed). PBs can be used to buy a wide range of services once they are safe and	England	Controlled cross-sectional survey of random sample. Self-completed postal questionnaire. Telephone	1049 RR: 53% n=558 180 (I) 378 (C) Older people were excluded	Physical (32%), Intellectual (34%), Mental health (5%)	Average age: 52 (I) 55 (C) Female: 66% (I) 64% (C) Ethnic/racial minority: 7% (I) 6% (C)	Social Services Funding	A random sample of ‘traditional’ service users.

First Author (year)	Pub Status (linked)	Program Name	Intervention Description	Country	Design	N	Type of disability	Sample Characteristics	Funding Source	Control Condition
			legal. Plans must be approved by the local authority.		assistance available where necessary.	126 (I) 276 (C)				

C – Control / I – Intervention
P – Published in peer reviewed journal / NP – Not published in peer reviewed journal
Linked – Linked to other identified titles / Not Linked – Not linked to other identified titles
PwD - Person(s) with a lifelong Disability /Dementia
RR – Response Rate
*Data for the minors and the older cohort [65+ (2 sites) / 3-17 years and 60+ (1 site)] were excluded. Older cohort was excluded as there was no way to determine who had a life-long disability and who was receiving age-related home support.
** Uncontrolled pre-post longitudinal study not included. Control only used at time 3.

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APPENDIX 2.5 - EXCLUDED STUDIES

The references pertaining to the 215 studies excluded from the systematic review are listed within this Appendix. The table below demonstrates the primary reason for exclusion for study characteristics for a selection of studies, however the complete table will be provided as an online supplement for the Campbell Collaboration publication.

Study	Primary reason for exclusion
(Arntz & Thomsen, 2011)	**Population** – This study relates to frail older people (only) without any indication to a lifelong disability.
(Irvine et al., 2011)	**Population** - Only 7% of the overall sample appear to have a disability.
(Abbott & Marriott, 2013)	**Intervention**- This study focuses on managing one's finances at a micro level.
(Isaacson, Cocks, & Netto, 2014)	**Intervention** – This study focuses on the transition of young people from the family home, but individualised funding was not the main concern.
(Ageing and Aged Care, 2012)	**Study Design** – Outcomes were measured < 6 months after beginning the intervention.
(Ramakers et al., 2007)	**Study Design** – This was a cross-sectional survey design but there was no control group for part 5 of the study, which was the only part with relevant data.
(Alakeson, 2008)	**Empirical Data** – Discusses / references intervention of interest but does not collect empirical data
(Robert Wood Johnson Foundation, 2013)	**Empirical Data** – This study was based on a review of the 'Cash & Counseling' literature – references cross checked.
(Anderson, Wiener, & Khatutsky, 2006)	**Outcome** - Outcomes measured were workforce variables not health and social care outcomes
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APPENDIX 2.6 - RISK OF BIAS IN INCLUDED QUANTITATIVE STUDIES

Study: Beatty (1998)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?		x	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	x		
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	x		.
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?			NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?		x	

Quality Rating (Good, Fair, or Poor) (see guidance)
Rater #1 initials: 6/10 (4 NA) = 60% - Fair
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Benjamin (2000)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?		x	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance for x-sectional
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			CD
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?			NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)? *NOTE: All analyses incorporated sampling weights and accounted for design effects (Kish 1967) using the Stata statistical software package (StataCorp 1997).*	x		

Quality Rating (Good, Fair, or Poor) (see guidance)

Rater #1 initials: 7/10 (4 NA) = 70% - Good

Rater #2 initials:

Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Conroy (2002)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?		x	
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?		x	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?			NA
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	x		
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants? *NOTE: They were well described and where available reliability scores provided*	x		
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?		x	31%
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?		x	
Quality Rating (Good, Fair, or Poor) (see guidance)			
Rater #1 initials: 6/10 (4 NA) 60% Fair			
Rater #2 initials:			
Additional Comments (If POOR, please state why):			

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Brown (2007)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?	x		
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	x		9 months
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	x		
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?		x	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	x		

Quality Rating (Good, Fair, or Poor) (see guidance)
Rater #1 initials: 9/11 (3 NA) = 82% - Good
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Caldwell (2007)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?		x	Control – 21%
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?		x	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	x		For intervention group
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	x		
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?			NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	x		See notes on potential effects of attrition

Quality Rating (Good, Fair, or Poor) (see guidance)
Rater #1 initials: 6/10 (4 NA) = 60% - Fair
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Glendinning (2008)	Cochrane - Quality and Risk of bias scores for Randomised Controlled Trial	
	Score: Low (High Risk of Bias)	Support for judgement: Due to the complex social intervention the usual standards expected in a clinical RCT were not feasible. However every effort was made to adjust for potential bias.
Selection bias. Random sequence generation Allocation concealment	Yes Not reported	An analysis of sample representative and other bias can be seen section 4.4 (page 43) "no significant differences between the IB and comparison groups, with the sole exceptions of prior receipt of carer support (where levels of service receipt were in any case very low in both groups) and whether the user posed a risk to others"
Performance bias. Blinding of participants and personnel Assessments should be made for each main outcome (or class of outcomes)	No (not possible)	
Detection bias. Blinding of outcome assessment Assessments should be made for each main outcome (or class of outcomes)	No (not possible)	
Attrition bias. Incomplete outcome data Assessments should be made for each main outcome (or class of outcomes)	Both incomplete data and data by proxy respondents were considered during the analysis. Proxy responses were removed from analysis to see if results affected.	A subgroup called 'IB-accepted group' was created to represent those within the intervention group who accepted the IB (n – 458). Comparisons were drawn between this group and the comparison group where possible. Number of respondents was always highlighted for each outcome being reported and these varied considerably. Section c.2 (page 285 – 286) details the impact of proxy responses. In Chapter 6 we identified a number of associations between outcomes and IBs which ceased to be statistically significant once proxies were excluded. In the sample as a whole the proportion who reported feeling in control of their daily lives was 48 per cent in the IB group (n=493) and 41 per cent in the comparison group

		(n=437). Excluding proxies the proportion who reported feeling in control was 55 per cent in the IB group (n=287) and 49 per cent in the comparison group (n=299).
Reporting bias. Selective reporting	All intended outcomes were reported for whole sample and by subgroup.	
Other bias / limitations. Inappropriate influence from funders Cross over of between intervention and control Other	There was cross over between control and intervention (approximately 52 people)	There are several reasons why our sample may not be representative of the population of community (i.e. excluding those in residential care) social care service users as a whole. In particular this could be through pilot sites selecting or excluding specific types of service users to be put forward for the trial15. An unrepresentative sample may also result from non-response and sample attrition discussed above. For more detail see pages 43 -45.

Study: Glendinning (2008)	**Quality and Risk of bias scores for Cross-Sectional Studies**

Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?	x		
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?	x		
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?	x		6 months
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	x		
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?		x	
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	x		

Quality Rating (Good, Fair, or Poor) (see guidance)
Rater #1 initials: 8/11 (3 NA) = 73% - Good
Rater #2 initials:
Additional Comments (If POOR, please state why):

*CD, cannot determine; NA, not applicable; NR, not reported

Study: Woolham (2013)	**Quality and Risk of bias scores for Cross-Sectional Studies**		
Criteria	**Yes**	**No**	**Other (CD, NR, NA)***
1. Was the research question or objective in this paper clearly stated?		x	
2. Was the study population clearly specified and defined?	x		
3. Was the participation rate of eligible persons at least 50%?	x		
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?	x		
5. Was a sample size justification, power description, or variance and effect estimates provided?		x	
6. For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?		x	As per guidance
7. Was the timeframe sufficient so that one could reasonably expect to see an association between exposure and outcome if it existed?			NR
8. For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?			NA
9. Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?			NA
10. Was the exposure(s) assessed more than once over time?			NA
11. Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?		x	Not for costs
12. Were the outcome assessors blinded to the exposure status of participants?		x	
13. Was loss to follow-up after baseline 20% or less?			NA
14. Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?		x	Broadly comparable groups
Quality Rating (Good, Fair, or Poor) (see guidance)			
Rater #1 initials: 3/10 (4 NA) = 30% - Poor			
Rater #2 initials:			
Additional Comments (If POOR, please state why): The aims of the study are not clearly stated. While random assignment was used, the definition of the control group is ill-defined. There is no discussion of statistical power in relation to sample size. The two groups were considered broadly comparable on a number of demographic factors but no statistical data is presented.			

*CD, cannot determine; NA, not applicable; NR, not reported

APPENDIX 2.7 - RISK OF BIAS AND QUALITY IN INCLUDED QUALITATIVE STUDIES

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
Oliver (1992)	3/10	Moderate - This study was methodologically poor, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was limited in quantity (1st quartile of participants and 1st quartile of coded data). However, the study was conducted when very little was known about personal budgets in the UK – rich data
Zarb (1994)	7/10	Moderate - This study was methodologically sound, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was rich in meaning and quantity (3rd quartile of participants and 3rd quartile of coded data), although some data was related to ineligible population and was excluded from analysis.
Malette (1996)	7/10	Moderate - This study was methodologically sound, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was rich in meaning and quantity (3rd quartile of participants and 4th quartile of coded data).
Walker (1996)	5/10	Low - This study was fair methodologically, the aims and outcomes are relevant to the review, the discussion of findings lacks detail and the data was weak in terms of quantity and representativeness (2nd quartile of participants and 1st quartile of coded data). However, the study does give an early insight into consumer directed programmes.
Holman (1999)	3.5/10	Low - This study was poor methodologically (insufficient detail to assess), the aims and outcomes are relevant to the review, it was difficult to determine what findings related to what (limited raw) data, however the discussion was rich and provided useful insights into implementation issues at the early stage (2nd quartile of participants and 1st quartile of coded data).
Olmstead (1999)	0.5/10	Low - This study was very poor methodologically (insufficient detail to assess), the aims and outcomes are relevant to the review, the data was rich and findings are well grounded in the data, providing insights into the implementation of self-directed programs in the US at the very early stage of national roll-out, although limited in quantity and representativeness (1st quartile of participants (no PwD directly involved) and 2nd quartile of coded data).
Blumberg (2000)	2/10	Very Low - This study was poor methodologically (insufficient detail to assess), the aims and outcomes are relevant to the review, the data was rich although largely descriptive in nature and not linked well to other evidence and only represents one individual case (1st quartile of participants and 1st quartile of coded data).
Dawson (2000)	4/10	Low - This study was poor methodologically, the aims and outcomes are partly relevant to the review, although a lot of logistical and descriptive data was reported, although the design was not primarily qualitative, the findings seem to be grounded in the qualitative data with a particular focus on implementation, the data also makes a

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
		considerable contribution overall (2nd quartile of participants and 3rd quartile of coded data).
Glendinning (2000)	7/10	Moderate - This study was largely methodologically sound, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was rich in meaning and quantity, providing early insight into direct payment schemes in the UK when relevant data was scarce (3rd quartile of participants and represents the median number of coded text n = 148).
Leece (2000)	3/10	Low - This study was very poor methodologically, the aims and outcomes are somewhat relevant to the review, the findings however are well grounded in the data presented and the data provides early insight into direct payment schemes in the UK when relevant data was scarce, although it was limited in quantity and representativeness (1st quartile of participants and 1st quartile of coded data).
Pearson (2000)	6.5/10	Moderate - This study was methodologically sound, the aims and outcomes are relevant to the review. While the paper was somewhat disjointed it provides insightful findings into user experiences of using direct payments under different governing structures albeit limited in quantity and representativeness (2nd quartile of participants and 1st quartile of coded data).
Witcher (2000)	8/10	Moderate - This study was methodologically robust, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was rich in meaning (4th quartile of coded data), deciphering a very complex set of arrangements across Scotland, although the study was limited in terms of representativeness (2nd quartile of participants).
Smith (2001)	3/10	Low - This study was very poor methodologically (insufficient information to assess), while the aims and outcomes are somewhat relevant to the review, the findings are presented in an inaccessible manner. Although much of the data presented was not relevant, the relevant data was sizeable (3rd quartile of coded data) with sizeable participation (2nd quartile of participants).
Carmichael (2002)	6.5/10	Moderate - This study has methodological limitations (lacking detail) but the aims and outcomes are relevant to the review. Furthermore the findings are well grounded in the data presented and the data was rich in meaning and quantity (3rd quartile of participants and 2nd quartile of coded data).
Conroy (2002)	7/10	Moderate - This study was methodologically sound, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented, although it was difficult at times to disaggregate quantitative and qualitative data. The data was rich in meaning and quantity (3rd quartile of participants and 3rd quartile of coded data).
Eckert (2002)	6.5/10	High – Although there are some methodological limitations (for example insufficient information on ethics) this study represents a large number of titles reporting on the Cash and Counseling demonstration sites. The aims and outcomes are relevant to the review, the findings are well grounded in the data presented, and the data was extremely rich in meaning and quantity (4th quartile of

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
		participants and 4th quartile of coded data).
Young (2003)	8/10	Moderate - This study was methodologically sound, the aims were unclear but the outcomes are relevant to the review, the findings are well grounded in the data presented. The sample was considerable with a moderate richness in data presented (3rd quartile of participants and 2nd quartile of coded data).
Breda (2004)	7.5/10	Moderate - This study was methodologically sound, the aims were broad but the specific research question was relevant to the review, the findings are well grounded in the data presented. The data was rich in meaning and quantity (3rd quartile of participants and 4th quartile of coded data) providing rich insights into the experience of people from Belgium.
Jordan (2004)	1.5/10	Very low - This study was very poor methodologically (insufficient information to assess), while the aims were not particularly relevant, the reported findings were relevant to the review. The number of study participants were considerable (3rd quartile of participants), although no PwD were involved. Furthermore, the richness and quantity of data was limited (1st quartile of coded data).
Stainton (2004)	7.5/10	Moderate - This study was methodologically sound, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data was rich in meaning and quantity (2nd quartile of participants and 2nd quartile of coded data), conducted within two years of the introduction of personal budgets, these findings were very insightful at the time, particularly in Wales and the UK.
Emslie (2005)	7/10	Moderate - This study was methodologically sound, the aims were not completely in line with those of the review but the findings were relevant and were well grounded in the data presented. The data was rich in meaning and quantity (4th quartile of participants and 4th quartile of coded data) particularly around implementation. However the data was difficult to code due to the nature of reporting and not all data was eligible for analysis (for example, data relating to minors).
Rosenberg (2005)	5.5/10	Moderate - This study was fair methodologically; the aims were in line with the implementation element of the review and were well grounded in the data presented. The data was rich in meaning and quantity (4th quartile of participants and 3rd quartile of coded data) particularly around implementation of personal budgets in the UK at the early stages. No PwD were involved in the research directly.
Butler (2006)	8.5/10	Moderate - This study was methodologically robust, the aims were not entirely in line with the reviews but the findings were relevant and were well grounded in the data presented. While the focus was mainly on family members as representative for people with developmental disabilities, the data was rich in meaning and quantity (4th quartile of participants and 3rd quartile of coded data).
Sanderson (2006)	4.5/10	Low - This study was poor methodologically (insufficient information to assess), while the aims and outcomes are somewhat relevant to the review, the findings are limited in richness and representativeness (1st quartile of coded data and 2nd quartile of participants).

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
Speed (2006)	6.5/10	Low - This study was moderate methodologically, the aims and outcomes were in line with the review, while the findings provided a unique and rich insight into the first-hand experience of one individual case study, however the representativeness and quantity of data was limited (1st quartile of participants and 1st quartile of coded data).
Alakeson (2007)	2/10	Very low - This study was very poor methodologically (insufficient information to assess), while the aims were somewhat relevant, the reported findings were relevant to the review. The number of study participants were considerable (3rd quartile of participants) and it highlighted the unique perspective of mental health users. However, the richness and quantity of data was limited (1st quartile of coded data).
Caldwell (2007)	7.5/10	Moderate - This study was methodologically sound, the aims were in line with the reviews and the findings were relevant and were well grounded in the data presented. The focus was mainly on family members as representative for people with intellectual/developmental disabilities, the data was limited in meaning and quantity (1st quartile of participants and 1st quartile of coded data).
Dimitriadis (2007)	6/10	Moderate - This study was moderate methodologically, the aims were largely in line with the reviews and the findings were relevant. While much of the data presented was descriptive, the relevant findings were well grounded in the data presented, and were rich in quantity (3rd quartile of coded data). However the representativeness was limited (1st quartile of participants).
Adams (2008)	5.5/10	Moderate - This study was fair methodologically, the aims were and outcomes were relevant to the review, the findings are well grounded in the data presented. The sample was considerable, as were the richness and quantity (4th quartile of participants and 3rd quartile of coded data).
Daly (2008)	8/10	Moderate - This study was methodologically rigorous, the aims and outcomes are relevant to the review and the findings are well grounded in the rich data presented. However the representativeness and quantity was limited and this cohort of people were already researched as part of the large scale IBSEN study (2nd quartile of participants and 1st quartile of coded data).
Dinora (2008)	8/10	Low – As a mixed methods study the methodology was robust, the aims and outcomes were relevant to the review, however the qualitative findings were limited in terms of richness (based solely on open-ended questions) and while the reach was considerable, the quantity of relevant data was minimal (4th quartile of participants and 1st quartile of coded data).
Glendinning (2008)	9/10	High - This study is methodologically rigorous, the aims and outcomes are relevant to the review, the findings are well grounded in the data presented and the data is rich in meaning and quantity (4th quartile of participants and 4th quartile of coded data).
Homer	6.5/10	Moderate - This study was methodologically sound, the aims and

First Author (year)	CASP score	**CerQual confidence score** (High, Moderate, Low, Very low)
(2008)		outcomes were relevant to the review and the findings were well grounded in the data presented. The sample was considerable (even with ineligible data removed), as were the richness and quantity (2nd quartile of participants and 3rd quartile of coded data), particularly for an under-researched part of the UK (Scotland).
Lord (2008)	6.5/10	Moderate - This study was methodologically sound, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. The sample was considerable (given the document analysis component), while the quantity was limited (4th quartile of participants and 2nd quartile of coded data).
Shaw (2008)	2.5/10	Low - This study was very poor methodologically, the aims and outcomes were not particularly in line with the review, however the data does represent an under-researched population (deafblind) and the findings were grounded in rich qualitative data (2nd quartile of participants and 3rd quartile of coded data).
Coyle (2009)	6.5/10	Moderate - This study was methodologically sound, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. However the sample and quantity of data was limited (1st quartile of participants and 2nd quartile of coded data).
Rogers (2009)	6/10	Moderate - This study was moderate methodologically, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. However the sample and quantity of data was limited (1st quartile of participants and 2nd quartile of coded data), however the sample did represent an under-researched group (mental health users).
Sayles Wallace (2009)	7.5/10	Moderate - This study was methodologically robust, the aims were in line with those of the review, the findings were well grounded in the data presented. While the sample was small (1st quartile of participants), capturing the parent representative perspective for adult children with a severe intellectual disability, the data was rich in meaning and quantity (3rd quartile of coded data).
Eost- Telling (2010)	6.5/10	High - This study was methodologically sound, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. The sample was considerable, representing both user experience and staff implementation perspective. Furthermore, data was rich in quality and quantity (3rd quartile of participants and 4th quartile of coded data).
Kinnaird (2010)	7/10	Moderate - This study was methodologically robust, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. While the sample was limited, it represented an under-researched cohort (people with dementia) and staff implementation perspective. The data was rich in quality and quantity (2nd quartile of participants and 4th quartile of coded data).
Leahy (2010)	6/10	Moderate - This study was moderate methodologically, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. The sample was limited, but the data was rich in quality and quantity (2nd quartile of participants and 4th

First Author (year)	CASP score	CerQual confidence score (High, Moderate, Low, Very low)
		quartile of coded data).
Priestley (2010)	4.5/10	Moderate - This study was poor methodologically, the aims and outcomes were not particularly in line with the review and a lot of descriptive and 3rd party perspectives were reported. However, where relevant findings were reported, they were grounded in the data, represented a sizeable number of participants and were rich in quantity (4th quartile of participants and 4th quartile of coded data).
Vinton (2010)	8/10	Low - This study was methodologically sound, the aims and outcomes were relevant to the review and the findings were well grounded in the data presented. Although the sample was considerable, there was limited qualitative data in both richness and quantity (3rd quartile of participants and 1st quartile of coded data).
Williams (2010)	6/10	Very low – Although this study is methodologically moderate, the aims and outcomes only partially meet the inclusion criteria, however the social workers interviewed do discuss implementation issues, and findings are grounded in the data collected. The data is limited in richness and quantity (1st quartile of participants and 1st quartile of coded data).
Wilson (2010)	5/10	Moderate - This study was fair methodologically; the aims and outcomes were in line with the review; however the data is limited in richness, since it simply represents responses to open-ended questions and other comments. However, the sample was considerable and the data plentiful (4th quartile of participants and 4th quartile of coded data).
Campbell (2011)	8.5/10	Moderate - This study was methodologically sound, the aims and outcomes were relevant to the review. The findings were difficult to code however, i.e. determining what was based on empirical data vs researcher interpretation OR lived experiences vs potential implementation challenges/facilitators. However the sample and quantity of data was plentiful (3rd quartile of participants and 4th quartile of coded data).
Hatton (2011)	2.5/10	Low - This study was very poor methodologically, but the aims and outcomes were in line with the review. The qualitative element of this study is limited in richness (comments and responses to open end questions), however the data does represent a large sample therefore captured a broad spectrum of views (4th quartile of participants and 2nd quartile of coded data).
Lambert (2011)	7/10	Moderate - This study was methodologically sound, the aims and outcomes were largely in line with the review, the findings were grounded in the data, which was rich in meaning and quantity (3rd quartile of participants and 3rd quartile of coded data).
Newbronner (2011)	9/10	High - This study was methodologically robust, the aims and outcomes were in line with the review, the findings were grounded in the data, which was rich in meaning and quantity (3rd quartile of coded data). Half the sample had to be excluded but the remaining sample of mental health users was considerable (3rd quartile of participants)
Ridley	6.5/10	Moderate - This study was moderate methodologically, the aims and

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
(2011)		outcomes were largely in line with the review, the findings were grounded in the data, which was rich in meaning and quantity, with a considerable sample (4th quartile of participants and 3rd quartile of coded data).
Secker (2011)	2.5/10	Very low - This study was very poor methodologically (insufficient information to assess). While the aims and outcomes were relevant to the review and the findings were limited in terms of richness, mainly based on survey comments. The sample was also modest in size (1st quartile of participants and 2nd quartile of coded data).
Rummery (2012)	5/10	Low - This study was fair methodologically. The aims and outcomes were not particularly in line with the review but the qualitative findings were relevant, particularly the focus group data. The sample size was bolstered by the mixed method approach (3rd quartile of participants and 2nd quartile of coded data).
Sheikh (2012)	7/10	High - This study was methodologically sound, the aims and outcomes were in line with the review, the findings were grounded in the data, which was rich in meaning and quantity, having been captured over a prolonged period of time, capturing changes over time (3rd quartile of participants and 4th quartile of coded data).
Gross (2013)	7.5/10	Moderate - This study was methodologically sound, while the aims and outcomes were not particularly in line with the review, the findings were relevant, grounded in the data, and relatively rich in meaning and quantity (2nd quartile of participants and 2nd quartile of coded data).
Hatton (2013)	2.5/10	Moderate - This study was very poor methodologically, but the aims and outcomes were in line with the review. The qualitative element of this study is limited in richness (comments and responses to open end questions), however the data does represent a large sample therefore captured a broad spectrum of views (4th quartile of participants and 3rd quartile of coded data).
Rees (2013)	7/10	Moderate - This study was methodologically sound, the aims and outcomes were in line with the review, the findings were relevant and grounded in the data, the sample was relatively modest but the data was rich in meaning and quantity (2nd quartile of participants and 4th quartile of coded data).
Bola (2014)	6/10	Moderate - This study was moderate methodologically, the aims and outcomes were largely in line with the review although with a particular focus on uptake, the findings were relevant and grounded in the data, the sample represented an under researched group (mental health users) and the data was rich in meaning and quantity (3rd quartile of participants and 4th quartile of coded data).
Junne (2014)	6/10	Moderate - This study was moderate methodologically, the aims and outcomes were largely in line with the review although with a particular focus on risk, the findings were relevant and grounded in the data, which was moderate in meaning and quantity (2nd quartile of participants and 2nd quartile of coded data).

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
Buchanan (2014)	6.5/10	Moderate - This study was moderate methodologically, the aims and outcomes were in line with the review although with a particular focus on risk. While the sample was small (1st quartile of participants), the findings were relevant and grounded in the data, which was moderate in meaning and quantity (3rd quartile of coded data).
Waters (2014)	2/10	Very low - This study was very poor methodologically. While the aims and outcomes were relevant to the review and the sample size considerable (4th quartile of participants), the findings were limited in terms of richness, mainly based on survey comments. Very little qualitative data was presented (1st quartile of coded data).
Coles (2015)	7.5/10	Low - This study was methodologically sound, the aims and outcomes were not particularly in line with the review (focusing on parents managing budget on behalf of adult child with a disability). However relevant data was presented although it was limited meaning and quantity (1st quartile of participants and 1st quartile of coded data).
Glendinning (2015)	9.5/10	Moderate - This study was methodologically robust, the aims and outcomes were somewhat in line with the review although with a particular focus on the carers role, the findings were relevant and grounded in the data, but represented a relatively small sample and were moderate in meaning and quantity (2nd quartile of participants and 1st quartile of coded data).
Hamilton (2015)	9.5/10	High - This study was methodologically robust, the aims and outcomes were in line with the review, with a particular focus on mental health users, the findings were relevant and grounded in the data, which was rich in meaning and quantity (4th quartile of participants and 3rd quartile of coded data).
Jepson (2015)	8.5/10	Moderate - This study was methodologically robust, the aims and outcomes were in line with the review, with a particular focus on dementia and implementation issues when providing funding to recipients that do not have capacity to consent. The findings were relevant and grounded in the data, representing a considerable sample (4th quartile of participants). The richness of data was somewhat limited however in depth and quantity (2nd quartile of coded data).
Jones (2015)	8/10	High - This study was methodologically robust, the aims and outcomes were largely in line with the review although the funding had a particular 'accommodation' focus. The findings were relevant and grounded in the data, which were rich in meaning and quantity (4th quartile of participants and 4th quartile of coded data).
Laragy (2015)	7/10	Moderate - This study was methodologically sound, the aims and outcomes were in line with the review with a particular focus on implementation. The findings were relevant and grounded in the data, however the sample size was limited and the richness of data was moderate in meaning and quantity (1st quartile of participants and 2nd quartile of coded data).
O'Brien (2015)	6.5/10	Moderate - This study was moderate methodologically, the aims and outcomes were in line with the review and the findings were relevant and grounded in the data. While the sample size was limited, it

First Author (year)	**CASP score**	**CerQual confidence score** (High, Moderate, Low, Very low)
		represented an under-researched population (Irish), the data was rich in meaning and quantity (1st quartile of participants and 3rd quartile of coded data).
Fleming (2016)	9/10	High - This research is extremely valuable, it utilises rigorous qualitative methodology to provide detailed assessment of individualised funding in Ireland. It provides pragmatic recommendations and how structures and process can be improved. In addition to highlighting how important these services are to people with a disability. (MH) While the sample size represented the median number of participants (n = 44), the data were rich in meaning and quantity (3rd quartile of coded data). (PF)
McGuigan (2016)	5/10	Low - This study was fair methodologically, the aims and outcomes were in line with the review and the findings were relevant and grounded in the data. The sample size was moderate and the richness of data was limited due to the more quantitative approach to data collection (survey) (2nd quartile of participants and 2nd quartile of coded data).

APPENDIX 2.8 - CHANGES TO FULL-TEXT SCREENING TOOL (CAPTURING OUTCOME AND METHODOLOGICAL DETAIL)

Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review

Study ID: _______ **Coder:** _______ **Date:** ___

APA Citation: *(PF to insert)*______________________________

Section A: Full Text Eligibility Screening Form	**Study Name**

Has a state funded personal budgeting intervention been utilised for a minimum of 6 months?

- ☐ Yes
- ☐ Majority (state %)
- ☐ Unsure
- ☐ No, then STOP!

Is the study population aged over 18 years of age?

- ☐ Yes
- ☐ Majority (state %)
- ☐ 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, including outcomes of interest?

☐ Yes
☐ Unsure
☐ No, then STOP!

List the outcomes reported:

Is the study:

☐ Quantitative
☐ Qualitative
☐ Mixed methods (including open ended questions in a quantitative study)

If the study design is quantitative (ONLY), it should be EXCLUDED on the basis of: single-case design, pre-post study without a control group, non-matched control groups, or groups matched post-hoc after results were known.

EXCLUDED ON THIS BASIS ☐

Any other comments:

APPENDIX 2.9 – DESCRIPTION OF PRIMARY, SECONDARY, ADVERSE AND OTHER OUTCOMES REPORTED

Table A2.9.1: Measures of quality of life in each study

Study	Outcome measure used	Reliability	Validity
Brown et al. (2007)	Single question on perceived QoL ‘How Satisfied with Way Spending Life These Days?’	Not reported	Not reported
Conroy et al. (2002)	“Quality of Life Changes” Scale asks each person to rate his/her quality of life “A Year Ago” and “Now.” Ratings are given on 5 point, Likert scales, and covers 14 domains including health, friendships, safety, and comfort.	Interrater reliability was found to be .76	Not reported
Glendinning et al. (2008)	Perceived Quality of life – using a seven-point scale ranging from ‘So good, it could not be better’ to ‘So bad, it could not be worse’. In addition Psychological well-being was measured using General Health Questionnaire.	GHQ - Cronbach’s Alpha was 0.92	Not reported
Woolham (2013)	Psychological well-being was measured using General Health Questionnaire.	Not reported	Not reported

Table A2.9.2: Measures of client satisfaction in each study

Study	Outcome measure used	Reliability	Validity
Beatty (1998)	Personal Assistance Satisfaction Index - The items cover a range of issues regarding satisfaction with the delivery of personal assistance services, including cost of services, control over assistants' schedule, availability of assistants, safety, and consumer-assistant interactions.	Internal consistency high, with a Cronbach's alpha of .88	Not reported
Benjamin (2000)	Client satisfaction measures were adapted from those previously developed on medical outcomes and on home care. Variables included: Technical quality, service impact, general satisfaction and interpersonal manner.	Not reported	Not reported
Brown et al. (2007)	Satisfaction with paid care received was measured based on 1. the way paid caregiver helped with personal care, household activities and routine health care, 2. time of day paid worker helped, 3. level of difficulty in changing caregiver schedule and 4. satisfaction with overall care (transportation & use of care-related equipment).	Not reported	Not reported
Caldwell (2007)	Service satisfaction. Service satisfaction consisted of five items. Examples of these items are: ‘‘To what degree do you get the kind of services you want?’’ and ‘‘In an overall sense, how satisfied are you with the services you receive?’’ A 5-point scale was used for each item, from 1 (not at all) to 5 (very much).	Alpha reliability of the scale for total sample at Time 3 was .96	Not reported
Glendinning et al. (2008)	Satisfaction and quality of services. Measures of satisfaction and quality of care were based on quality indicators derived from the extensions to national User Experience Surveys for older home care service users and younger adults.	Cronbach’s Alpha of 0.80	Not reported

Table A2.9.3: Measures of physical functioning in each study

Study	Outcome measure used	Reliability	Validity
Benjamin (2000)	While functional status (Katz and Akpom 1976; Lawton 1971) was recorded in telephone interview, this was only reported with regards to unmet needs	NA	NA
Brown et al. (2007)	Within the overall 'Health and Functioning' category physical functioning was measured by asking respondents if they were 'Not independent in last week: 1) getting in or out of bed, 2) bathing and 3) using toilet/diapers. These ADL were used a coefficients in the effectiveness analysis.	NA	NA
Glendinning et al. (2008)	Difficulties with Activities of Daily Living Scale (ADL) were collected at baseline to act as a coefficient within a multiple regression. Therefore individual ADL data are not presented.	NA	NA
Woolham (2013)	Activities of Daily Living Scale (ADL) - a simple measure by which the ability of those taking part to carry out everyday activities of daily living could be assessed	Not reported	Not reported

Table A2.9.4: Measures of costs data in each study

Study	Outcome measure used	Reliability	Validity
Brown et al. (2007)	1. Monthly costs presented for intervention and control groups.	Not reported	Not reported
Dale & Brown (2005)	2. Costs presented mean treatment and control with associated Treatment-Control Differences.		
Glendinning et al. (2008)	The cost of social care packages are presented as weekly costs. Mean costs (per week) presented for intervention and control groups for 1. Health Care Costs and 2. Care management costs. Incremental cost effectiveness ratios for ASCOT and GHQ outcomes measures are also presented (using pre/post design).	GHQ - Cronbach's Alpha was 0.92	Not reported
Woolham (2013)	Mean package costs (per week) by care group for intervention and control groups. Costs represent costs of care management for the control groups and of staff time plus advocacy and support service time for intervention group. Infrastructure costs excluded for both groups. Scatterplots are used to examine intervention and control differences based.	Not reported	Not reported

Table A2.9.5: Measures of adverse outcomes in each study

Study	Outcome measure used	Reliability	Validity
Benjamin (2000)	Unmet service needs measured by 1. Number of ADL needs unmet due to not needs (0-6) having help and 2. IADL unmet Number of IADL needs unmet due to not needs (0-5) having help.	Not reported	Not reported
	'Physical and psychological risk' whereby client yelled at, stolen from, pushed, shoved, neglected, ignored, injured while assisted or received unwanted sexual advances or carer under the influence	Not reported	Not reported
Brown et al. (2007)	Comparisons drawn for intervention / control reporting 1. Unmet needs for help with daily living activity 2. Paid caregiver was rude or disrespectful and 3. Unmet needs for person assistance with household activities, personal care and transportation. 4. Care-related problems and events including 'had a fall', 'Contractures Developed/Worsened', 'Bedsores Developed/Worsened' and 'had urinary tract infection'	Not reported	Not reported
Caldwell (2007)	A modified version of the Family Support Index (Heller & Factor, 1993; Heller et al., 1999) was used to measure unmet service needs. This index included a list of 28 common types of services used by individuals with disabilities and families. Families were asked whether they used each service. If families were not using a service, they were asked whether they needed it. Unmet needs for each service were totalled.	Not reported	Not reported
Conroy (2002)	**Challenging behaviour** scale is complementary to the Adaptive Behaviour scale. It is composed of 14 items detailing various maladaptive behaviours on a 100-point scale, with higher scores indicating less challenging behaviour.	Not reported	Not reported
Glendinning et al. (2008)	Psychological ill-health using GHQ-12. By scoring each item as 0 or 1, sums them, and then calculates the proportion of people with a total score of 4 or higher, which is conventionally interpreted as indicating that they are at risk of psychological ill-health.	Cronbach's Alpha was 0.92	Not reported

Table A2.9.6: Measures of other health and social care outcomes in each study

Study	Outcome measure used	Reliability	Validity
Benjamin (2000)	'Sense of security' – How safe client feel with provider and how well they get along with provider.	Not reported	Not reported
Caldwell (2007)	Community participation of individuals with developmental disabilities Community participation was measured using the Community Integration Scale (Heller & Factor, 1991), which measures frequency of participation in eight common community activities	Alpha reliability at Time 3 was .66.	Not reported
Conroy (2002)	Choice making – 'Decision control inventory' – 10 point scale of 35 decision making ratings where 0 denotes a choice is made entirely by paid staff and 10 denotes a choice made entirely by the focus person (and/or unpaid trusted others)	Interrater reliability of .86	Not reported
	Integration – 'Harris poll of Americans with and without disabilities' - measuring how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of citizens without a disability.	Interrater reliability (.97)	Not reported
	The Individual Planning Process – includes a scale to measure the "Elements of the Planning Process", designed to reflect the degree to which planning is carried out in a "person-centred" manner.	Not reported	Not reported
Glendinning et al. (2008)	Self-perceived health - based on a (previously used) five point scale that asks respondents to rate their health in general according to five categories ranging from 'Very good' to 'Very bad'.	Not reported	Not reported
	Social care outcomes using Adult Social Care Outcomes Toolkit (ASCOT) is a preference weighted indicator that reflects need for help and outcome gain from services across seven domains ranging from basic areas of need such as personal care and food and nutrition to social participation and involvement and control over daily life.	ASCOT – Cronbachs alpha was 0.74.	Not reported

APPENDIX 2.10 - COMPLETE LIST OF QUALITATIVE THEMES, SUBTHEMES AND LEVELS OF CODING

	MACRO		**MESO**		**MICRO**		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
1	**Contributing factors**						
2		3rd parties					
3							
4			Local Authority / Funders				**62**
5			Organisational attributes				**5**
6				Org. cultural practices			**4**
7					Pay-rise		**1**
8			State government				**5**
9				Political power			**5**
10							
11		Access to funds					**105**
12			How money was used				**116**
13				ADL			**108**
14				Attend courses / classes / clubs			**31**
15				Childcare			**6**
16				Health and fitness			**29**
17				Home improvement			**21**
18				Hours of Trad Care			**18**
19					Day Centre		**15**
20				Household goods			**3**
21				intimate care			**43**
22				Medical Equipment			**6**
23				Medicine / medical supplies			**12**
24				Paid assistance			**155**
25				Personal care			**32**
26				Respite hours			**55**
27				Technology / assistive tech			**56**
28				Therapy			**23**
29				Transport			**51**
30			Spending criteria/ restriction				**102**
31				Want vs. need			**9**
32		Conditions / arrangements					
33			accountability				**31**
34			Communication				**72**
35				different forms of expression			**17**
36				Fam. expect to be consulted			**13**
37					Ask questions		**2**
38				Word of mouth			**27**
39					School		**3**
40			Dedicating time				**21**
41			Engagement				**6**
42			Information				**177**
43				guidance / advice			**113**
44			Org. support				**26**
45			Practical support				**30**
46			Promotion of I.F.				**23**
47			Training				**136**

	MACRO		**MESO**		**MICRO**		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
48				Rekindle ability to choose			**1**
49		HR					**56**
50			advocacy				**35**
51			Carer				**28**
52			Centralised staff				**16**
53				in-house			**5**
54			Frontline staff				**21**
55			GP				**7**
56			health and safety				**12**
57				Home is workplace			**2**
58			Independent provider / facilitator				**8**
59			New recruits				**6**
60				Job benefits			**17**
61			No previous exp.				**10**
62			one-to-one				**26**
63			PA skills / role				**100**
64				Healthcare			**55**
65			Previous exp				**243**
66			Supervision				**38**
67			Supporter attribute				**6**
68		Interpersonal relationships					**93**
69			Consumer attributes				**10**
70				articulate			**1**
71				Modest			**4**
72				Open to new ideas			**12**
73				proactive			**18**
74			Hands on				**11**
75			sense of obligation				**17**
76			Staff attitudes				**6**
77			tension				**8**
78		Limitations					**52**
79		Location / Setting					**3**
80			Informal setting				**33**
81			Living alone				**3**
82			Own home				**54**
83			residential settings				**11**
84		The system					**30**
85			Challenge the system				**18**
86			No change in practice				**44**
87				based on existing system			**3**
88			Rigorous systems				**4**
89			Social benefits system				**2**
90			two tier system				**3**
91		User attributes					
92			Changing preferences				**14**
93				Avoid segregation / group based			**9**
94				Does not want trad. ser			**37**
95				Needs change			**40**
96			cultural, language & religious factors				**18**
97			Loudest voice				**3**
98			Need for proxy				**8**
99			Older people				**12**
100			Severity / type of disability				**84**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
101							
102	**Implementation Challenges**						
103		Imp, Challenge - Staff / Org. Perspective					**404**
104			Fear				**94**
105				Flood the system			**5**
106				Impact on existing services			**40**
107					Expands workforce		**1**
108					Large caseloads		**2**
109					Privatisation of care		**3**
110						Competing services	**3**
111						Disjointed services / supports	**13**
112						Economies of scale??	**4**
113				Misuse			**23**
114					Fraud		**10**
115					Reviewing Receipts not important		**1**
116					self-destructive to misuse		**2**
117				Safeguarding			**49**
118					risk aversion		**9**
119						bankrupt	**3**
120			Staff scepticism				**14**
121				Prof. avoidance			**4**
122				Pressure to promote			**5**
123			Accommodating different levels of need				**1**
124				Different backgrounds / life experience			**6**
125				High support needs			**45**
126				Little support required			**5**
127				required ongoing support			**33**
128		Perceived Negative / Challenging Aspects					**820**
129			Cross-cutting challenges				
130				increased workload			**39**
131				Inequitable distribution of funds			**25**
132				intrusive			**6**
133				Lack of trust			**38**
134				Not inclusive			**39**
135				Relinquish control			**28**
136				Risk			**69**
137				Stressful			**102**
138				Too complex			**69**
139			External factors				
140				3rd party			
141					Abuse		**12**

	MACRO		**MESO**		**MICRO**		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
142					Bad attitude / Hostile		**41**
143						Avoidance	**6**
144						Discouraged	**10**
145					Overskilled		**3**
146					Paternalistic		**36**
147						Authoritarian	**3**
148						Controlled by regime	**5**
149						Patronising / demeaning	**13**
150					Relationship balance		**22**
151					Serve own interests		**13**
152						Designed to benefit others	**4**
153					Staff turnover / retention		**79**
154						Finding competent staff	**10**
155						Rurality	**24**
156					Toll on carer		**91**
157						assumption	**5**
158					unresponsive		**20**
159					Weak network of support		**36**
160				Change unsettling			**35**
161				Conflated publicity			**3**
162					failure to promote		**33**
163						Not publicised	**19**
164				Delay in process			**121**
165				Financial issues			**93**
166					Disappointment with level of funding		**47**
167					high costs		**9**
168						Unit pricing	**3**
169					Lack of work benefits		**3**
170					Low pay / wage		**52**
171						Working hours + vol	**27**
172					No transitionary money		**3**
173					Payroll & Tax		**87**
174						Money to pay for infrastructure	**2**
175				increased bureaucracy			**70**
176				Lack of clarity			**91**
177					Unclear roles		**36**
178				No time			**18**
179					Time consuming		**40**
180			Individual factors				**0**
181				Fear of IF ending			**40**
182					Lose services		**4**
183				Lack of independence			**6**
184				Negative emotions			**3**
185					Burnt out		**5**
186					lack of motivation		**11**

	MACRO		MESO		MICRO		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
187					lonely and isolated		**20**
188					not coping		**5**
189				No employment opportunities			**3**
190				Not for everyone			**18**
191					DP not appropriate		**4**
192					not for the faint hearted		**2**
193				personal issues			**2**
194					Behavioural		**29**
195					Managing ill health		**21**
196					Self-neglect		**7**
197		Potential problem / Area for improvement					
198			Disabling practices				**3**
199				Disability Awareness (soc. oppression)			**11**
200					A wish, not a right		**4**
201					Public perception		**22**
202				Facility-based (segregated) activities			**7**
203				Override PwD / Funds gatekeeper			**42**
204					3rd party pressure		**18**
205					Suggestions ignored		**2**
206					Only option / no alternatives		**36**
207						Don't have control	**4**
208						Hands tied	**3**
209						More restricted now	**5**
210						no choice	**2**
211				Perceived inability (3rd party)			**42**
212			Financial issues				
213				Budget cuts			**21**
214					claw back funds		**4**
215					Freeze expansion		**2**
216					IF end when Goal achieved		**5**
217				Charges for PwD			**18**
218				Keeping funding source separate			**27**
219					Conflating funding sources		**6**
220				Not cost saving			**8**
221				Unsustainable			**33**
222					Hidden costs		**30**
223						out of pocket	**12**
224			Human Resources				**1**
225				Available support			**224**
226					Over/under-estimate needs		**15**
227						less hours than needed	**17**
228						Subjective	**2**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
229					Need additional help		**11**
230					conflict of interest		**3**
231					Less contact with services		**5**
232					rely on informal supports		**24**
233					over-reliant on 1 person		**4**
234					Finding flatmate		**2**
235				Behaviour Change			**19**
236					accepting help		**6**
237					Avoid preconceived ideas		**2**
238					Learned passivity		**35**
239					Struggle to let go		**4**
240					unrealistic expectations		**27**
241				minimum level of training			**15**
242					need skills and knowledge		**72**
243					No formal training		**27**
244						Disciplinary role as employer	**2**
245				Respecting boundaries			**19**
246					conflict		**36**
247			Negative emotions / perceptions				
248				Big / more responsibility			**29**
249					daunting		**22**
250						apprehensive	**2**
251					struggle		**6**
252				Burden			**12**
253					Ask too much		**6**
254					Guilt		**8**
255				Suspicious			**7**
256					destroy informal supports / familism		**4**
257					Paying lip service to I.F.		**2**
258					penalised for honesty		**1**
259					Penalised for working		**7**
260					Set up to fail		**4**
261				vulnerability			**21**
262					reluctant to ‘rock the boat’		**5**
263					What happens when parents die?		**7**
264			Operational				
265				Cumbersome systems			**13**
266					duplication		**23**
267						repeatedly explain	**2**
268					Fire fighting		**9**
269						focus on crisis / acute /	**4**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
						deficit	
270					Inappropriate / wrong focus		**28**
271						fit for purpose	**3**
272						Medical model	**8**
273						Not a priority	**8**
274						Targets / costs vs. quality	**10**
275					inflexible / too rigid		**56**
276				Inconsistent approaches			**49**
277					Unclear procedure / legislation		**2**
278				Info needs			**305**
279					Inaccessible		**12**
280					Inaccurate information		**14**
281						Too much	**3**
282						outdated	**2**
283					Mixed messages		**30**
284					unaware		**5**
285				Legal challenges			**14**
286					liability		**2**
287				Transitionary period			**8**
288							
289	**Implementation facilitators**						
290		Imp. Facilitator - Staff / Org. perspective					**292**
291		Mechanisms of success					
292			Active community member				**24**
293				existing community resources / mainstream			**37**
294			Buy-in				**15**
295				commitment			**24**
296			control and choice				**104**
297				control of family			**3**
298				control of their disability / life			**45**
299			early intervention				**10**
300				preventative			**3**
301			Employment considerations				
302				Good employer / employment practice			**32**
303					higher / appropriate rate of pay		**18**
304					Treat well		**4**
305				Hire family			**125**
306					Siblings involved		**4**
307					Knows what needs to be done		**43**
308					Would do anything		**7**
309				I'm the Boss / Power shift			**29**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
310					Influence purchasing power		**16**
311					Power to sack		**23**
312					Set terms of employment		**37**
313				Known to PwD/Family - Familiarity			**22**
314					Hire non-family		**4**
315					Hire friend		**42**
316			flexibility				**177**
317			Future planning/ Purpose				**74**
318				Aspirations			**25**
319					Exceeded expectations		**4**
320				Have a plan			**2**
321				Have long term view / vision			**26**
322					Aim High		**3**
323					Short term / achievable goals		**26**
324				Recovery plan			**3**
325			Hands-off approach				**41**
326			Holistic approach / comprehensive				**18**
327			Inclusive				**27**
328			increased knowledge				**25**
329				knowing how much money			**16**
330				Understanding I.F.			**79**
331					support hours vs. services		**1**
332			Integration of services				**6**
333				Integrating information			**2**
334			Needs led				**135**
335			Outcome focussed				**25**
336				Health, social care outcome			**30**
337				Mental health or emotional wellbeing			**58**
338				QoL			**28**
339			Positive risk taking				**7**
340			Quick and Easy / Convenient				**26**
341				simplify / user-friendly			**4**
342			Range of services				**17**
343				quality of services			**88**
344				tailored			**15**
345					Supporting differently		**4**
346				Variety is spice of life			**5**
347			Relationships				
348				(Financial) recognition for vol work			**41**
349				active listening skills			**4**
350					felt heard		**7**
351				Better understanding			**46**
352				collaborative relationships			**52**

	MACRO		**MESO**		**MICRO**		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
353					Shared understanding		**32**
354					Shared learning		**20**
355				Deeper engagement			**7**
356				Dignity / Respect			**47**
357				Friendships from trad. services			**5**
358				Manage expectations / ppl management			**28**
359				Meaningful activity			**3**
360					encourage active role		**1**
361				Moral support			**43**
362				Network of support			**306**
363				PA attribute			**95**
364					Good disposition		**8**
365					Live close by		**14**
366					Proactive staff		**2**
367					responsive		**24**
368					shared interests / life-stage		**26**
369						Age appropriate	**5**
370				satisfaction with staff			**19**
371				Shift focus to positive			**6**
372				Strong leadership			**3**
373				trust			**82**
374				Use humour			**4**
375			Smooth transition				**4**
376			tangible examples				**8**
377			Thinking innovatively / creatively				**80**
378			Transparency				**12**
379		Perceived benefit					**662**
380			<dependent on supports				**57**
381			Avoid institutionalisation				**18**
382			Back to / remain in work				**47**
383			Community integration				**151**
384			Complement existing vol. supports				**14**
385			Continuity of Care / Service / Life				**121**
386				Reliability			**19**
387			Contribute to family life				**24**
388			Enhance skills				**50**
389				Continue self-improvement			**10**
390				Life skills training			**30**
391			enhanced relationship				**91**
392			Formalise alternative supports				**9**
393			Freedom				
394				Freedom (to choose) / individualisation			**84**
395					how you're supported		**107**
396					When you're		**87**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
					supported		
397					Where you're supported		**36**
398					Who supports you		**149**
399						Find the best fit	**9**
400						request specific people	**16**
401				Personal freedom / I have my life back			**14**
402					Autonomy		**10**
403					Freedom to make mistakes		**4**
404					Self-determined		**82**
405					Self-directed		**98**
406					self-reliance		**23**
407					Sense of empowerment		**46**
408					Space and freedom		**8**
409			greater appreciation for money				**6**
410			greater efficiency				**3**
411			Improve family life				**128**
412			improved self-image /self-belief / self-esteem				**53**
413				Adulthood recognition			**3**
414				build confidence			**5**
415					confidence		**82**
416				hope / positive outlook			**48**
417					enhanced self-awareness		**8**
418					improved mood		**4**
419					Less stress / anxiety		**37**
420					Resilient		**4**
421						Self-managing behaviour	**21**
422					Self-worth		**12**
423				Increased vitality			**2**
424				motivated			**18**
425				positive emotional experiences			**13**
426					Benefits outweigh negatives		**6**
427					Peace of mind		**6**
428						felt cared for	**2**
429						Safe and secure	**14**
430						Fears alleviated	**24**
431					Trickle-down effect (happiness)		**3**
432						unexpected	**8**
433						I'm happy if they're happy	**6**
434				Richer life			**16**
435				Successful			**7**
436			In-tune with needs				**14**
437			independence				**85**
438				independent as			**33**

	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	LEVEL 2	LEVEL 3	LEVEL 4	LEVEL 5	LEVEL 6	
				possible			
439			More bang for buck / Can do more				
440				Better / new opportunities			**58**
441					Civic participation / volunteering		**32**
442					Get outdoors		**22**
443					Recreational Opps		**90**
444					Social opps		**142**
445				choosing cheaper option / value for money			**40**
446			New friendships				**30**
447			Not a burden				**29**
448			Org. / Gov't cost saving				**16**
449			privacy				**13**
450				own bedroom			**2**
451			Reduced cost overheads				**5**
452			Reduced medication / hospitalisation				**13**
453			To stay at home				**29**
454				in-home support			**27**
455							
456	**Process**						**25**
457		Admin / Management					**235**
458			Shared management				**10**
459			Separate funding streams				**3**
460			Governance				**17**
461				Developing SOPs			**3**
462				Develop policy			**2**
463					Adult protection policy		**5**
464			Annual vs monthly budget				**3**
465			Forms / Paperwork				**198**
466		Logistics					
467			Audit				**4**
468			Banking				**2**
469				Additional bank account(s)			**22**
470			Basic system of organising				**6**
471			Centralised services				**10**
472			client data management				**12**
473			Monitoring				**136**
474				risk panel			**4**
475				Complaints procedure			**9**
476				Review			**64**
477					lack of / absent		**8**
478			PA / staff recruitment				**174**
479				Vetting supports			**20**
480				Switching agency			**3**
481				Rostering			**9**
482				Roles clearly specified			**14**
483				Poach agency staff			**5**
484				Place adverts			**18**

	MACRO		**MESO**		**MICRO**		**Coded pieces of text**
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
485				Multiple assistants/ providers			**28**
486				Dismissing PA			**25**
487					fire staff		**4**
488				Employ directly			**78**
489					Setting wage		**2**
490					employment law		**18**
491					Employment contract		**10**
492			streamline				**3**
493				fast track process			**2**
494				Standardisation			**7**
495		Setup					
496			Uptake				**38**
497				Drop-out			**10**
498			Network building				**49**
499				room mate			**6**
500				Power of attorney / trustee			**9**
501				PA's children			**5**
502			Allocation calculation				**51**
503				RAS			**4**
504			Application/ enrolment				**19**
505			Assessment				**127**
506				Capacity			**25**
507				estimating hours needed			**2**
508				self-assessment			**15**
509				Community care assessment			**2**
510			determine eligibility				**22**
511			How money can be used				**130**
512				Pooling resources			**8**
513				Contingency funds / plan			**18**
514				extra transition costs			**3**
515				Use up allocation			**16**
516				Negotiations			**10**
517				Sign-off plans / budget / spend			**41**
518			Initial set up				**46**
519				set up as a company / business			**4**
520			Journey of discovery				**7**
521				Decision Making			**32**
522				prioritise requests			**2**
523				learn to dream			**4**
524				identify / organise resources			**48**
525				Identify goals			**33**
526				Choosing I.F.			**138**
527			Letter of agreement				**3**
528				consent vs understand			**4**
529			PCP / Support plan				**135**
530			Planning and outreach				**16**
531			referral routes / mechanisms				**5**
532			Tendering process				**5**
533		Types of supports					

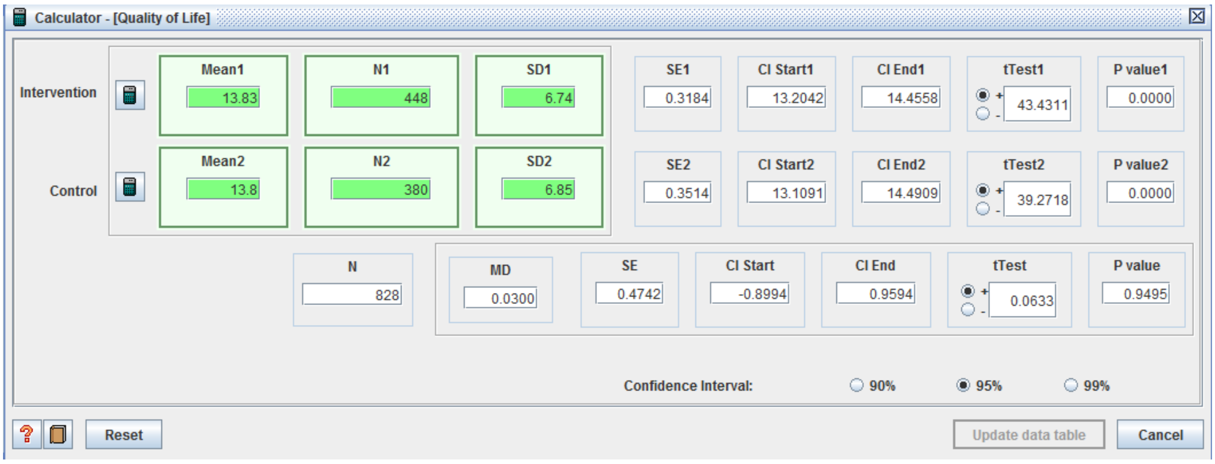
	MACRO		MESO		MICRO		Coded pieces of text
	LEVEL 1	**LEVEL 2**	**LEVEL 3**	**LEVEL 4**	**LEVEL 5**	**LEVEL 6**	
534			Wide range of people				**3**
535			Peer support				**55**
536			Offer continuum of SDS				**2**
537			disability led advisory councils				**25**
538			Local Support Orgs				**145**
539				User-led orgs.			**16**
540			Emergency support				**71**
541			Direct Payment				**4**
542			Brokerage / managed model				**11**
543			Agency involvement				**236**
544				Professionals / Practitioners			**234**
545					Carer lead officer		**4**
546					Case / care manager / coordinator		**38**
547				I.F. coordinators / Support Brokers			**256**
548					intermediary		**25**
549					Coordinator attributes		**14**
				TOTAL CODED SECTIONS OF TEXT			**17961**
	Total Level 1 Themes	**Total Level 2 Themes**	**Total Level 3 Themes**	**Total Level 4 Themes**	**Total Level 5 Themes**	**Total Level 6 Themes**	
	4	**19**	**142**	**192**	**144**	**43**	**544**

A2.11.1 - QUANTITATIVE ANALYSIS

Table A2.11.1 - Results from WinPepi – Glendinning et al. (2008)

Outcome	Study arm	Sample size	Proportion (positive / yes)	Upton chi square	p-value
Quality of life	Intervention	504	0.45	1.16	0.28
	Control	439	0.49		
Quality of life (excluding proxies)	Intervention	308	0.41	0.08	0.77
	Control	302	0.42		
Client satisfaction	Intervention	478	0.78	7.54	< 0.01
	Control	431	0.70		
Client satisfaction (excluding proxies)	Intervention	268	0.78	4.22	<0.05
	Control	288	0.70		
Psychological ill-health	Intervention	448	0.36*	0.84	0.36
	Control	380	0.33*		
Psychological ill-health (excluding proxies)	Intervention	344	0.37*	0.00	0.98
	Control	300	0.37*		
Self-perceived health	Intervention	507	0.35	2.20	0.14
	Control	446	0.40		
Self-perceived health (excluding proxies)	Intervention	311	0.33	0.03	0.87
	Control	317	0.34		

*Higher scores indicate worse ill-health



Calculator - [Quality of Life]

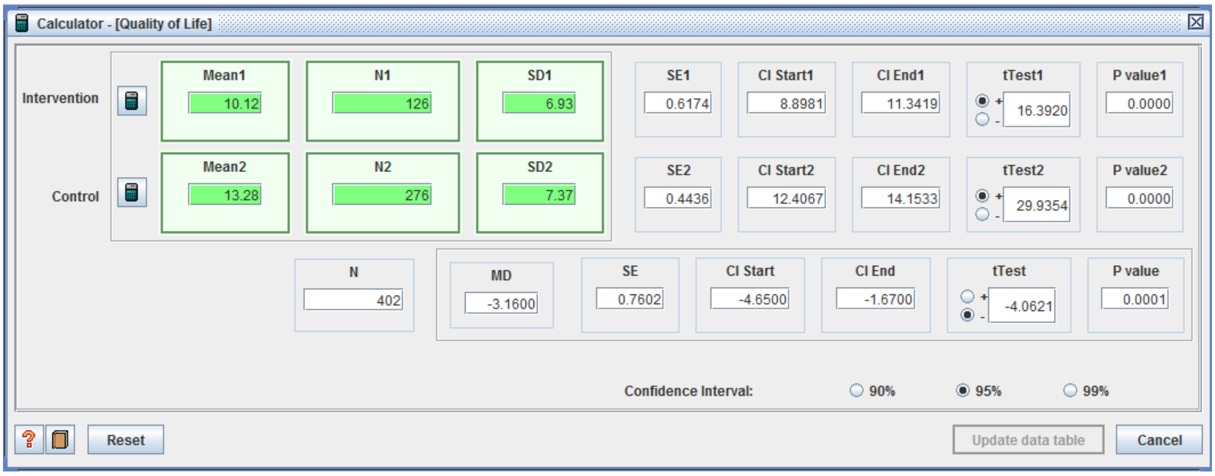
Intervention: Mean1 13.83 | N1 448 | SD1 6.74 | SE1 0.3184 | CI Start1 13.2042 | CI End1 14.4558 | tTest1 ● + ○ - 43.4311 | P value1 0.0000

Control: Mean2 13.8 | N2 380 | SD2 6.85 | SE2 0.3514 | CI Start2 13.1091 | CI End2 14.4909 | tTest2 ● + ○ - 39.2718 | P value2 0.0000

N 828 | MD 0.0300 | SE 0.4742 | CI Start -0.8994 | CI End 0.9594 | tTest ● + ○ - 0.0633 | P value 0.9495

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.1 Quality of Life –Psychological Wellbeing – Glendinning et al. (2008)



Calculator - [Quality of Life]

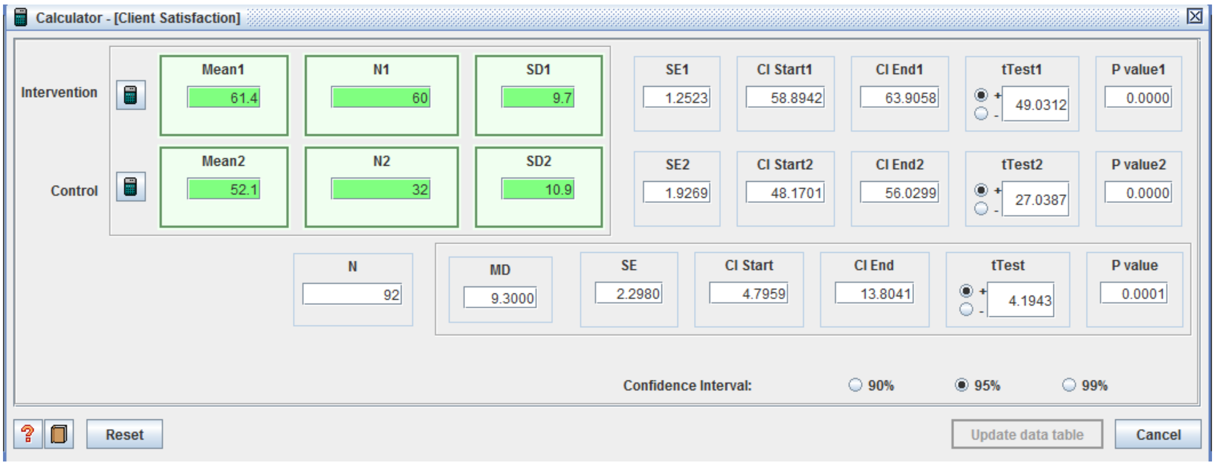
Intervention: Mean1 10.12 | N1 126 | SD1 6.93 | SE1 0.6174 | CI Start1 8.8981 | CI End1 11.3419 | tTest1 ● + ○ - 16.3920 | P value1 0.0000

Control: Mean2 13.28 | N2 276 | SD2 7.37 | SE2 0.4436 | CI Start2 12.4067 | CI End2 14.1533 | tTest2 ● + ○ - 29.9354 | P value2 0.0000

N 402 | MD -3.1600 | SE 0.7602 | CI Start -4.6500 | CI End -1.6700 | tTest ○ + ● - -4.0621 | P value 0.0001

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.2 Quality of Life –Psychological Wellbeing – Woolham & Benton (2013)



Calculator - [Client Satisfaction]

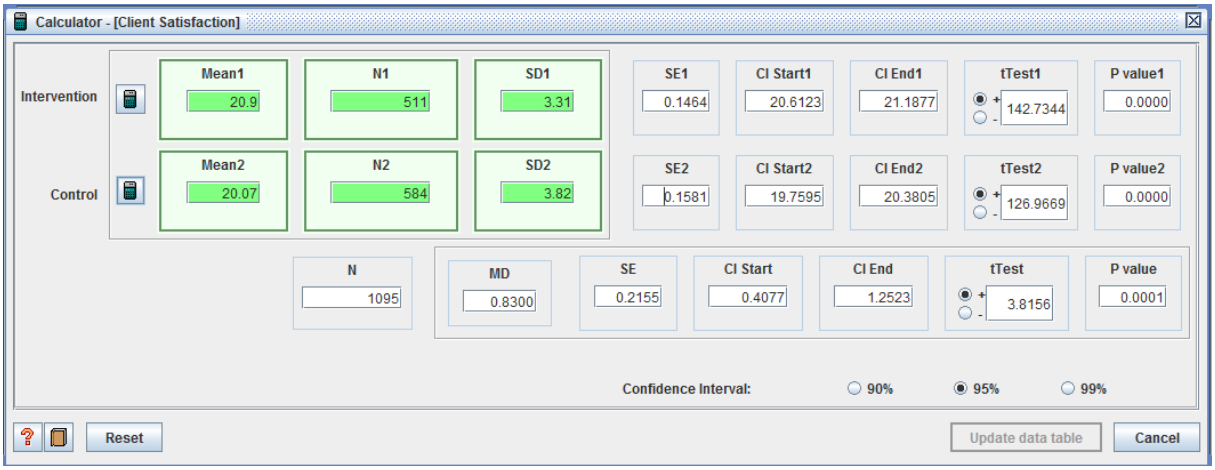
Intervention: Mean1 61.4 | N1 60 | SD1 9.7 | SE1 1.2523 | CI Start1 58.8942 | CI End1 63.9058 | tTest1 ● + ○ - 49.0312 | P value1 0.0000

Control: Mean2 52.1 | N2 32 | SD2 10.9 | SE2 1.9269 | CI Start2 48.1701 | CI End2 56.0299 | tTest2 ● + ○ - 27.0387 | P value2 0.0000

N 92 | MD 9.3000 | SE 2.2980 | CI Start 4.7959 | CI End 13.8041 | tTest ● + ○ - 4.1943 | P value 0.0001

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.3 Client Satisfaction – Beatty et al. (1998)



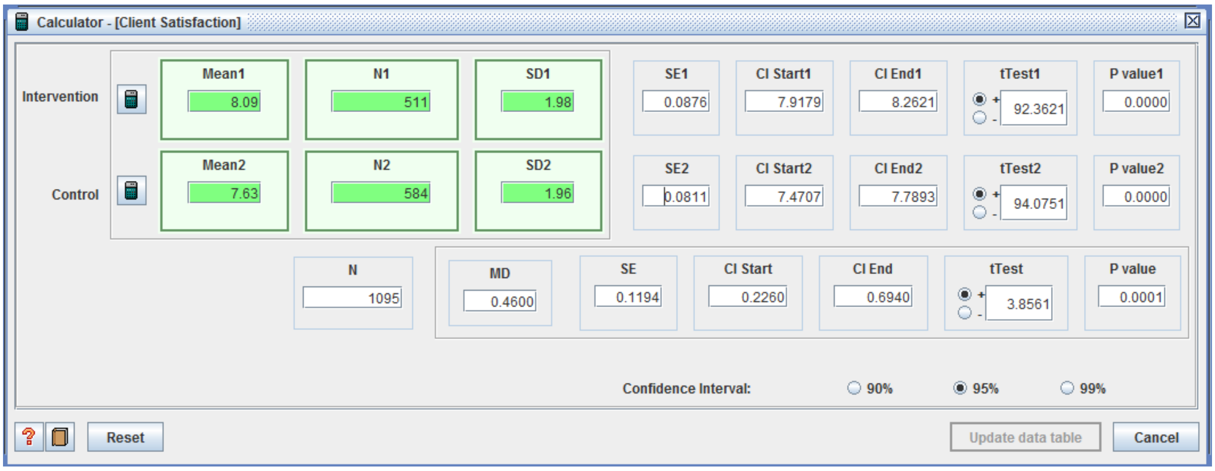
Intervention: Mean1 20.9; N1 511; SD1 3.31; SE1 0.1464; CI Start1 20.6123; CI End1 21.1877; tTest1 ● + ○ - 142.7344; P value1 0.0000

Control: Mean2 20.07; N2 584; SD2 3.82; SE2 0.1581; CI Start2 19.7595; CI End2 20.3805; tTest2 ● + ○ - 126.9669; P value2 0.0000

N 1095; MD 0.8300; SE 0.2155; CI Start 0.4077; CI End 1.2523; tTest ● + ○ - 3.8156; P value 0.0001

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.4 Client satisfaction (Technical Quality) – Benjamin et al. (2000)



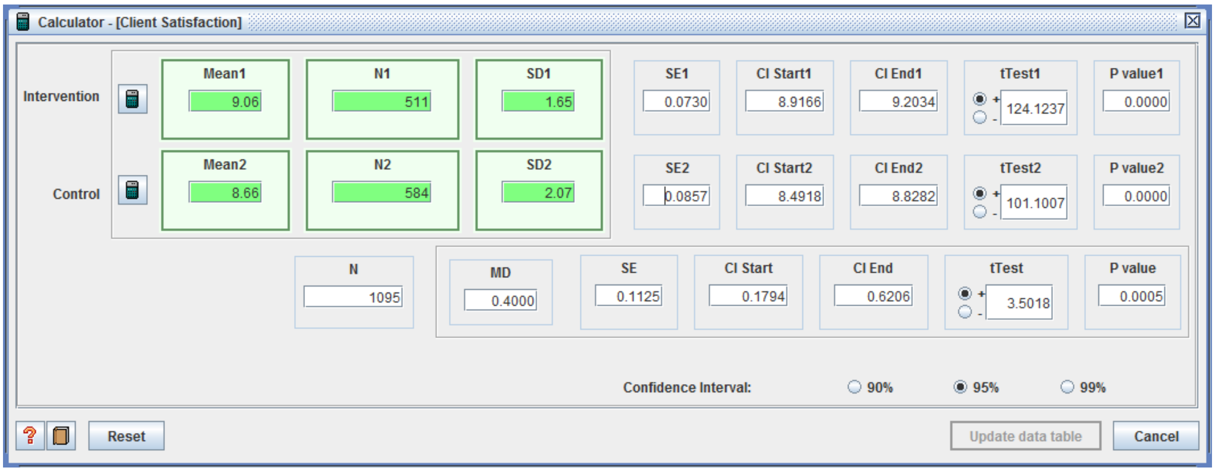
Intervention: Mean1 8.09; N1 511; SD1 1.98; SE1 0.0876; CI Start1 7.9179; CI End1 8.2621; tTest1 ● + ○ - 92.3621; P value1 0.0000

Control: Mean2 7.63; N2 584; SD2 1.96; SE2 0.0811; CI Start2 7.4707; CI End2 7.7893; tTest2 ● + ○ - 94.0751; P value2 0.0000

N 1095; MD 0.4600; SE 0.1194; CI Start 0.2260; CI End 0.6940; tTest ● + ○ - 3.8561; P value 0.0001

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.5 Client satisfaction (Service Impact) – Benjamin et al. (2000)



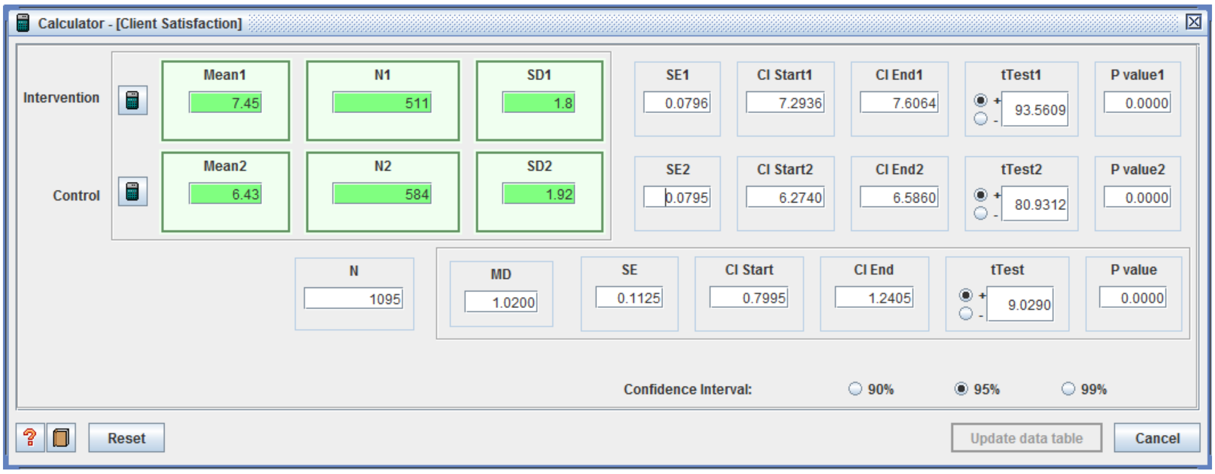
Intervention: Mean1 9.06; N1 511; SD1 1.65; SE1 0.0730; CI Start1 8.9166; CI End1 9.2034; tTest1 ● + ○ - 124.1237; P value1 0.0000

Control: Mean2 8.66; N2 584; SD2 2.07; SE2 0.0857; CI Start2 8.4918; CI End2 8.8282; tTest2 ● + ○ - 101.1007; P value2 0.0000

N 1095; MD 0.4000; SE 0.1125; CI Start 0.1794; CI End 0.6206; tTest ● + ○ - 3.5018; P value 0.0005

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.6 Client satisfaction (General Satisfaction) – Benjamin et al. (2000)

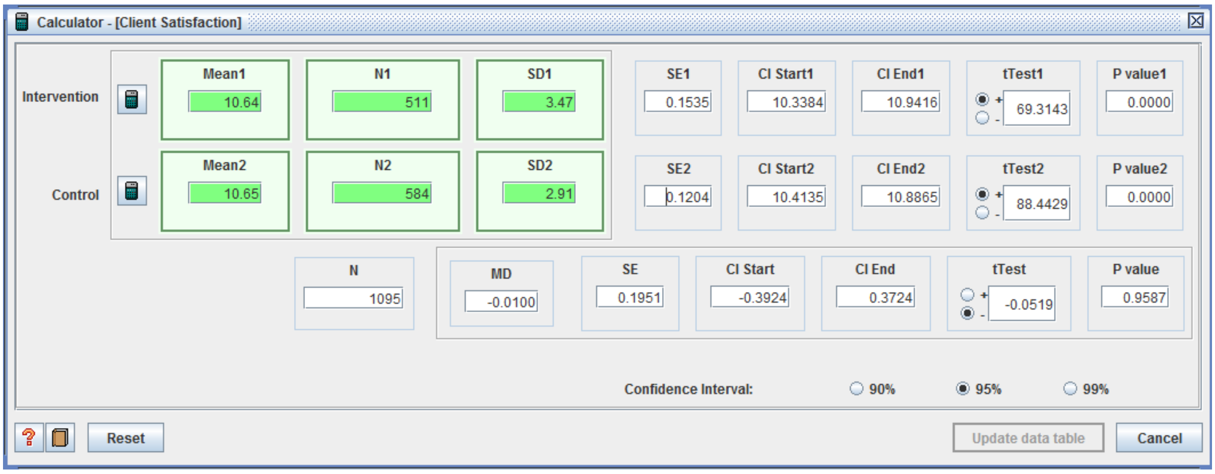

Calculator - [Client Satisfaction]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1 7.45	N1 511	SD1 1.8	SE1 0.0796	CI Start1 7.2936	CI End1 7.6064	tTest1 ● + ○ - 93.5609	P value1 0.0000
Control	Mean2 6.43	N2 584	SD2 1.92	SE2 0.0795	CI Start2 6.2740	CI End2 6.5860	tTest2 ● + ○ - 80.9312	P value2 0.0000

N 1095 | MD 1.0200 | SE 0.1125 | CI Start 0.7995 | CI End 1.2405 | tTest ● + ○ - 9.0290 | P value 0.0000

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.7 Client satisfaction (Interpersonal Manner) – Benjamin (2000)

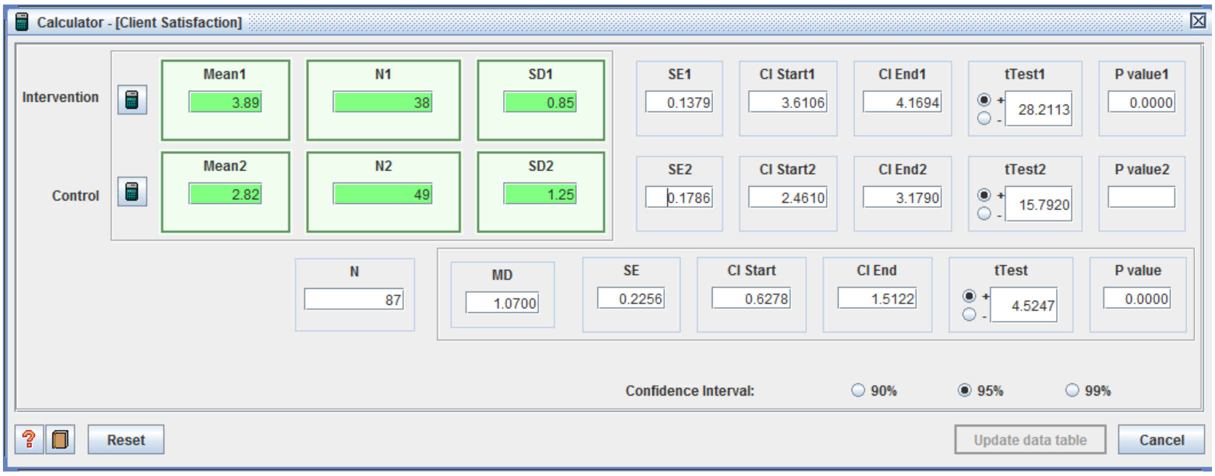

Calculator - [Client Satisfaction]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1 10.64	N1 511	SD1 3.47	SE1 0.1535	CI Start1 10.3384	CI End1 10.9416	tTest1 ● + ○ - 69.3143	P value1 0.0000
Control	Mean2 10.65	N2 584	SD2 2.91	SE2 0.1204	CI Start2 10.4135	CI End2 10.8865	tTest2 ● + ○ - 88.4429	P value2 0.0000

N 1095 | MD -0.0100 | SE 0.1951 | CI Start -0.3924 | CI End 0.3724 | tTest ○ + ● - -0.0519 | P value 0.9587

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.8 Client satisfaction (Provider shortcomings) - Benjamin et al. (2000)

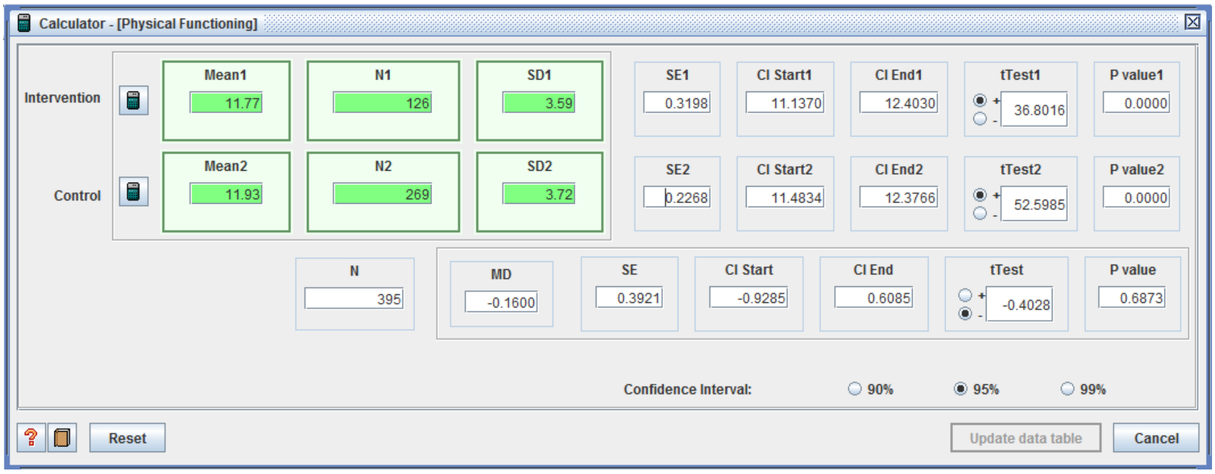

Calculator - [Client Satisfaction]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1 3.89	N1 38	SD1 0.85	SE1 0.1379	CI Start1 3.6106	CI End1 4.1694	tTest1 ● + ○ - 28.2113	P value1 0.0000
Control	Mean2 2.82	N2 49	SD2 1.25	SE2 0.1786	CI Start2 2.4610	CI End2 3.1790	tTest2 ● + ○ - 15.7920	P value2

N 87 | MD 1.0700 | SE 0.2256 | CI Start 0.6278 | CI End 1.5122 | tTest ● + ○ - 4.5247 | P value 0.0000

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.9 Client Satisfaction – Caldwell et al. (2007)

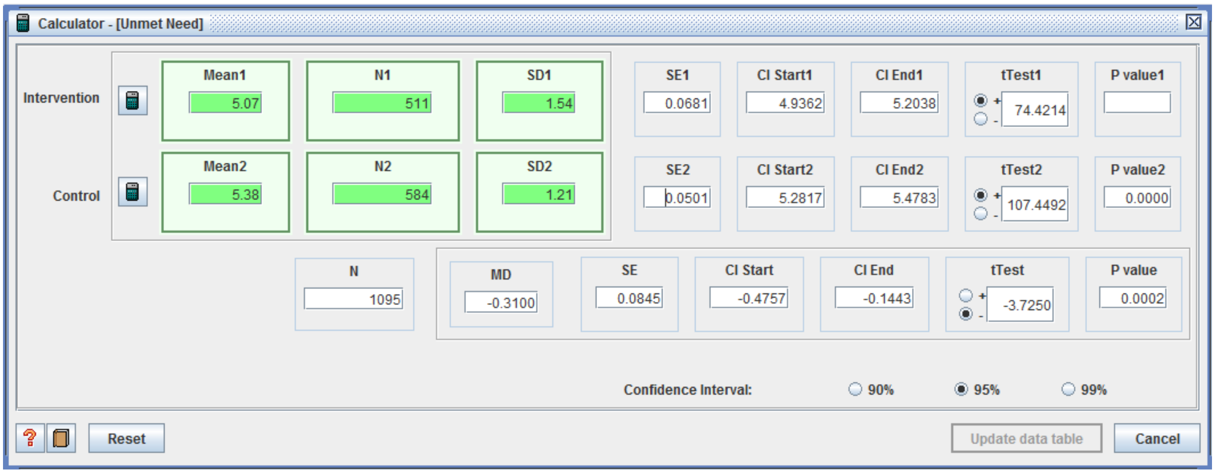

Calculator - [Physical Functioning]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1: 11.77	N1: 126	SD1: 3.59	SE1: 0.3198	CI Start1: 11.1370	CI End1: 12.4030	tTest1: ● + ○ - 36.8016	P value1: 0.0000
Control	Mean2: 11.93	N2: 269	SD2: 3.72	SE2: 0.2268	CI Start2: 11.4834	CI End2: 12.3766	tTest2: ● + ○ - 52.5985	P value2: 0.0000

N: 395
MD: -0.1600
SE: 0.3921
CI Start: -0.9285
CI End: 0.6085
tTest: ○ + ● - -0.4028
P value: 0.6873

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.10 Physical Functioning – Woolham & Benton (2013)

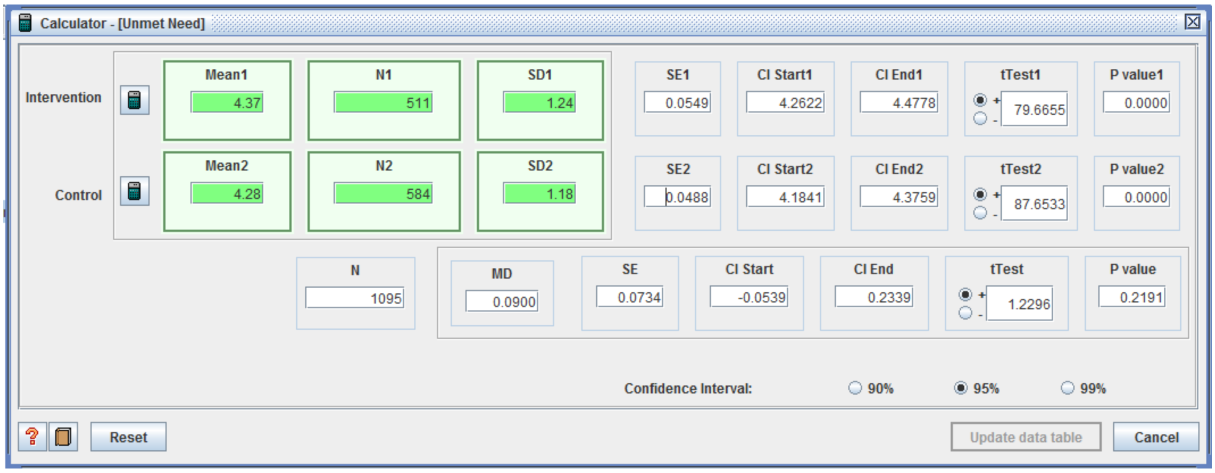

Calculator - [Unmet Need]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1: 5.07	N1: 511	SD1: 1.54	SE1: 0.0681	CI Start1: 4.9362	CI End1: 5.2038	tTest1: ● + ○ - 74.4214	P value1:
Control	Mean2: 5.38	N2: 584	SD2: 1.21	SE2: 0.0501	CI Start2: 5.2817	CI End2: 5.4783	tTest2: ● + ○ - 107.4492	P value2: 0.0000

N: 1095
MD: -0.3100
SE: 0.0845
CI Start: -0.4757
CI End: -0.1443
tTest: ○ + ● - -3.7250
P value: 0.0002

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.11 Unmet need – ADL – Benjamin et al. (2000)

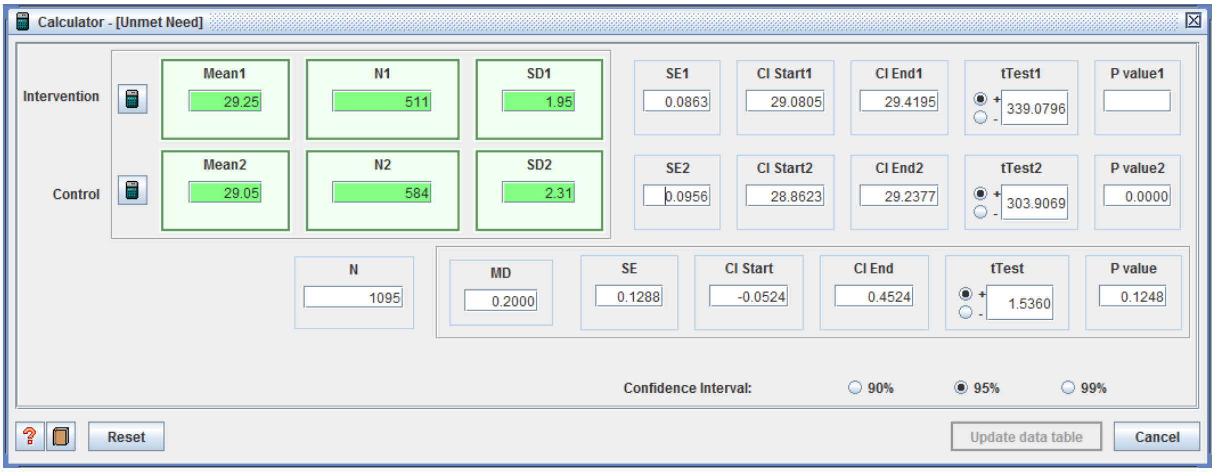

Calculator - [Unmet Need]

	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	Mean1: 4.37	N1: 511	SD1: 1.24	SE1: 0.0549	CI Start1: 4.2622	CI End1: 4.4778	tTest1: ● + ○ - 79.6655	P value1: 0.0000
Control	Mean2: 4.28	N2: 584	SD2: 1.18	SE2: 0.0488	CI Start2: 4.1841	CI End2: 4.3759	tTest2: ● + ○ - 87.6533	P value2: 0.0000

N: 1095
MD: 0.0900
SE: 0.0734
CI Start: -0.0539
CI End: 0.2339
tTest: ● + ○ - 1.2296
P value: 0.2191

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.12 Unmet need – IADL – Benjamin et al. (2000)

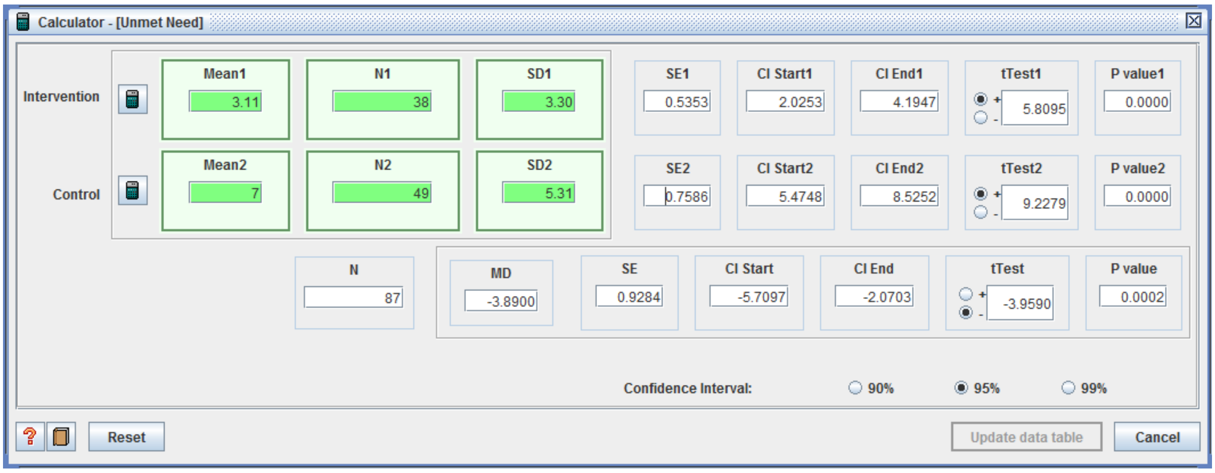


	Mean1	N1	SD1	SE1	CI Start1	CI End1	tTest1	P value1
Intervention	29.25	511	1.95	0.0863	29.0805	29.4195	● + ○ - 339.0796	
	Mean2	N2	SD2	SE2	CI Start2	CI End2	tTest2	P value2
Control	29.05	584	2.31	0.0956	28.8623	29.2377	● + ○ - 303.9069	0.0000

N	MD	SE	CI Start	CI End	tTest	P value
1095	0.2000	0.1288	-0.0524	0.4524	● + ○ - 1.5360	0.1248

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.13 Unmet need – Physical or psychological risk – Benjamin et al. (2000)

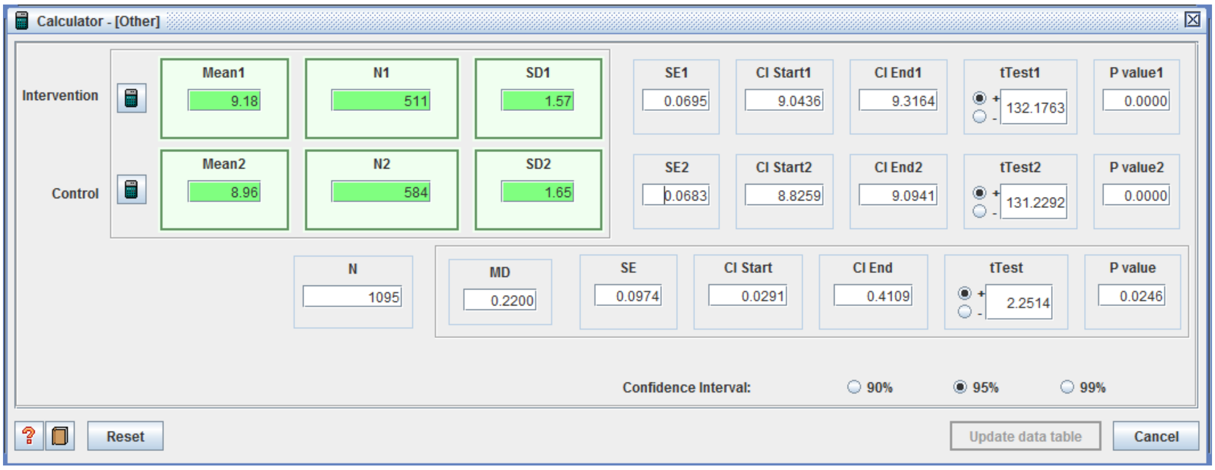


	Mean1	N1	SD1	SE1	CI Start1	CI End1	tTest1	P value1
Intervention	3.11	38	3.30	0.5353	2.0253	4.1947	● + ○ - 5.8095	0.0000
	Mean2	N2	SD2	SE2	CI Start2	CI End2	tTest2	P value2
Control	7	49	5.31	0.7586	5.4748	8.5252	● + ○ - 9.2279	0.0000

N	MD	SE	CI Start	CI End	tTest	P value
87	-3.8900	0.9284	-5.7097	-2.0703	○ + ● - -3.9590	0.0002

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.14 Unmet need – Caldwell et al. (2007)

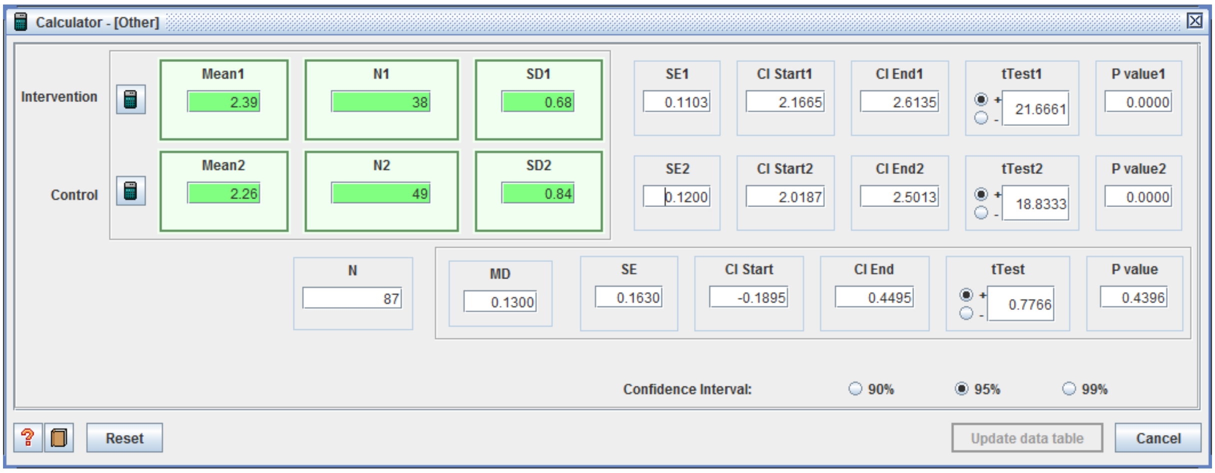


	Mean1	N1	SD1	SE1	CI Start1	CI End1	tTest1	P value1
Intervention	9.18	511	1.57	0.0695	9.0436	9.3164	● + ○ - 132.1763	0.0000
	Mean2	N2	SD2	SE2	CI Start2	CI End2	tTest2	P value2
Control	8.96	584	1.65	0.0683	8.8259	9.0941	● + ○ - 131.2292	0.0000

N	MD	SE	CI Start	CI End	tTest	P value
1095	0.2200	0.0974	0.0291	0.4109	● + ○ - 2.2514	0.0246

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.15 Other – Sense of security – Benjamin et al. (2000)

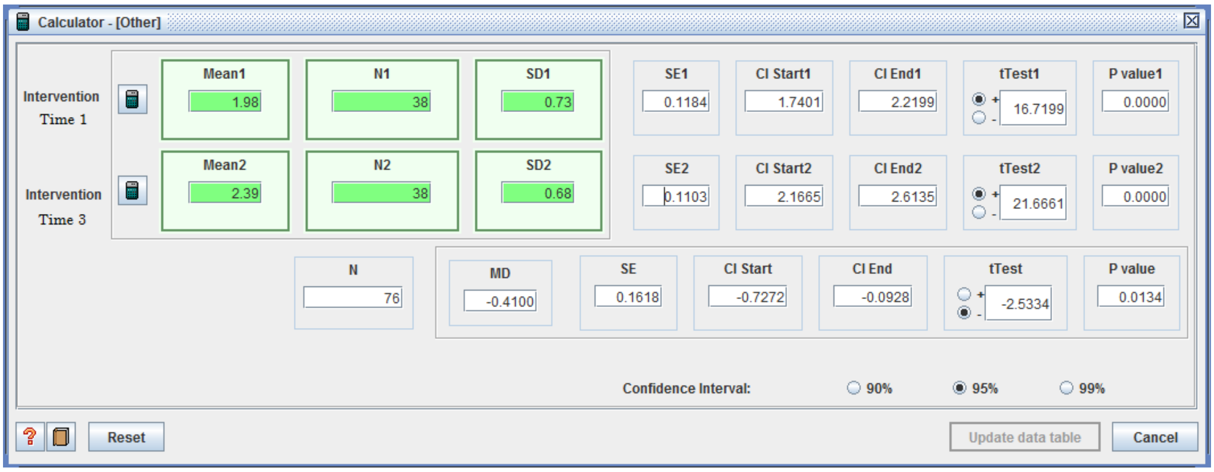


	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	2.39	38	0.68	0.1103	2.1665	2.6135	● + ○ - 21.6661	0.0000
Control	2.26	49	0.84	0.1200	2.0187	2.5013	● + ○ - 18.8333	0.0000

N: 87
MD: 0.1300
SE: 0.1630
CI Start: -0.1895
CI End: 0.4495
tTest: ● + ○ - 0.7766
P value: 0.4396

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.16 Other – Community Participation – I vs C – Caldwell et al. (2007)

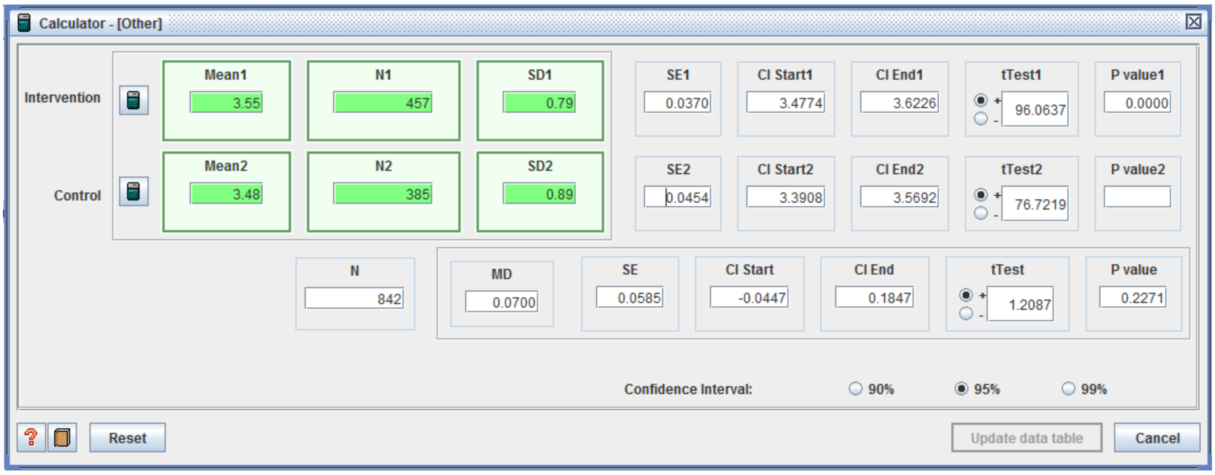


	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention Time 1	1.98	38	0.73	0.1184	1.7401	2.2199	● + ○ - 16.7199	0.0000
Intervention Time 3	2.39	38	0.68	0.1103	2.1665	2.6135	● + ○ - 21.6661	0.0000

N: 76
MD: -0.4100
SE: 0.1618
CI Start: -0.7272
CI End: -0.0928
tTest: ○ + ● - -2.5334
P value: 0.0134

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.17 Other – Community Participation – T1 to T3 – Caldwell et al. (2007)



	Mean	N	SD	SE	CI Start	CI End	tTest	P value
Intervention	3.55	457	0.79	0.0370	3.4774	3.6226	● + ○ - 96.0637	0.0000
Control	3.48	385	0.89	0.0454	3.3908	3.5692	● + ○ - 76.7219	

N: 842
MD: 0.0700
SE: 0.0585
CI Start: -0.0447
CI End: 0.1847
tTest: ● + ○ - 1.2087
P value: 0.2271

Confidence Interval: ○ 90% ● 95% ○ 99%

Figure A2.11.18 Other – ASCOT – Glendinning et al. (2008)

A2.11.2 - QUALITATIVE ANALYSIS

A2.11.2.1 Overarching (Macro) theme 1: Implementation facilitators

Perceived benefit (n = 3,295)

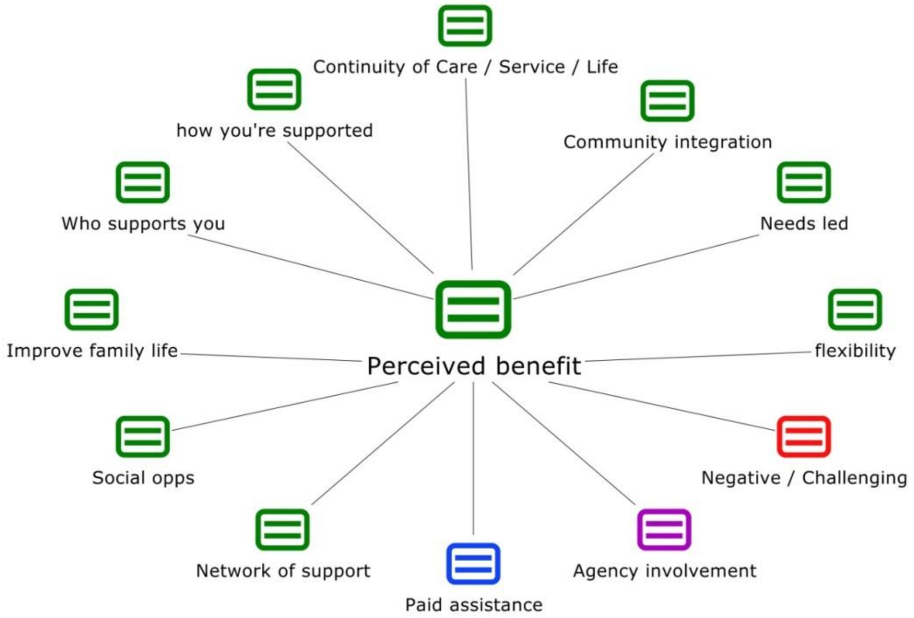


Figure A2.11.19: Codes co-occurring with 'perceived benefits' 50 times or more

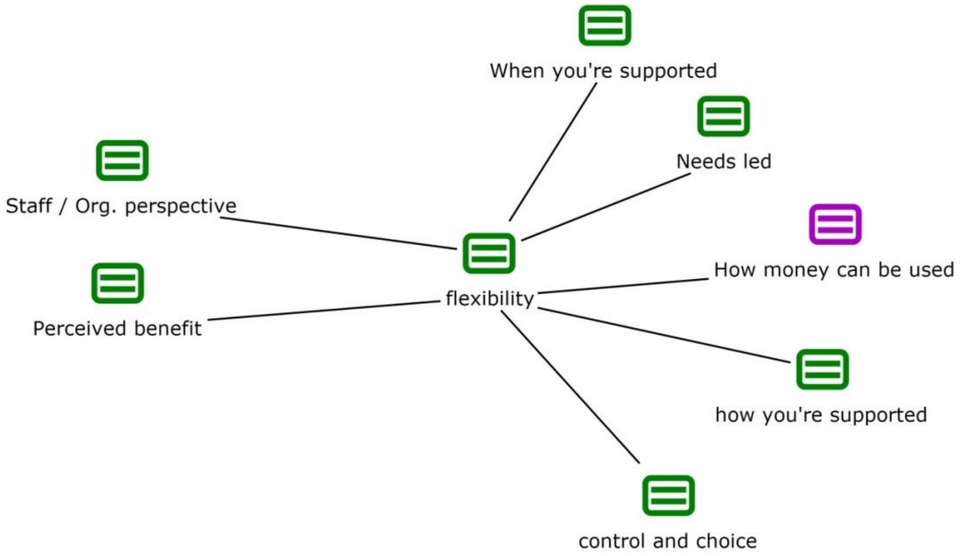


Figure A2.11.20: Codes co-occurring with 'flexibility' 12 times or more

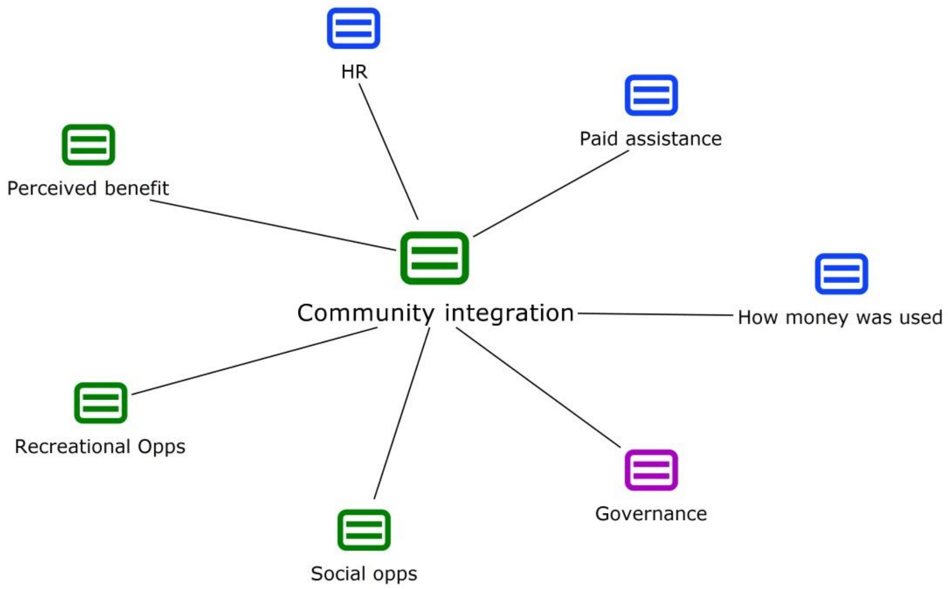


Figure A2.11.21: Codes co-occurring with 'community integration' 10 times or more

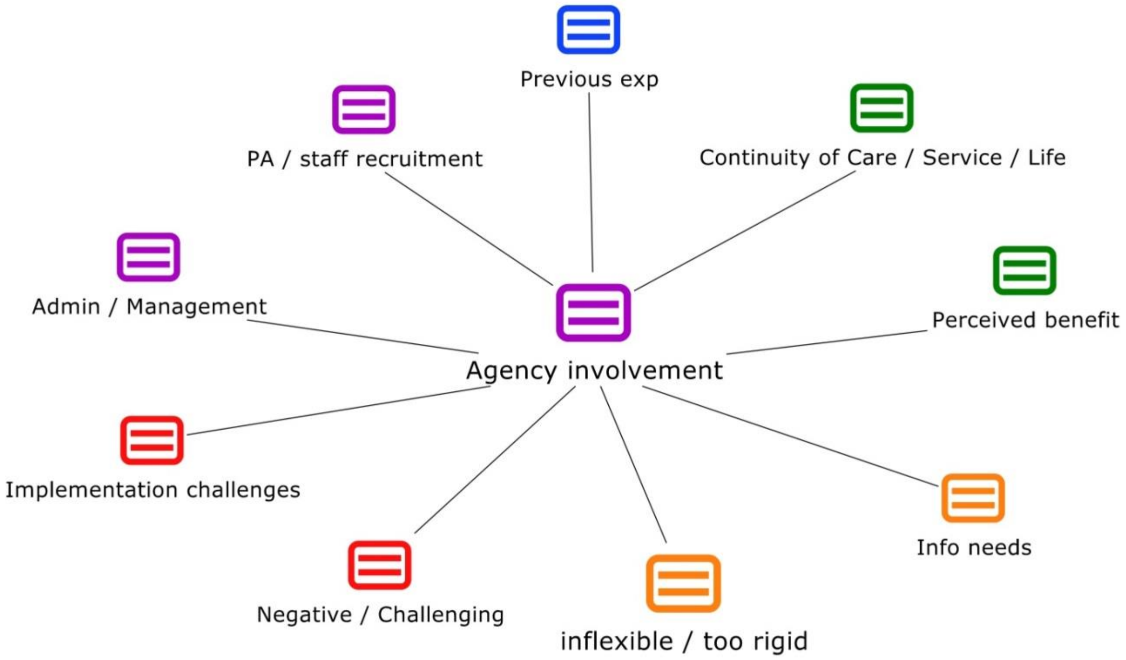


Figure A2.11.22: Codes co-occurring with 'Agency involvement' 15 times of more

Network of support

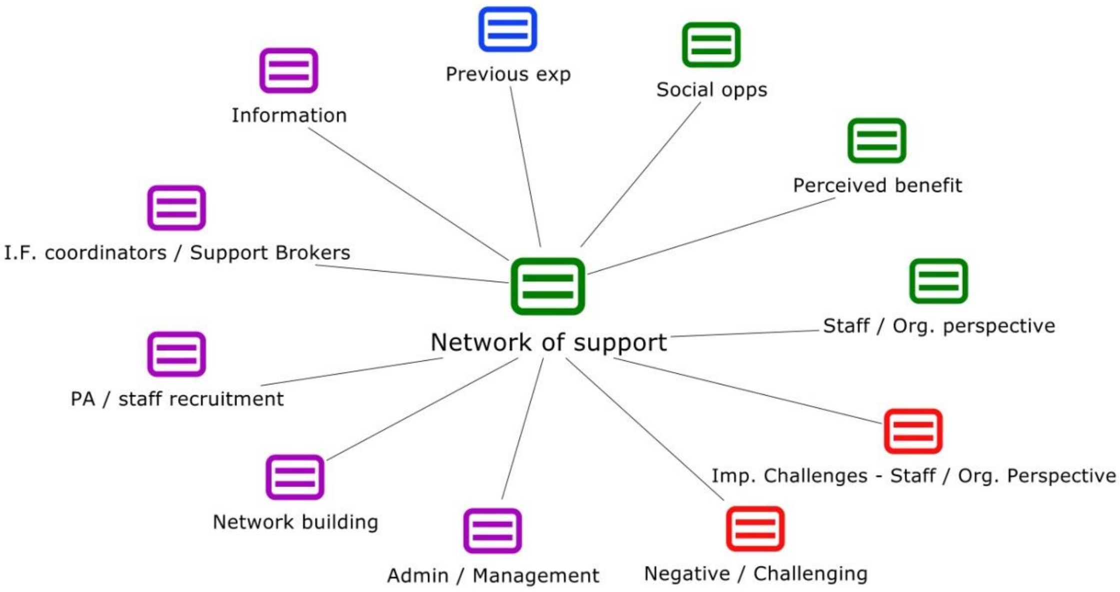


Figure A2.11.23: Codes co-occurring 12 times of more with ‘network of support’

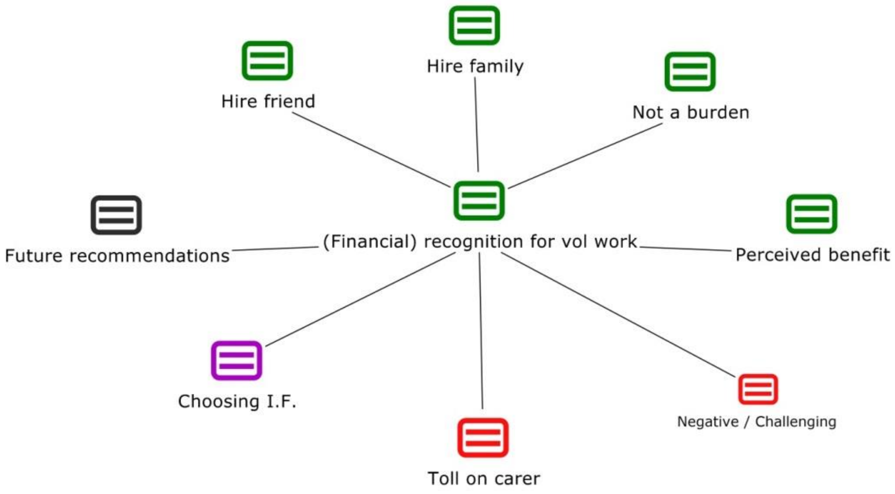


Figure A2.11.24: Codes co-occurring 3 times of more with ‘Financial recognition for voluntary work’

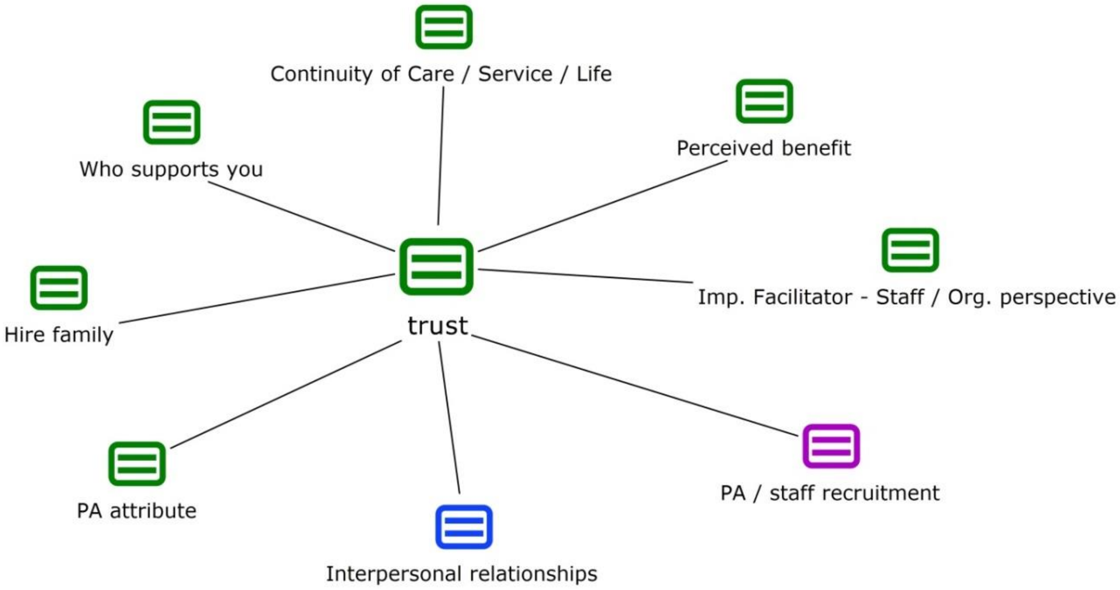


Figure A2.11.25: Codes co-occurring 6 times of more with 'trust'

Implementation facilitators from staff/organisational perspectives (n = 292)

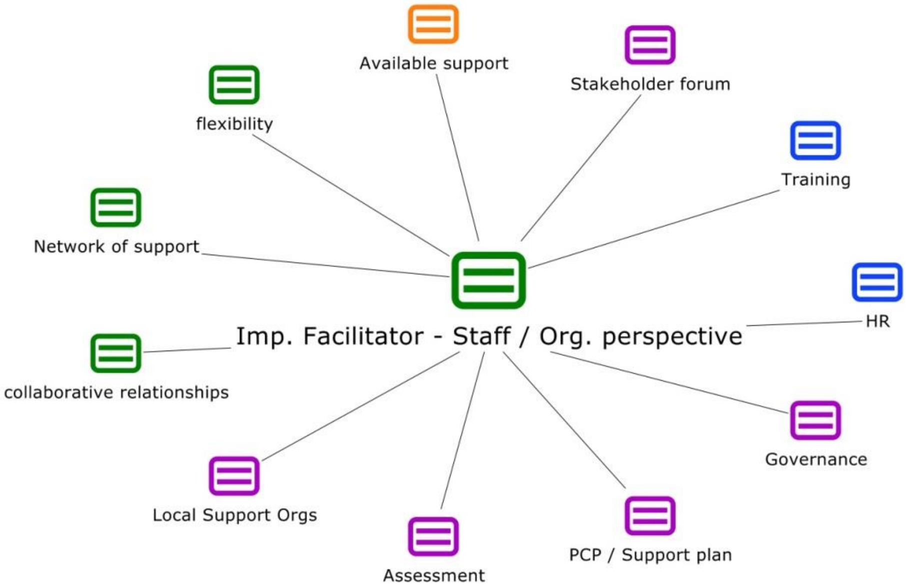


Figure A2.11.26: Codes co-occurring 15 times of more with 'Implementation facilitator – Staff / Organisational Perspective'

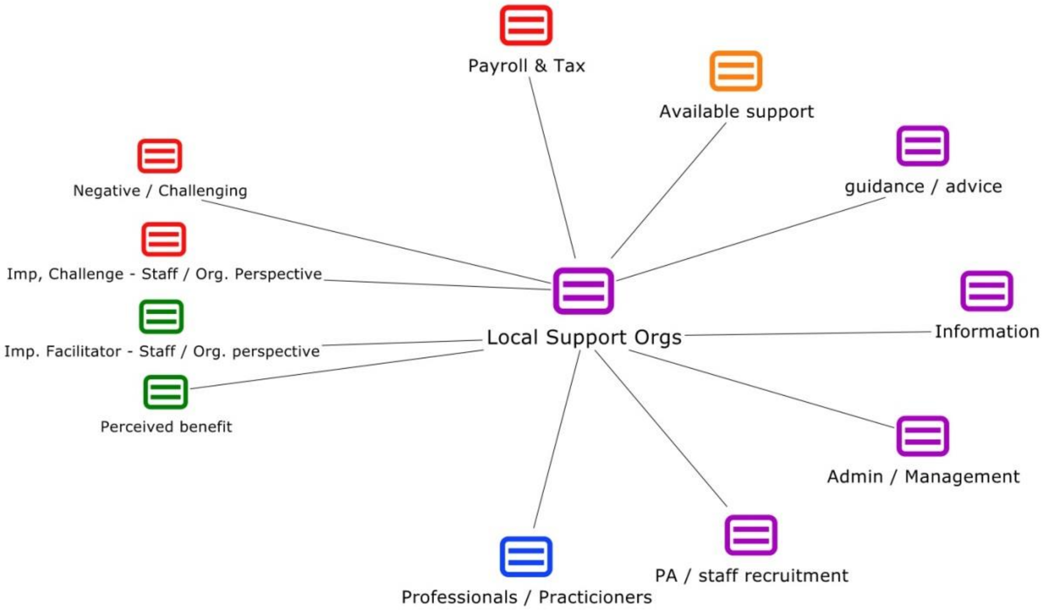


Figure A2.11.27: Codes co-occurring 10 times of more with 'Local support organisations'

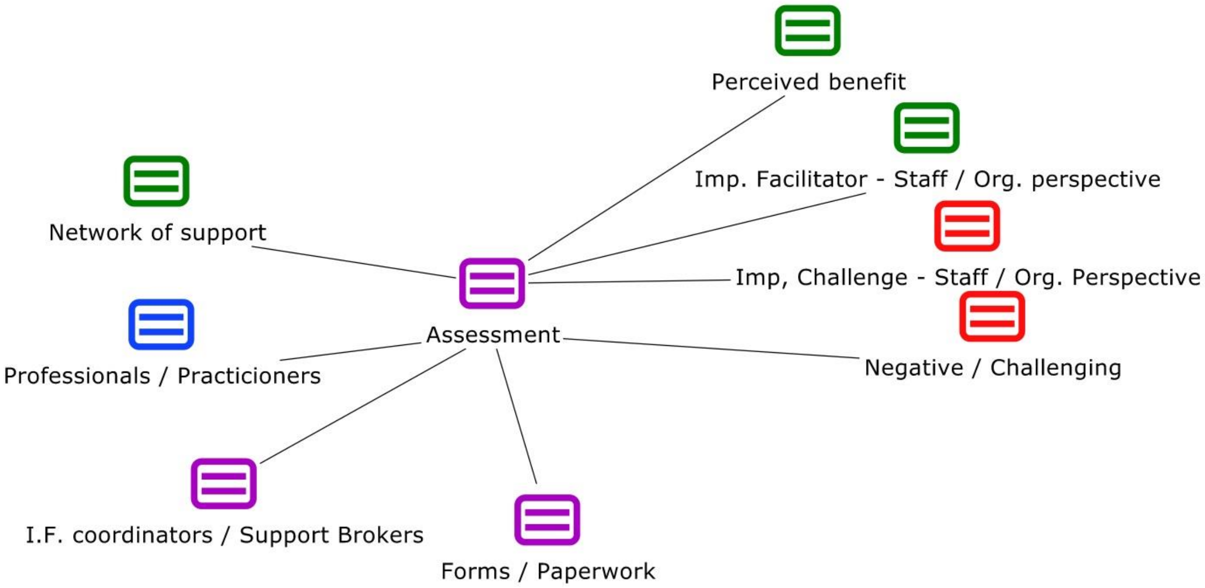


Figure A2.11.28: Codes co-occurring 10 times of more with 'assessment'

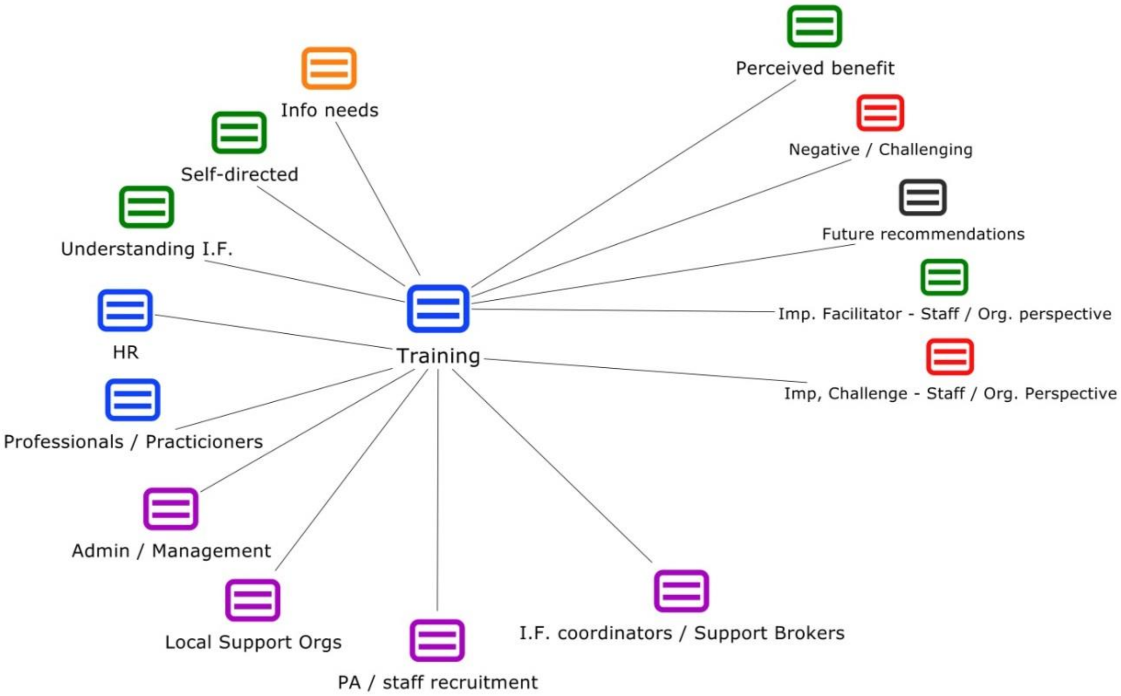


Figure A2.11.29: Codes co-occurRing 8 times of more with 'training'

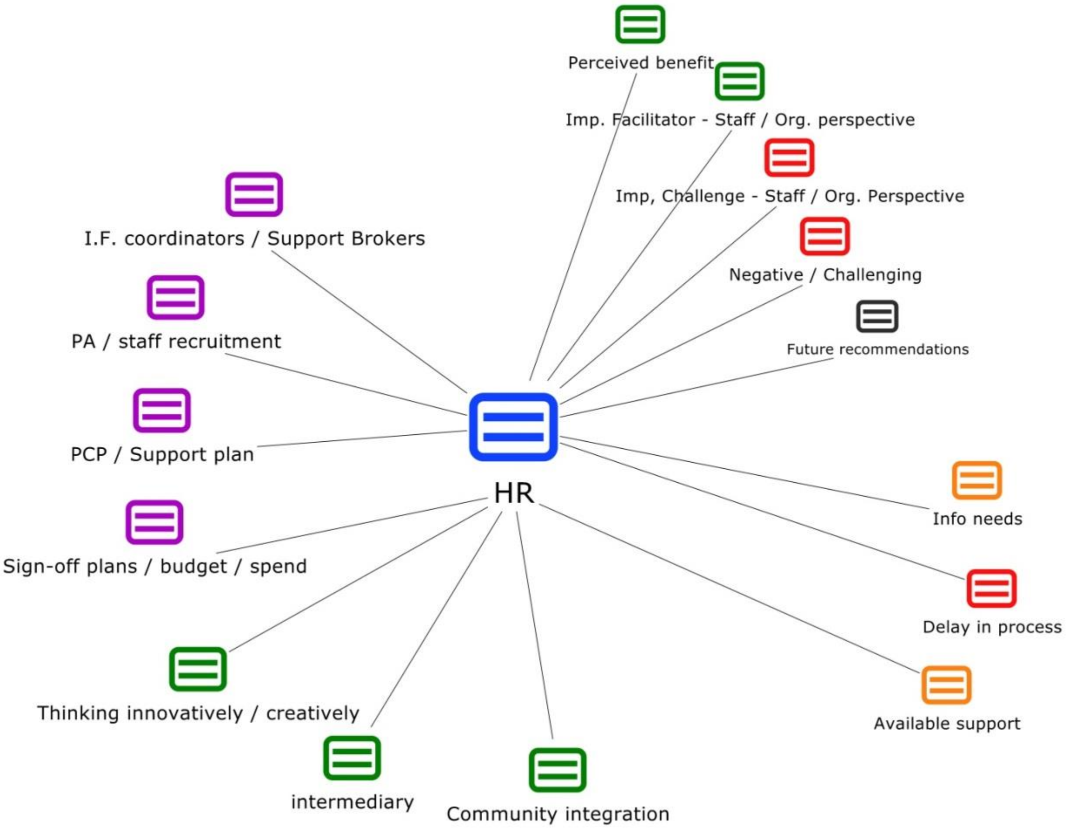


Figure A2.11.30: Codes co-occurring 10 times of more with 'Human resources'

A2.11.2.2 Overarching (Macro) theme 2: Implementation challenges

Perceived Challenges / Negative aspects (n = 2,640)

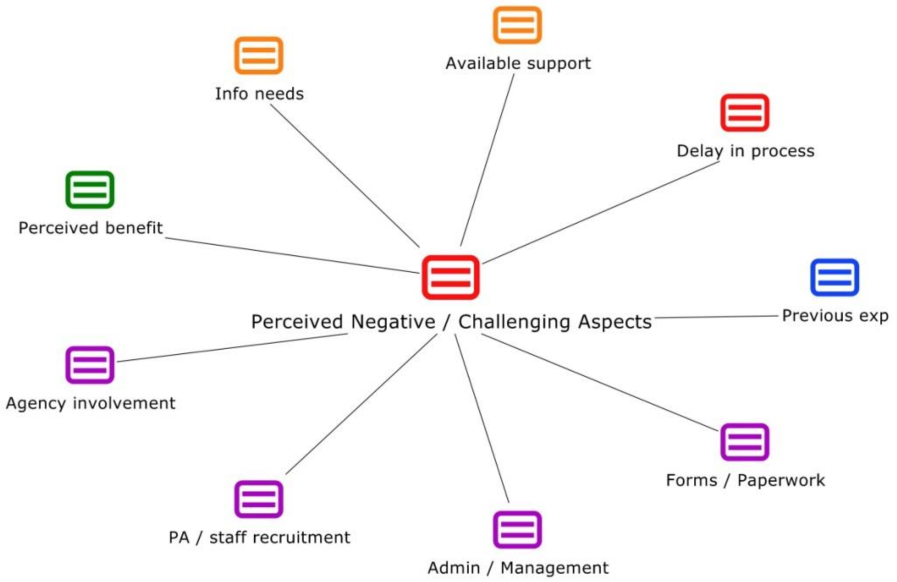


Figure A2.11.31: Codes co-occurring with ‘Perceived negative / challenging aspects’ 60 times of more

Potential problems/Areas for improvement (n = 1,692)

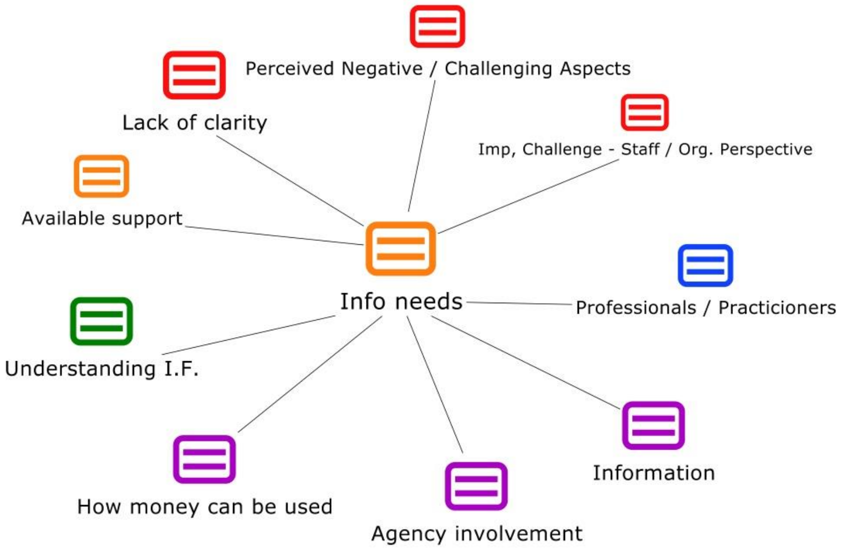


Figure A2.11.32: Codes co-occurring 15 times of more with ‘Information needs’

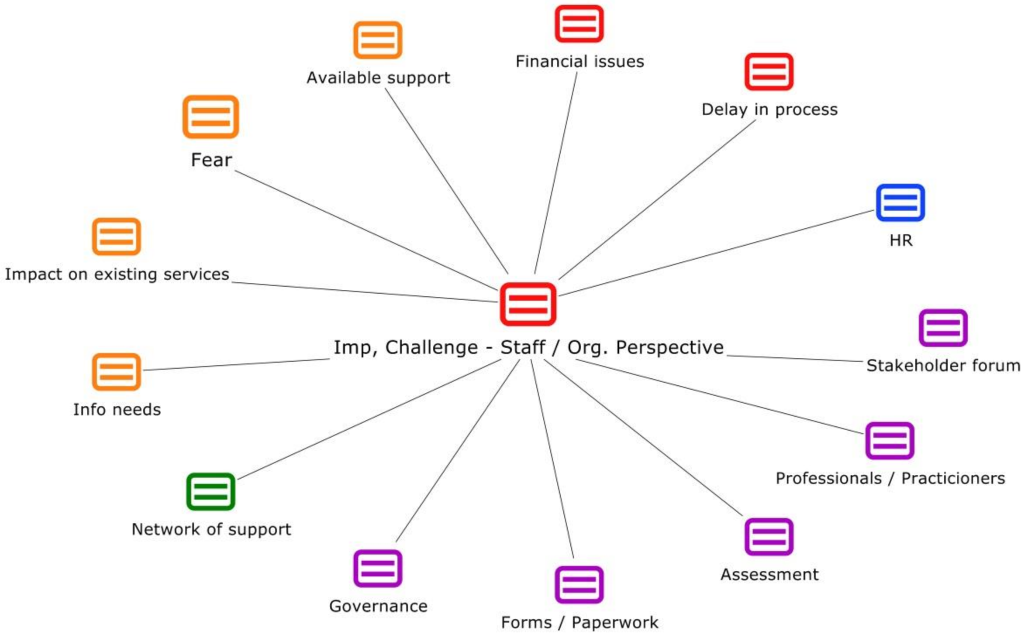


Figure A2.11.33: Codes co-occurring 18 times of more with 'Implementation challenges from perspective of staff / organisational representatives'

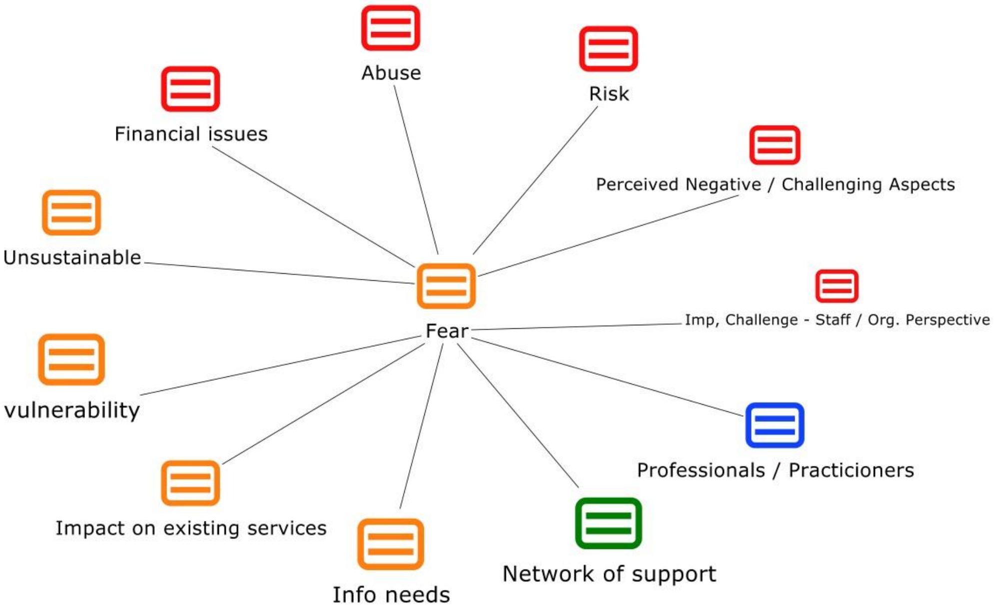


Figure A2.11.34: Codes co-occurring 5 times of more with 'Fear'

APPENDIX 3 –RESEARCH OUTPUTS

A3.1 - PEER REVIEWED PUBLICATIONS

Published

Fleming, P., Furlong, M., McGilloway, S., Keogh, F., Hernon, M., & Stainton, T. (2016). *Protocol: Personal Budgeting Interventions to Improve Health and Social Care Outcomes for People with a Disability: A Systematic Review*. In The Campbell Library, (pp. 73). Retrieved from http://campbellcollaboration.org/lib/project/350/

Fleming, P., McGilloway, S., & Barry, S. (2016a). Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland. *Journal of Applied Research in Intellectual Disabilities, 30*(2), 383–394. doi:10.1111/jar.12249

Fleming, P., McGilloway, S., & Barry, S. (2016b). The successes and challenges of implementing individualised funding and supports for disabled people: an Irish perspective. *Disability & Society, 31*(10), 15. doi:10.1080/09687599.2016.1261692

Under review

Fleming, P., McGilloway, S., Hernon, M., O'Doherty, S. R., Furlong, M., Keogh, F., & Stainton, T. ((2017 - under review)). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. Retrieved from http://campbellcollaboration.org/lib/project/350/

A3.2 - PUBLICATIONS / MEDIA OF PROFESSIONAL INTEREST

Fleming, P. (2016a). *How personal budgets are working in Ireland: Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland*. In G. Trust (Series Ed.), www.genio.ie, (pp. 24). Retrieved from www.genio.ie/personal-budgets

Fleming, P., McGilloway, S., & Barry, S. (2016c). What are 'Personal Budgets' and what have we learned from developments in Ireland? (103). Retrieved from Frontline: The Irish Voice of Intellectual Disability website: http://frontline-ireland.com/personal-budgets-learned-developments-ireland/

Fleming, P. (2016b). Opening Kingdons Policy Window : Translating disability research into practice. *SPHeRE Network*.

Fleming, P., McGilloway, S., & Barry, S. (2015). Individualised funding in Ireland: Identifying and implementing lessons from elsewhere (101). Retrieved from Frontline: The Irish voice for intellectual disability website: http://frontline-ireland.com/individualised-funding-in-ireland-identifying-and-implementing-lessons-from-elsewhere/

B. Salisbury (Producer). (2015). *Research Findings on Four Individualized Funding Projects in Ireland* [Retrieved from https://www.youtube.com/watch?v=dVoaDckHAQY

Fleming, P. (2017). Policy Brief: Individualised funding for people with a disability: The SPHeRE Network.

Fleming, P., McGilloway, S., Keogh, F., Barry, S., & Healy, J. (2017 (Draft)). *Supporting Policy Implementation for Personalised Budgets in Ireland*. Psychology. Maynooth University.

Fleming, P., & McGilloway, S. (2017 (Draft)). *Identifying and tackling challenges in undertaking mixed-methods systematic reviews: an exemplar from the field of disability* Psychology. Maynooth University.

A3.3 - NATIONAL AND INTERNATIONAL CONFERENCES

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S. R., Keogh, F., & Stainton, T. (2018, 11th January). A mixed-method systematic review examining the effect of Individualised Funding interventions on health and social care outcomes for people with a disability. Paper presented at the SPHERE Network, 4th Annual Conference - The Value of Patient and Public Involvement in Research, Healthcare and Health Planning, Royal College of Surgeons in Ireland, Dublin.

Fleming, P., McGilloway, S., & Barry, S. (2017). *Past, Present and Future: Mapping day-service provision for people with intellectual disabilities over 15 years*. Paper presented at the SPHERE Network, 3rd Annual Conference: Supporting Solutions: Connecting Research, Policy & Practice, Royal College of Surgeons, Dublin, Ireland

Fleming, P. (2017). *The benefits of personal budgets, experiences from the disability sector*. Paper presented at the IGS Symposium: Exploring the establishment of a statutory homecare scheme in Ireland.

Fleming, P., McGilloway, S., & Barry, S. (2016d). *Individualised funding for people with a disability in Ireland: the successes and challenges of implementing four pilot initiatives*. Paper presented at the SPHeRE Network 2nd Annual Conference - "Population health and health services research in Ireland: current trends and future directions" Royal College of Surgeons, Dublin, Ireland.

Fleming, P., McGilloway, S., & Barry, S. (2016e). *Mapping 15-year trends of day service provision for people with intellectual disabilities in Ireland – is policy-driven individualisation a reality yet?* Paper presented at the *17th Healthcare Interdisciplinary Research Conference - Contemplating the Past, Present and Future*, School of Nursing and Midwifery, Trinity College Dublin, Ireland.

Fleming, P. (2016c). *Demystifying personal budgets*. Paper presented at the Inclusion Ireland & Down Syndrome Ireland Seminar: Towards the government's taskforce on personal budgets, Gibson Hotel, Point Village, Dublin, Ireland. http://www.inclusionireland.ie/content/news-items/1504/inclusion-ireland-and-down-syndrome-ireland-host-successful-personal-budgets

Fleming, P. (2016d, 26 – 28 September). *Undertaking a mixed-methods systematic review: navigating a complex intervention with broad inclusion criteria and internationally diverse terminology.* Paper presented at the What Works Global Summit, London.

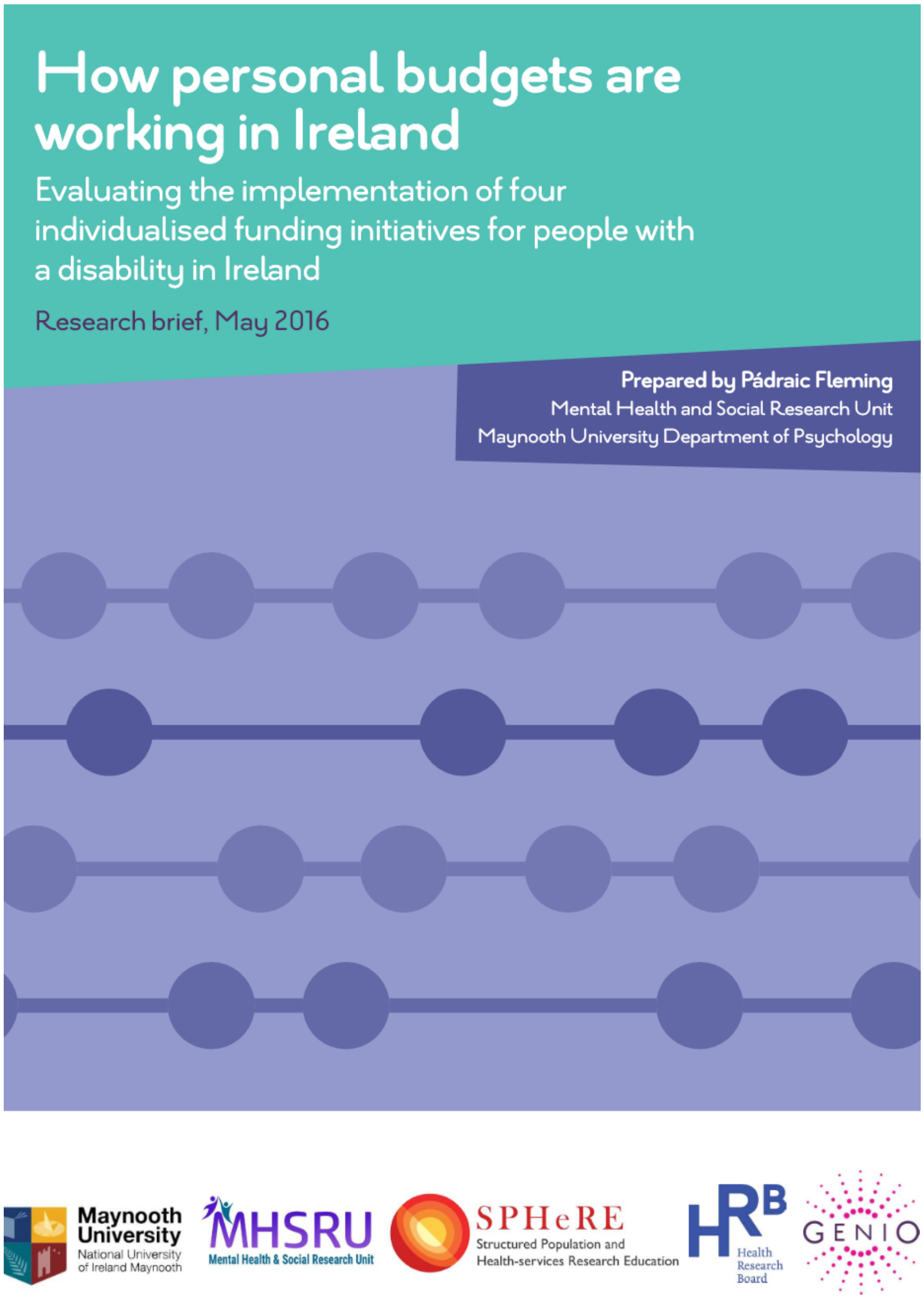
Fleming, P. (2015). Participatory research evaluating individualised funding for people with a disability. *SPHeRE Network, 2*.

Fleming, P., McGilloway, S., & Barry, S. (2015a). *An Evaluation of the Development and Implementation of Personal Budgets for People with a Disability in Ireland*. Paper presented at the 12th Annual Psychology, Health and Medicine Conference - Improving health and well-being: Better futures for all, Stranmillis University, Belfast.

Fleming, P., McGilloway, S., & Barry, S. (2015b). *Individualized Funding: The Experiences, Barriers and Facilitators Associated with Implementing Four Pilot Initiatives in Ireland*. Paper presented at the Claiming Full Citizenship: Self Determination, Personalization, Individualized funding. 2015 International Conference, The Hyatt Regency, Vancouver, Canada. http://interprofessional.ubc.ca/ClaimingFullCitizenship2015

APPENDIX 3.4 - HOW PERSONAL BUDGETS ARE WORKING IN IRELAND

This is the published manuscript of a research brief published by the Genio Trust on 01/05/2016, available online from https://www.genio.ie/our-impact/research-evidence/personal-budgets-ireland



How personal budgets are working in Ireland

Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland

Research brief, May 2016

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Contents

Research Briefing

Focus of this research brief

This document is aimed at anyone who is interested in the practicalities, successes and challenges of implementing individualised funding initiatives in Ireland. Those who may be interested include:

- People living with a disability.
- Those providing informal supports for people with a disability, such as family members, friends, members of the wider community.
- Personal assistants / key workers and other paid support for individuals with a disability.
- Staff members currently implementing individualised funding initiatives.
- Service providers considering moving to an individualised funding model or incorporating an individualised funding arm into their current service model.
- Researchers.
- Funders.
- Policy makers/drivers such as civil servants and elected members of government.
- The Health Service Executive (HSE) and other health service staff.

There were four organisations involved in this evaluation. The briefing document will present a summary of the main lessons learned according to the key people involved in these four individualised funding initiatives, including individuals with a disability who participated in the initiatives, family members, paid and unpaid advocates; and staff members from within the four organisations.

A number of recommendations will be made at the end of the briefing document. These are based on the key lessons presented and are intended to inform, challenge and promote discussion among the readership.

Introduction: Individualised funding

Individualised funding is an umbrella term for various different funding mechanisms that aim to provide personalised and individualised support services for people with a disability. Many other descriptors which vary across contexts are captured within the umbrella term of 'individualised funding' (see Table 1). Indeed, new terms continue to emerge, as organisations attempt to implement this relatively new model, each striving to meet the individual needs of people with a disability.

While the terminology around individualised funding differs, the principles are consistent, based on self-determination, choice, control and, very often, person-centred planning. The initiatives generally aim to place the person with a disability at the centre of the decision making process, with a view to recognising people's strengths, preferences and aspirations. This can empower people to shape public services, including health and social care, by allowing those in receipt of such services to identify their needs, and to make choices about how and when they are supported (Fleming, Furlong, et al., 2016).

Historical context

The disability sector is complex with considerable variation internationally in terms of progress and models of service delivery, and is often deeply influenced by policy and practices from the past. Historically in Ireland, as in many other countries, family- and advocate-led organisations became the driving force for change, eventually forming voluntary organisations and semi-autonomous non-governmental-organisations (NGOs), funded largely by the Government. These became the main provider of vocational training, sheltered work and other activities for people with a disability, and continue to deliver services within geographical designated areas to this day.

During the 1960s, the medicalised model of service provision became increasingly 'specialised' with professionals recommending the necessary services to address the health care needs of people with a disability. However, in more recent years, a shift in international policy began to move the disability sector towards an individualised and person-centred model, drawing on a more holistic view of what is required to live a fulfilled and healthy life, including personal and social care needs. In Ireland, a number of policy documents based on international best practice have been developed (Department of Health, 2012; Health Service Executive, 2011, 2012). Most recently, the "Value for Money and Policy Review of Disability Services in Ireland" (2012) – currently used as the benchmark for achieving disability sector improvements - recommends, amongst other things, the provision of 'supports' rather than 'services', using person-centred plans, individualised supports and personal budgets to bring Ireland in line with the global changes within the disability sector (Fleming, McGilloway, & Barry, 2016).

Table 1 - Terminology used to describe individualised funding

Country	Terms used	Source of money	Support / Care mechanism
U.S.A	➲ Self-Determination programs ➲ Cash and Counseling ➲ Consumer Directed Care / Support	Medicaid waivers at State level	➲ Independent consultant ➲ Fiscal intermediary services
U.K.	Direct Payments	Local Authority	Personal assistant
	Individual Budget	Local Authority	Package of care from multiple sources
	Block funding from the Social Care budget	Social Care budget	Residential costs and associated care costs
	Independent Living Fund	Department for Social Security	Care from agency OR personal assistant
	Other terms used: ➲ Recovery Budget ➲ Personal Budget ➲ Personal Health Budget ➲ Microboard	*Other funding sources:* ➲ Supporting People fund ➲ Access to work funding ➲ Disabled Facilities Grants	
Netherlands	Person-centred budget	Dutch Welfare State	Package of self-determined care. Assisted by employed care worker (Often Informal (family) carers).
Ireland (Presented in this report)	Independent Support Broker / Brokerage	➲ Innovation funding for pilot ➲ Ongoing funding from HSE	Package of care from multiple sources / residential costs
	Direct payments	➲ Innovation funding for pilot ➲ Ongoing funding from HSE	Package of care from multiple sources / residential costs
	Self-management model	Innovation funding for pilot	Community Connector

Country	Terms used	Source of money	Support / Care mechanism
Canada	Direct Payment / Direct Funding	Community Living British Columbia (CLBC)	Supports and services for the individual as agreed to by the individual, agent and CLBC facilitators and CLBC analysts
	Host Agency Funding	Community Living British Columbia	
	Other terms used: ➲ Self-managed care ➲ Individualised funding program ➲ Support for Interdependent living		
Australia	➲ Microboard ➲ Self-directed funding ➲ Consumer-directed care ➲ Local Area Co-ordination Program ➲ Shared management model ➲ Self-management (direct payments)		
Other terms used internationally	Indicative allocation, Individual service fund, Managed account, Managed budget, Notional budget, Personalised care, Pooled budget, Self-directed care, Self-directed support, Virtual budget, Cash-for-care.		

Data sourced from: (Carter Anand et al., 2012; Fleming, McGilloway, & Barry, 2015b; Power, 2010; Webber, Treacy, Carr, Clark, & Parker, 2014)

Research Briefing

Overview of four Irish initiatives

In response to these policy recommendations, Genio provided innovation funding for organisations to pilot individualised funding initiatives in four locations throughout Ireland. These initiatives, which may be categorised in different ways, are described below:

Model	Population	Funding Mechanism	Supports	Status
Direct Payment Provided to people with different disabilities (& their families) in Ireland to enable people to purchase their own services, mainly Personal Assistance. Run by the ÁT Network, Dublin.	Mainly people with physical disabilities but also includes people with other disabilities. 20 members at time of evaluation.	Individual sets up own company whereby they manage finances, hire necessary staff & purchase services directly from providers..	**1. Staff** ➲ Act as Intermediary between individual & HSE. ➲ Support person to use Direct Payment including: o Resources. o Training. o Research & Innovation. o Communication / Events **2. Circle of Support**	Exited pilot stage & is receiving HSE funds on person by person basis. National expansion underway.
Direct Payment using Broker Provided support to young adults with disabilities to arrange & access services, to meet their training needs in a community setting. This is a pilot called 'Bridging the Gap', run within a HSE service in Donegal.	People with physical, intellectual & developmental disabilities. 11 individuals participated in the pilot.	Direct payment was held centrally & managed on behalf of participant using pre-existing systems. The broker & client developed a PCP (person-centred plan), identified & costed various elements of plan.	**1. Broker** ➲ Negotiated price of services ➲ Liaised with organisational staff & review group. **2. Governing / Monitoring** ➲ Facilitated meetings ➲ Developed admin forms ➲ Financial review Group o reviewed PCP o approved expenditure o monitored progress	No mechanism was available to unbundle existing funding when innovation funding ended. On hold until funding mechanism is put in place.

Model	Population	Funding Mechanism	Supports	Status
Independent Support Broker Supporting people with disabilities to live self-directed lives by negotiating with HSE to release funds usually allocated to traditional service providers for use as personal budget. This is called PossibilitiesPlus, run from within a service provider organisation in County Kildare.	People with physical, intellectual & developmental disabilities. 9 individuals participating in pilot at time of evaluation.	Finances & human resources were managed centrally by the 'brokerage service' - utilising pre-existing systems within the organisations traditional service arm. All other mechanisms were separate. Cash provided to individuals for daily expenses.	**1. Staff** ➲ Intermediary between individual / their family & HSE to determine: how much money allocated; is it adequate to meet needs; & is it available to use as personal budget. ➲ Get to know the individual & their support structure - formalise or develop circle of (informal) supports. ➲ Recruit support worker to work with individual **2. Encourage Circle of Support to:** Think creatively, network & try out new experiences.	Exited pilot stage & is receiving HSE funds on a person by person basis. HSE has commenced referring individuals to the service.
Self-management model where individuals planned & managed their training, work, education & recreational activities with the help of a 'Community Connector'. This is a pilot called ConnectAbility, run from within the National Learning Network in Kerry.	Young adults (18 – 25) with intellectual / developmental disabilities or mental health problems. 5 individuals	Finances were held centrally & managed by the organisations pre-existing systems. However individuals, with help from the community connector, decided how & where the money was spent.	**Community Connector** ➲ Assisted individuals to design their own program, choosing activities & providers that met their needs best ➲ Community based training activities were identified to help individuals manage community participation e.g. money management skills, driving lessons.	No mechanism was available to unbundle existing funding when innovation funding ended. Project ended.

Study aims and objectives

The principal aim of this research evaluation was to identify and explore the successes and challenges of implementing individualised funding initiatives within an Irish context.

Methods

Four organisations were involved in the evaluation. Those who participated in the research included: people with a physical, intellectual or developmental disability; their family members and other advocates; and staff from the four organisations. In total there were twenty people with a disability, twelve family members/advocates and twelve staff involved. International literature and organisational documents were initially examined. These helped the researcher develop a set of questions to ask research participants during in-depth interviews. All interviews were analysed together to identify common themes that emerged within the four pilots. Further detail on the methods can be seen in the flowchart below:

Study approval

- Study proposal submitted to academic panel for approval

Ethics

- Ethical approval received from the Social Research Ethics Subcommittee in Maynooth University (Reference: SRESC-2014-059)
- Researcher Garda vetted ahead of any data collection

Consent

- All four organisations consented to participate. Staff invited individuals from three initiatives to participate. Most of these individuals gave consent for the researcher to contact them directly. For one initiative staff were invited to participate while secondary data* was used for participants.
- A second stage of consent was undertaken prior to interviews. At this stage all the relevant information (provided in writing previously) was revisited and explained.

Document Analysis

- Important documents that were used in the development and implementation of the projects were provided to the researcher by staff. These documents provided insight and helped the researcher to determine important questions to ask project participants.

Interviews

- The researcher travelled to meet staff and project participants. Interviews lasted on average 70 minutes and were recorded and later transcribed. Secondary data for a small number of participants was also transcribed.
- Number of study participants: 12 staff - 20 project participants - 12 advocates

Analysis

- Each line of every interview was read and coded.
- These codes were categorised into themes that were reoccurring. This is known as thematic analysis. A computer analysis software (MAXQDA) was used to assist this process. 200 codes in total were created. This consisted of 5,554 segments of text.

Themes

- 6 main themes were identified. These were: Stakeholders; Process; Impact; Systems; Organisational; and Community. The remaining codes (200) were subcatergorised under these main headings
- There were 5 levels of detail, going from: Level 1 - Broad catergory to Level 5 - Detailed information

*Note: Secondary data consisted of video files publicly available on the internet, in which participants were discussing their experiences of the individualised funding scheme in question.

Findings

The evaluation was primarily interested in the successes and challenges of implementing individualised funding initiatives within the Irish context. As a result the facilitators of successful implementation and the barriers to successful implementation will be presented below under the 6 main themes identified in the evaluation.

1. The role of stakeholders

One of the main influences on the implementation of individualised funding was the nature of the stakeholders involved. The key stakeholders identified in the evaluation were:

- People with a disability – physical, intellectual, developmental or related to mental health.
- Advocates
  - Natural supports – extended family, partners, friends, neighbours, work colleagues, and members of wider community.
  - Paid supports – Personal assistants, key workers, independent support broker, mentor, allied health professionals, administrative & other organisational staff, educators, disability managers within HSE, service providers.

Facilitators of successful implementation

The availability of a 'circle' of natural supports provided significant benefits for participants in terms of helping them learn to actively engage with the community, especially when learning new social, decision-making and independent living skills. Where no circle of support existed, formal supports (e.g. organisational staff, broker, key worker or mentor) worked hard to identify and engage with potential advocates. Supporters who worked best within this new and evolving environment were described as practical, amenable, friendly and encouraging in their approach. Other personal attributes that were important included having: vision; innovation; personal experience of disability; a willingness to challenge stakeholders and an active role in the community. Essential for all stakeholders was an appreciation of an individual's abilities, passions and interests.

Barriers to successful implementation

While family members and other paid and unpaid supports were integral to successful implementation, there were certain behaviours/attributes which limited the extent of these successes. These included: treating the individual with a disability as a child rather than an adult; assuming an incapacity to undertake certain tasks based on past experience, or the disabling effects of the traditional paternalistic model of service provision; doing simple and more complex tasks on behalf of the individual; and being over-protective due to previous negative experiences or fears/anxiety associated with the unknown. These appeared to be due, at least in part, to damaged relationships with traditional service providers and health professionals as a result of previous hardships / negative experiences.

2. Process-related factors

The process of developing a personal budgeting initiative began with the host organisations (three pre-existing, traditional service providers & one voluntary group of individuals with a disability) intensively researching international experiences of implementing individualised funding initiatives. In some cases, this involved visiting programmes in the UK and the US. Such site visits were particularly useful due to the absence of any individualised funding initiatives in Ireland previously. The next step was to recruit and, in some cases, train independent support brokers / community connectors, after which the recruitment of participants began. This varied across all four initiatives but involved either informal word-of-mouth or formal HSE referrals via the host organisation. For one of the organisations, the first participants became the future directors/board members of the individualised funding initiative. There were achievements in terms of accessing HSE funds, with the amount of money provided usually based on the cost of traditional day or residential services.

Facilitators of successful implementation

Essential to the process was giving 'a voice' to the individual with a disability, listening to them and acting upon their wishes. For many individuals who had previously participated in a very structured and prescriptive support environment, decision-making did not come easily. Therefore, considerable time was required to get to know the individual (this is applicable for close relatives also who needed to re-evaluate what they thought they knew about their relative with a disability). This involved identifying the best means of enabling that individual to express their preferences. It was also considered very important to have an organic and informal process, with a flexibility to change and adapt to the individuals' new and emerging independent life.

The process also benefited from being needs-led and innovative, harnessing community spirit. For example, the hosting of participatory meetings with the new and growing circle of support worked well in terms of: involving the person with a disability; exploring their preferences; identifying activities within the community; and actively involving the support network in the persons' life plan and goal aspirations. During the early stages of implementation, it was also useful to have formal supports (support brokers/community connectors) more actively involved and leading these meetings if necessary. Over time, this leadership role and responsibilities were transferred to the individual with a disability and their new support network. Lastly, it was considered important to have the role of formal paid supports clearly outlined from the beginning so that a trusting and sustainable relationship could be developed whilst the provision of an easy and equitable access route to individualised funding was also critically important, with access routes being developed and formalised during the pilot initiatives.

Barriers to successful implementation

One of the most challenging aspects of implementation for all four initiatives was access to funding. With no national resource allocation system in place, each individual case was different and required a very time consuming and often very difficult process to get funds released from the block grants of service providers or directly from the HSE. Two initiatives never managed to get funds reconfigured by the HSE so that they could be used on an ongoing basis after the pilot. As an alternative, they used pre-existing staff and systems to support and resource implementation, while the Genio innovation funding was used to provide the actual individual budgets for the duration of the pilot.

For the other (more sustainable) initiatives, meetings were held between the HSE disability manager, support staff, family members, and in some cases the individual with a disability. In many cases, the individual funds, as allocated from the HSE, were tied up in another day or residential service provider, even if the individual no longer attended those services. This challenging and overly burdensome process had the potential to lead to burnout for the individual, their family and support services. Participants reported that the time and energy invested by advocates in negotiating the release of funds could have been better spent in overcoming other person-specific issues related to the supports they needed to live a full life, such as identifying activities / pursuits, educational or job opportunities.

The lack of a national resource allocation system also meant that the route to accessing individualised funding was not clear. In other words, many people did not know that the option existed. If they did know about the pilot initiatives, there was no application process or apparent eligibility criteria. The initial recruitment of individuals in two initiatives was informal in nature whilst a HSE referral or a mix of informal and formal recruitment was utilised by the other two initiatives. The lack of transparency was flagged by participating individuals as being unequal and inequitable. However, the pilot initiatives made good progress over time in addressing these kinds of teething difficulties and in developing and formalising this process by: generating informational materials (text and video); hosting public information events; and creating websites that included eligibility criteria, contact information and an application form in one case.

3. Impact

Individualised funding initiatives aim to improve the lives of people with a disability by giving them more control and choice over what they do with their lives and how they are supported. Ultimately, the goal is to move toward a self-determined life. With that in mind, the pilot initiatives were reported to have had many positive impacts on the lives of the individuals with a disability and their support network. There were also challenges identified and the research findings shed light on potential ways to successfully manage those challenges. As a result of the individualised funding and associated activities, individuals described themselves as more **successful – confident – adaptive – skilled - empowered - independent - in control** – and with a **greater sense of purpose**. However, without the appropriate support mechanisms and social and interpersonal skills in place, there was the potential for individuals to become overwhelmed with their new life circumstances. A fear of isolation for these participants was also in evidence, having left many life-long friends behind in the traditional centre-based services. This fear, among other things, occasionally led to anxiety, lack of trust, defensiveness and a defeatist, apathetic mentality whereby the person focussed on their disability rather than their abilities. However, it should be noted that this was the exception rather than the rule, but still a potential risk to highlight, should these initiatives be rolled-out into the future.

Facilitators of successful implementation

It was acknowledged by all of the initiatives involved that undertaking a journey of discovery alongside the individual with a disability was an excellent starting point. If following a certain 'discovery' model, it was important to have the flexibility to change direction, turn back, skip a section, take a break or restart the journey if necessary. The initiatives utilised, and in some cases developed, various tools to facilitate this journey of discovery. For example, the Social Role Valorisation model was one such approach which helped to take people out of the devalued roles they previously occupied and put the steps in place for a more valued social position (Blakely & Dziadosz, 2015). Here, a number of factors were important in improving people's outcomes. These included: providing opportunities to develop independent life skills, social and community supports and engagement with new opportunities and experiences. Appendix one (p.20) outlines how pilot participants decided to spend their allocated funds to achieve these outcomes. The associated benefits were often unexpected and substantial. The available evidence indicated further that changes in the 'mind-set' of paid support and natural supports - to focus on ability rather than disability - had enabled people with a disability to trust their instincts, to voice their preferences / concerns and to challenge the status quo.

Barriers to successful implementation

An important observation during this research was that people with a disability (particularly an intellectual or developmental disability) have a tendency to want to please, which often translates to doing what they think others want them to do. However, a potential for less positive or negative outcomes arose if this tendency went unchecked or worse still, if it was enabled. A further barrier arose in relation to informal supports who had over-protective or paternalistic relationships with the individual. For example, where an individual had made progress in terms of developing independent travel skills, the opportunity to practise these new life skills was avoided due to anxiety and fears on behalf of family members. Indeed, such risk adverse behaviour was recognised among family members themselves during the research. This was not helped by future uncertainty in terms of whether individualised funding coupled with a fair and equitable resource allocation system, would be rolled out nationally.

4. Systems-related factors

The four organisations implementing individualised funding also developed, tested, revised and rolled out operational systems. Some worked within the constraints of pre-existing organisational processes and procedures, whilst another was given 'a blank canvas'. These new systems were deemed acceptable by participants and their advocates, thereby representing an improvement on traditional services. The systems put in place aimed to formalise processes around: 'de-bundling' money from the 'block grant' within the HSE; getting funds released from other service providers no longer providing services; governance; allocation of funds to individuals; reporting to HSE; training and mentoring for individuals and their support network; recruitment of clients; recruiting and training staff; monitoring progress; health and safety checks; and administrative / legal / accounting support for those managing their own business. Similarities across initiatives were most evident around the mechanisms used to engage and develop informal support networks.

Facilitators of successful implementation

With perceived improvements across a range of personal, health and social care domains, the new systems were championed by many individuals with a disability and their family members/informal supports. Staff working within the four organisations had long standing relationships with HSE senior staff members and local disability offices. This created a sense of trust and assurance for HSE staff who were otherwise cautious about releasing funds to individuals. Governance issues were of less concern due to the presence of an 'intermediary body', in this case the organisations piloting the individualised funding initiatives. These pre-existing relationships led to successes around the 'de-bundling of money' and subsequent flexibility around the allocation and use of funds. The strong and transparent reporting systems also helped to reassure HSE officials.

Barriers to successful implementation

While there was considerable flexibility provided to individuals engaging with the individualised funding initiatives, there were also potential barriers to success when it came to systems. The most striking was the anxiety and uncertainty due to the lack of a national resource allocation system. The need to consult with HSE officials on a person-by-person basis caused unnecessary burden for both organisational staff and individuals seeking to release funds. Against a reported backdrop of constantly having to 'fight the system' (for families and individuals), this overly complex system posed a real risk of demotivation, disengagement and burn-out. Alternative systems of money allocation and monitoring of spending led to considerable administrative burden for individual support networks. This was an important deterrent particularly for individuals with an intellectual disability. Without national systems in place, sustainability was constantly being scrutinised. This uncertainty posed a challenge for individuals and families to completely disengage with traditional service providers, often making informal arrangements to return if and when the individualised funding initiatives ceased.

For staff members, the system of de-bundling money was reported to have adversely impacted the amount of time left to develop other aspects of the programme. For example, some processes around 'getting to know individuals' and 'building community connections' were standardised in order to save time and make processes more easily replicable. There was a risk here of losing the individuality that lies at the core of these new initiatives and this is something that perhaps staff could be aware of going forward. For example, the use of 'petty cash' for one person was a source of great independence whilst for another it caused unnecessary confusion, anxiety and fear.

Collectively, these findings suggest that a national resource allocation system is an important prerequisite for these initiatives to be ultimately successful. Importantly, the National Disability Authority (NDA) has carried out a significant body of work on possible resource allocation systems, although there is no conclusion as yet (National Disability Authority, 2015). However, international experience from Canada and the UK warns against becoming overly focussed on the systems because this has the potential for stakeholders to lose sight of the personal and social values that inspired individualised funding in the first place (Fleming, McGilloway, & Barry, 2015a, 2016 (Under Review)).

5. Organisational factors

Our findings indicated that the organisations that embarked upon this innovative journey of implementing individualised funding schemes had a steep learning curve and many associated rewards and challenges. There was a real sense of accomplishment and pride among these early adopters, with a perception that they were paving the way forward in a dynamic and changing sector. Nevertheless, with slower than anticipated progress and a certain amount of resistance experienced along the way, the path to success was not smooth and indeed the challenges are ongoing.

Facilitators of successful implementation

Frontline staff seemed to be motivated by senior staff members who were passionate about individualised funding. In fact, it was cited by one staff member as one of the most impactful interventions that he witnessed over his entire career, with real tangible benefits for the individuals with a disability. For many, these motivational factors stemmed from seeing, first hand, the perceived improvements in the quality of life, personal achievements and circumstances of participating individuals and their families. Often this was reflected in the commitment demonstrated by individuals who had previously been apathetic about traditional services. Staff appeared to be motivated by observing how real value for money could be achieved, both in terms of cost savings when purchasing services, and by achieving more 'bang for your buck' socially and personally through the enhanced quality of services. This sense of accomplishment was enriched through personal storytelling and celebrating the successes associated with challenging the status quo. While these factors seem simple they had a real impact, enabling a positive work culture in what was otherwise a difficult path to follow at first.

Barriers to successful implementation

It was very important for organisations to ensure that they had buy-in from staff members and individual support networks. Where people were overly cautious or too afraid to relinquish the traditional way of doing things, success was more difficult to achieve. This sense of cautiousness was present for most people involved, even those championing individualised funding.

Participating individuals had engaged with traditional services, some over years, others for decades and changing human behaviour takes time. Once again these insecurities were associated with the sustainability of individualised funding, with no tangible governmental commitments in evidence, beyond policy documents.

At an organisational level, there was also an apparent resistance to change both internally and externally. For one project, senior staff members (somewhat removed from implementation of the new initiative) were mistrusting of the national policy move towards individualised funding, suspecting that it was a money saving measure on behalf of funding bodies. There also appeared to be an underlying degree of mistrust around organisational changes in governance and the associated power shift from service provider towards service recipient. These misgivings subtly appeared to transcend the ranks, and ultimately had a demotivating effect on frontline staff. Others perceived the funding bodies in question to be disengaging with the new individualised funding model outlined in national policy.

At a more practical level, there were other potential barriers to success for those implementing the pilot initiatives. These included: staff limitations in terms of manpower and time management (particularly around de-bundling money while building a strong circle of support for individuals); an over-emphasis on the monitoring process; confusion and misinformation about what other pilot initiatives were doing; identifying resources and building trusting relationships within the community; maintaining the health and safety of those participating in the initiatives and people management (particularly in relation to over-protective, resistant or sceptical family members). Key recommendations can be seen at the end of this report, which go some way to address these potential barriers.

6. The role of the community

Community integration is one of the key goals of individualised funding and is also one of the most substantial differences between historically institutionalised service provision and also with the current traditional model of group, segregated and centre-based service provision. Research participants, when explaining the key advantages of the new individualised funding model, very often compared their new and improved circumstances to those previously experienced in traditional arrangements. Community-based benefits were consistently reported in relation to the individualised funding model although there were also obstacles to overcome, such as ensuring individuals develop their social skills while maintaining personal safety. These formed part of the learning experience for all stakeholders including members of the general public.

Facilitators of successful implementation

The opportunity to engage with activities and services that are provided to the general public was one of the greatest successes of these initiatives in terms of community. For participants, they were exposed, sometimes for the first time (on an individual basis), to businesses, civil society groups, recreational and leisure facilities. Any initial apprehensions or anxiety were quickly overcome; indeed such anxieties would be expected of anyone undertaking a new experience for the first time. Members of the general public who actively engaged with individuals appeared to become more understanding and more aware with regard to the fact that no exceptional or additional effort is required to provide services or to meet the needs of individuals with a disability when compared to the general population. Where specific needs (e.g. one-to-one teaching rather than a group teaching environment) arose, these were generally easy to accommodate.

The paid support (broker/support worker/community connector) acknowledged that it was generally good practice to notify service providers (e.g. tutors in adult community courses) of specific needs or behaviour traits to be expected, particularly if it was their first time mentoring a person with a disability (as was often the case). This was person-specific and generally such pre-emptive practices were not required. The arrangement of one-to-one service provision was another facilitator of success. Unlike a group-based setting, this ensured a personalised service that moved at the appropriate pace. It also provided some time and space for everyone involved to become accustomed to the new dynamic. However, immediate integration into group activities was the preference of others thereby increasing opportunities for social interaction and the associated benefits for all involved. Friendships often blossomed from community integration, leading to a natural expansion of the informal circle of support.

Barriers to successful implementation

For many people with a disability, it was their first time to independently engage with services within the general community. This often required assistance at the beginning while learning important independence and social skills. One of the most basic and often challenging skills was money management (i.e. paying for items and taking change). For some, acquiring these new skills was a steep learning curve and was somewhat overwhelming. As always, the pace at which community integration progressed needed to be tailored to individual need. Some people were more cautious, while others sometimes 'threw caution to the wind' in order to enthusiastically embrace this new sense of independence. For those implementing the initiatives, the latter approach highlighted potential health and safety concerns. There was also the risk of overwhelming members of the community who were otherwise open, for example, to providing work experience opportunities. As a result, there was the need to manage expectations around the receptiveness of the wider community. While generally there were no problems, there was a small risk of an adverse reaction from members of the public. Balancing the paternalistic instinct to protect the individual with a disability, and acknowledging the need for some degree of positive risk-taking, was a major challenge for the support networks. Such over-protectiveness had the real potential to hamper progress for individuals.

The findings from this research suggest a number of ways in which the process of implementing individualised funding might be improved if rolled out in Ireland. These suggested recommendations are outlined on the next page.

Recommendations for the implementation of individualised funding

For individualised funding to be successful in Ireland, it is important to:

- Focus on an individual's abilities, passions and interests and encourage independence and personal responsibility by avoiding paternalistic behaviour. Over-protective instincts should be constantly assessed by anyone who is actively engaging with people with a disability.
- Provide an easy and transparent access route from the outset for people who wish to avail of individualised funding; this should include information around eligibility and what is expected as part of the 'sign-up' process.
- Provide targeted training for support workers / personal assistants etc. including:
  - A discovery process framework that includes: Facilitating decision-making - People management skills - Facilitating behaviour change
- Provide training and real-life opportunities around decision-making for individuals with a disability; this should include considerations about how they expect the decision to change their current situation, why that is important and who will be affected by the decision.
- Retain individuality - avoid standardised procedures as much as possible (e.g. the use of petty cash should not be rolled out across the board, but rather offered on a case-by-case basis).
- Be clear about roles and responsibilities as early as possible; this avoids misunderstandings at later stages when paid supports become less involved.
- Ensure social contacts and friendships are maintained with those with whom individuals once shared the centre-based services; new community-based friendships should also be encouraged and facilitated.
- Assess whether individuals prefer group environments or one-to-one arrangements.
- Advocate for a national resource allocation system, but do not become overly focussed on these systems; whilst not ideal, evidence suggests that much can be achieved within the current framework.
- Use existing relationships with staff within disability offices to build a sustainable and equitable system.
- Ensure that senior staff members within organisations implementing individualised funding positively champion and promote individualised funding, particularly during challenging periods.
- Share stories and celebrate achievements - use social networks, blogs, print, video and other media to highlight success stories and grow momentum.
- Develop collaboration and build a unified network of advocates in order to strengthen the national presence. Valuable lessons have been learned by several organisations and many individuals over the past three years. It is important that these people engage and network in order to share ideas, top tips and pitfalls whilst focusing on shared goals rather than organisational differences.

Appendix 1

How did people decide to spend their money?*

Activities of daily living

(e.g. mobility assistance, shopping assistance, driving, booking holidays)

- Personal assistant hours

Education / Classes

- Cooking skills (one-to-one mentoring)
- Forklifting course
- Literacy classes (free in local adult education centre)
- Numeracy / Money management skills
- Nutrition course
- One-on-one mentoring for 'Driving theory test'
- Pedestrian training (using pedestrian crossing, understanding road signs)
- Personal development course
- Pottery class (evening classes)
- SafePass (health and safety in construction industry)
- Teagasc (agricultural and food development) course
- Welding course

Equipment

- Laptop / other hardware & software programmes for college course
- Pen friend (to assist with writing)
- Slow cooker
- Specialised cooker and microwave particularly suited to people with a visual impairment
- Specialised equipment to enable independent cooking (e.g. safe chopping utensils)
- Specialised table

Exercise / Gym / Sport

- Paid support to accompany / assist at gym
- Paid support to participate in outdoors pursuits e.g. hill walking / visiting caves
- Swimming coach / personal trainer
- Swimming in local pool
- Yoga class
- Zumba class

Health and Social Care needs

- Counselling (for main informal supporter to deal with transition)
- Hydrotherapy pool sessions
- Key worker hours (independent living skills)
- Occupational therapy hours (one-to-one)
- Physiotherapy
- Private vision test and 'National Council for the Blind' consultation
- Speech therapy hours (one-to-one)

Leisure activities

(generally requires paid support to assist and ensure safety precautions in place)

- Aqua Park
- Attending farmers market
- Attending nail bar (manicure)
- Body boarding
- Bowling (with others in group home)

- Fishing equipment
- Horse riding
- Segway tour
- Set dancing

Residential

- Group home costs (with ongoing training for independent living)
- Paid support to assist with organising and managing family home renovation to enable independent living
- Paid support to assist with purchasing own home (independent living)

Social activities

- Meeting friends for tea/coffee in local café
- Paid support for community integration activities (e.g. working front of house in local theatre)
- Paid support for leisure travel abroad
- Paid support to accompany to cinema
- Paid support to attend concert
- Paid support to attend football match in national stadium
- Social club (evenings)

Transport

- Bicycle (for leisure and practical purposes)
- Driving test
- Mobility Scooter
- One-to-one mentoring for independent travel skills (e.g. using public transport)
- Taxi (usually in evening when public transport unavailable or unsafe)

Work / Job

- Administrative support for running own business (e.g. accounts, tax, contracts, HR)
- Materials to support organisation of support (circle of support meetings)

*Note: Some purchases were once-off, while others may have been ongoing (e.g. personal assistance - accounting for a large percentage of the total spend). However in some cases the smaller items or once-off purchases had a significant impact on an individual's personal gains (e.g. mobility scooter opened up many opportunities which were otherwise unattainable)

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APPENDIX 3.5 - INDIVIDUALISED FUNDING IN IRELAND: IDENTIFYING AND IMPLEMENTING LESSONS FROM ELSEWHERE

This is the submitted manuscript of an article published by Frontline magazine on 26/12/2015, available online from http://frontline-ireland.com/individualised-funding-in-ireland-identifying-and-implementing-lessons-from-elsewhere/.

Easy to Read summary:

- Traditionally, money for people with disabilities has been managed by service providers. Individualised funding allows a person with a disability to spend this money in whatever way they wish in order to meet their needs.
- There are different forms of individualised funding. One is where the person gets support to do paperwork and to identify and organise activities. The second is where the person does not want or need support for paperwork.
- Many other countries around the world have used individualised funding in the past and important lessons can be learned from their experience in order to ensure greater support for people with disabilities in Ireland.
- A team in Maynooth University has been conducting some research with people around Ireland who have a disability (including intellectual disability). These people have tried individualised funding and have talked about their experience.
- The key findings from that research show many successes for individuals including improved self-image, new and better life experiences, more control over life decisions and better social supports. Family members were able to overcome fears and grew more confident but were frustrated with the overly complicated process for accessing funding. Organisations developed ways to overcome challenges in order to promote positive change.
- The Irish government is being encouraged by policy makers, advocates and by the findings of this study to roll out a system to allow individuals to be assessed for an amount of money that will meet their personal, health and social care needs.

Main Article:

Traditionally, public funds allocated for people with a disability have been distributed among service providers to deliver a suite of services to meet all personal, health and social care needs. However, recent years have seen a greater emphasis on, and attendant policy shift toward, what has been called individualised funding. Individualised funding is an umbrella term for various funding mechanisms that aim to provide personalised and individualised support services for people with a disability. It aims to give people with a disability more control over their lives, the things they do and the people with whom they spend their time. It does this mainly by giving the 'spending power' to individuals, their families or advocates. Being in control of the money has the potential to open up considerable possibilities. Supports and activities can be purchased from the more traditional centre-based services as well as, or combined with, alternatives that are already available from within the community. The two most popular forms of individualised funding are 'Direct Payments' where the individual or legal guardian receives the funds directly and self-manages the administration and purchases. A second option is where individuals receive the support of an intermediary service. The level of service provided depends on individual needs and ranges from purely administrative support to personal and social care support. In both models, individuals receive high levels of support in the transition from traditional congregated service provision or if applicable during the transition from school into adult day services.

Four initiatives in Ireland have been funded by the Genio Trust to pilot individualised funding. Genio brings funders together to develop better ways to support disadvantaged people to live full lives in their communities (www.genio.ie). A multi-phase evaluation focussing on the implementation of these initiatives is currently being undertaken by staff in the Mental Health and Social Research Unit located in Maynooth University Department of Psychology. Initial findings from this evaluation were presented by the author at a recent international conference hosted by The Centre for Inclusion and Citizenship in the University of British Columbia, Vancouver called 'Claiming Full Citizenship – Self Determination – Personalization – Individualized funding' (Fleming, McGilloway, et al., 2015c).

In Ireland, there is currently no standardised 'Resource Allocation System' in place for assessing how much money an individual needs to meet their personal, health and social care needs. Since 2010, the National Disability Authority has conducted extensive research on possible systems and undertaken a two-phase feasibility study to pilot four resource allocation systems in order to determine which is the most suitable within the Irish context (NDA, 2015). The lack of such systems and the associated difficulties in accessing funds tied up in the current funding system has been seen as one of the most significant challenges for organisations implementing individualised funding in Ireland.

> *"The biggest single problem, and the biggest single delay has been trying to get the funding, and that comes in under a couple of headings. One is decoupling funding from a block grant…" (Staff member interviewed as part of evaluative research (Fleming, McGilloway, et al., 2015c)*

> *"If they didn't make it such a monumental struggle to get (the funding). Like that would break the heart of anybody" (Parent during participatory workshop as part of evaluative research (Fleming, McGilloway, et al., 2015c)*

While additional challenges were encountered during the implementation of the pilot projects, many of these can be, and have been, managed internally. These challenges often relate to the transition from the traditional mode of service delivery and the consequent need to equip individuals with the life skills, decision making skills and the natural support network required for these projects to be successful. Changes to organisational structures or equipping staff, individuals or advocates with hands-on experience of the individualised funding process have led to the natural emergence of individually tailored solutions. Furthermore, by looking outside of Ireland and learning from the experiences of other countries and their journey over the past two decades, practitioners and participants can strengthen the efforts in Ireland, accelerate the learning and avoid potential pitfalls into the future.

Individualised funding has been used with varying degrees of success since the 1970s, and up until recently, in countries as diverse as Canada, the US, the UK, Australia and New Zealand. Each jurisdiction obviously has its own structures and systems, benefits and challenges. There were two striking messages from the Vancouver-based international conference in October for those, in Ireland who are striving to build upon the policy commitments to provide personalised supports through individualised funding (Department of Health, 2012). Firstly, the challenges being experienced in Ireland have been experienced elsewhere and continue to be experienced, even with strong systems and processes in place. Secondly, while resource allocation systems are fundamental for individualised funding to operate in these countries, an over-emphasis on building strong systems can lead to a loss of the values associated with individualised funding. Unexpectedly, the uptake of individualised funding has been relatively low in Canada. A recent study, indicated a number of potential reasons for this including: how information was delivered; peer influences; lack of promotion; lack of understanding about the new system; lack of staff training and associated trickle-down effect of information; fear of isolation; frustration over amount of paperwork involved; families' risk-aversion and long term fears; fear of losing security associated with traditional services; and sense that wider community is unwelcoming (Bahadshah et al., 2015). All of these elements are also reflected, to some degree, in the Irish research being conducted by Fleming et al (2015c). In Ireland however, we have the advantage of learning from these experiences before individualised funding is widely adopted, thereby ensuring that the necessary resources are in place to alleviate a lack of training, information and stakeholder fears and concerns.

In New Zealand, where there was a marked increase in those using individualised funding during 2009-2014, research has indicated that individualised funding can lead to cost reductions in the delivery of disability services (Field, 2015). Furthermore, the use of story-telling and, in particular, the use of online videos (see http://tinyurl.com/stories-building-capacity) was advocated by an organisation called Manawanui as a means to address the challenge of informing families, to illustrate the impact of individualised funding on individuals' lives and to increase the effectiveness of professionals working with families (Janson, 2015). Organisations within Ireland have also harnessed online media to tell similar positive stories; for example, PossibilitiesPlus commissioned a short video whereby individuals availing of individualised funding spoke about their experiences. This video was produced by Fionnathan Productions - a social enterprise set up by a recipient of individualised funding through the ÁT network in Ireland (PossibilitiesPlus, 2014a). Genio has also produced a series of videos depicting personal stories from within their many disability and mental health projects that they have previously funded, including individualised funding through the ÁT network (Genio, 2011).

These videos bring to life many of the positive themes which emerged from the evaluative research in Ireland. For example, Fleming et al (2015c) found that the successes of individualised funding generally outweighed the challenges. For individuals with a disability the positive elements included: improved self-image with people describing more self-confidence, skills, a sense of leadership and success; the development of independent life skills; new experiences including the opportunity to travel independently (having received the relevant mentorship); the possibility to purchase items to assist individuals to function independently. There were also health improvements reported by some individuals, a greater sense of control and life purpose, all of which were facilitated by increased social support from family, friends and the wider community.

The benefits of the individualised model also extended to natural supports (such as family and friends) and organisational staff, processes and systems. For example, those providing informal support grew in confidence, whilst their fears about their friend or family member leaving the perceived security of traditional settings were alleviated; at the same time, their perceptions around the abilities of their family member with a disability were enhanced, as were their perceptions of their wider network of friends, colleagues and the general community. In terms of process, tools were developed to support individuals in identifying and organising activities within the community, the role of the intermediary support person was developed and a circle of support established in a participatory way with individuals, families, friends and other advocates.

Advances were made in de-bundling money from the block grant, although these were on an individual basis - dependent on individual disability managers; an uncertainty which further highlights the need for a national standardised system of resource allocation. For organisations, there were developments in building an enabling work culture, the trust between service provider, the HSE and families was enhanced and real and perceived value for money experienced. These and other findings from the evaluation of individualised funding by Fleming et al. will be published in due course, with a view to informing practitioners, decision makers in HSE, the Department of Health and the Department of Finance, but most importantly for individuals with a disability, their families, friends and advocates to help them understand the potential challenges that lie ahead with the individualised funding option, but also the potential life enhancing aspects which can be expected.

Our evaluation of individualised funding in Ireland is due for completion in 2017, but our preliminary findings support the policy commitments and advocate-led call-to-action to introduce a resource allocation system to enable and strengthen individualised funding and support. Furthermore, it is important that service providers in Ireland are encouraged to learn from projects both in Ireland and abroad in order to fast-track organisational, family and individual learning. By so doing, there is a real possibility that a robust, accessible and sustainable system of individualised funding can be rolled out in Ireland over the coming years.

Author bio

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APPENDIX 3.6 - WHAT ARE 'PERSONAL BUDGETS' AND WHAT HAVE WE LEARNED FROM DEVELOPMENTS IN IRELAND?

This is the submitted manuscript of an article published by Frontline magazine on 15/07/2016, available online from http://frontline-ireland.com/personal-budgets-learned-developments-ireland/.

A recent high profile seminar hosted by Inclusion Ireland and Down Syndrome Ireland (Monday 30th June 2016) and attended by over 200 people, focused on personal budgets for people with disabilities. The newly appointed Minister of State for Disability, Finian McGrath, was in attendance to hear presentations from national and international speakers, including researchers, experts from the UK, and advocates for the implementation of personal budgets in Ireland (Inclusion Ireland, 2016). This article is based, in part, on work which we presented at that seminar and which is being undertaken as part of a larger piece of research at Maynooth University. This research is investigating the implementation of four pilot projects in Ireland which are supporting the use of personal budgets. The aim of this article is introduce the concept of personal budgets and to explore what our research says about the practical considerations for families interested in personal budgets in Ireland.

Padraic Fleming presenting at 'Personal Budgets' Seminar – Gibson Hotel – May 30th 2016. Photograph compliments of Twitter user - Tom Scott @TomScott_SBHI

What is meant by personal budgets?

As highlighted in an earlier Frontline article (Fleming, McGilloway, & Barry, 2015b), ‘personal budgets’ refer to one of a number of different funding schemes/initiatives that are described collectively as ‘individualised funding’. For example, the four pilot projects located in various parts of Ireland are described as: 1) Direct Payments; 2) Independent Support Broker / Brokerage; and 3) Self-management model.

These models are not new in the sense that many countries around the world are funding disability supports through personal budgets, including Canada, the US, Australia, New Zealand, the Netherlands and the UK, amongst others. However, there is considerable variation in the ways in which ‘personal budgets’ are described internationally (see Figure A3.6.1).

Figure A3.6.1 - Different terms used internationally to describe ‘Personal Budgets’

Source of terms: (Fleming, 2016b)

Despite the many different terms that exist all of these funding and support initiatives – including those in Ireland - are essentially trying to achieve the same goal. Their aim is to provide funding directly to a person with a disability in parallel with a personalised support process. Together, these aim to increase the person’s level of control over what supports and services are purchased to meet their individual needs.

The alternative to personal budgets is access to services through service providers, as is the case in Ireland. Through the current/(traditional) funding model, an individual's funds are provided in the form of a block grant which means that the funding to provide services is based on the assumption that services will be provided in a group setting - and therefore funding is grouped together and provided to various service providers. The service providers, in turn, provide a suite of options to people with a disability.

Historically, these services were based in institutions, but more recently have been located in group-based day centres and residential centres, such as group homes, or to a lesser degree, independent living arrangements. Due to the nature of group activities, the options are limited and generally tend to be based on a weekly calendar of events. Furthermore, it is very difficult to cater for individual preferences when providing services within a group setting. While service providers endeavour to personalise and individualise services, the scope of what can be achieved is limited by the nature of group settings.

Personal budgets, on the other hand, allow the individual to decide how their needs, wants and aspirations are met. Indeed, they have been recognised by the United Nations as one way of achieving a self-determined life (United Nations, 2006). Unsurprisingly perhaps, personal budgets are rooted in the Independent Living Movement where choice and control are strongly emphasised (Jon Glasby & Littlechild, 2009). Our research has shown that people want to access services that are available to the general population. These services tend to be based in the community, thereby improving the opportunity for increased personal and social gains.

Personal budgets offer the kind of flexibility and personal decision making required to accommodate people's changing preferences and needs over time, something that is arguably more difficult to achieve when catering for a group of people. This process of self-determination can have many benefits; for example, participants in the pilot initiatives in Ireland viewed themselves as more successful – confident – adaptive – skilled - empowered - independent - in control – and with a greater sense of purpose (Fleming, 2016b).

What are the different personal budget models and how do they work for individuals and their families?

The variations in personal budget models reflect:

- the different mechanisms for managing the personal budget;
- organisational and contextual factors, such as health and social service delivery mechanisms and;

- different ways of allocating funds to an individual.

Two models provided as part of the pilot initiatives in Ireland, are described below.

'Direct Payments'

- This means that funds are provided directly to the person with a disability.
- In Ireland, Áiseanna Tacaíochta (the ÁT network) provides such a mechanism of direct funding.
- Each person availing of a personal budget is referred to as a 'leader' and each leader is provided with support to set up their own company, whereby they can manage their own lives, directly hire the supports required and purchase assistive technologies to promote greater independence.
- This model tends to have increased administrative responsibility in terms of tax, insurance and other statutory requirements. While supports are in place to assist with administration, this model (to date) tends to be most suitable for people with a physical or sensory disability. Having said that, the ÁT network is working closely with the informal support networks of individuals with other forms of disability.
- For more information see: www.theatnetwork.com

'Independent Support Broker'

- The pilot initiatives in Ireland that use(d) some form of a brokerage model included 'PossibilitiesPlus', 'Bridging the Gap' and 'ConnectAbility'.
- With this model of personal budget, there are more supports in place for the administrative burden on an ongoing basis.
- As a result, the funding is provided to an intermediary body (organisation) who manages the budget on behalf of the individual, working closely with the individual/family or support network to decide how that money is spent.
- In addition to administrative support, there are more intensive personal and social supports in place, particularly in the earlier stages, when people are transitioning from the traditional model of service provision or from school.
- Our research has shown that some people (particularly with an intellectual, developmental or psycho-social disability) can struggle with decision making. As a result, it is essential that people have a strong informal support network consisting of family, friends, neighbours, colleagues or members of the wider community.
- Where no such network exists, the brokerage service helps to successfully build such a network. Eventually, the brokerage service can take a step back, empowering the person with a disability and their support network to: 1) manage the decision making process; 2) identify activities and formal and informal support services within the community and; 3) access and manage them as necessary. (Fleming, 2016b)
- For more information see: www.possibilitiesplus.ie

What do families and advocates need to consider when their loved one is using/planning to use a personal budget (based on four pilots in Ireland)

- **Your help is essential**

Our research showed that the perceived benefits of personal budgets were enhanced when a strong circle of support was available to the individual. However, families typically needed guidance and support at first. This required skills to help their loved one successfully identify what their goals were and how to go about achieving those goals (Fleming, 2016b). There are various training opportunities available to help build these skills (Genio, 2016; Leap, 2016). Much of the training in this area builds upon the notion of personalisation - placing the individual with a disability at the centre of the decision making process, thereby recognising their strengths, preferences and aspirations and empowering them to identify their needs, and to make choices about how and when they are supported (Carr, 2010). Ongoing support is essential however, and it is important to develop and nurture a long-term sustainable network of support (including siblings and other younger relatives and friends).

- **'Positive risk taking' can be a good thing**

Families and particularly parents, can naturally be very protective of their children and when a child has a disability, this can become even more marked and can inadvertently lead to overpowering paternalistic behaviours. Individuals, family members and paid supports who took part in our research recognised this behaviour in themselves and others. They also acknowledged that this can create a significant barrier to progression. These behaviours are often based on fears and anxieties, and therefore tend to focus on a person's disability rather than their abilities. As a result, families need to be aware of such behaviours, which can often be quite subtle. They should strive instead to empower their loved one (difficult as this may be at first) to take positive risks, to try new experiences, to gain new independent skills and to allow them to explore the world on their own terms, having acquired the appropriate skills to do so. The phenomenon is not unique to Ireland of course. For instance, research has been carried out in Australia to help families become more aware of their unintentional negative behaviours, attitudes or attributes and to identify how best these might be managed (Curryer et al., 2015).

- **Embrace your community**

For many years, in the era of institutionalisation, people with disabilities were largely invisible within their communities. However, the mainstreaming of education has seen younger people with disabilities integrated within the schooling system along with their peers and friends. Unfortunately, current services for adults remain largely segregated from the wider community with ‘special’ activities, thereby ensuring that adults with disabilities remain congregated and isolated from their peers (Fleming, McGilloway, et al., 2016a). For younger people, the transition from mainstream school into disability-specific adult services can be very traumatic.

Personal budgets, on the other hand, provide an ideal opportunity to continue on this mainstream route and to seek out, and avail of, community-based services. Sometimes this may require a member of the individual’s support network to accompany them due to physical or psycho-social limitations. This could be a family member or friend, or a personal assistant/key worker who is paid from the personal budget. Our research has shown that community interaction had positive impacts for everyone involved. However, as might be expected, there was an initial period of adjustment for everyone, for example: 1) family members taking a step back, letting go of the ‘controls’; 2) individuals learning social norms and adjusting to new experiences and 3) members of the community realising that no exceptional or additional effort was required on their part to meet the needs of a person with a disability compared to the general public, and if such needs did arise, they were easily overcome. In this natural way, community integration raised awareness and reduced stigma.

Where to next?

It is reassuring to note that Minister McGrath, has publicly pledged his support for the implementation of personal budgets for people with a disability in Ireland (Inclusion Ireland, 2016). As part of this pledge, he has commissioned a taskforce to oversee the national roll-out of personal budgets. While PossibilitiesPlus and the ÁT network continue to support individuals in accessing and utilising a personal budget, they are currently limited by the lack of a national resource allocation system to help with the individual allocation of funds. They are also limited by the lack of national systems within the HSE to refer individuals to their services.

A number of organisations around Ireland are planning a submission to the taskforce in order to inform and guide their work, based on international best practice and ongoing independent research here in Ireland. While there is a sense that the disability sector is on the cusp of change, these processes take time and especially if they are to be implemented properly and in a way which will be sustainable and successful for years to come. The Inclusion Ireland / Down Syndrome Ireland seminar indicated a growing appetite for personal budgets in Ireland, but also increasing frustration with the lack of progress despite policy recommendations and promises from successive governments. Our findings suggest that it is important to build upon the growing momentum and the valuable lessons learned from our research of these four pilot initiatives in Ireland. For example, it may be prudent to begin to develop a unified and co-ordinated network of advocates including individuals, families, support networks and organisations in order to strengthen the national presence. Valuable lessons have been learned by a 'core' of several organisations and many individuals over the past three years and it is important , therefore, that this learning, knowledge and expertise are shared with others in order to help generate ideas, top tips and highlight pitfalls whilst also focusing on shared goals rather than organisational differences. It is also important to share personal stories and to celebrate achievements by, for example, harnessing social networks, blogs, print, video and other media to highlight success stories and grow momentum (Fleming, 2016b)

More details from the evaluation of the four pilot initiatives in Ireland has been published in an 'easy to read' report called *'How personal budgets are working in Ireland - Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland'*. This report can be downloaded for free from www.genio.ie/personal-budgets. The evaluation of individualised funding is ongoing, with the current phase examining international evidence of individualised funding to determine if personal budgets do in fact improve the health and social care outcomes for people with a disability. Research findings from this and other aspects of the project will continue to be published in various media.

APPENDIX 3.7 - SUPPORTING POLICY IMPLEMENTATION FOR PERSONALISED BUDGETS IN IRELAND

This manuscript presents an abbreviated version of a report, developed in conjunction with Genio, to inform policy and practice during the planning phase for national implementation of individualised funding in Ireland.

A3.7.1 Developing an assessment framework

This section will outline three implementation options/models for consideration by the Taskforce on Personalised Budgets in Ireland and the Departments of Health and Finance respectively. However, before proceeding, a framework based on policy (informed by international best practice), research and implementation science will be proposed for assessing the various modes; this framework comprises a checklist of assessment criteria which may be used to compare the various options; each criterion may be rated using a scorecard-type format as outlined in Figure A3.7.1, which will be referred to as 'INFINITE' (INdividualised FundINg ImplemenTation framEwork) henceforth. These criteria are discussed below.

A3.7.1.1 Overall Approach / Philosophy *(Criteria 1-2)*

Ireland is the last nation in the European Union to ratify the UNCRPD (Lennon, 2016). Arguably therefore, the first and core assessment criterion should refer broadly to the extent to which any new service model helps to promote and protect "all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity" (United Nations, 2006) (Figure A3.7.1: INFINITE Assessment Criterion Number 1 (AC #1)). Equally, it is important - in line with the vision of the Expert Reference Group involved in the Value for Money and Policy review (Department of Health, 2012) - that any new model should take a 'whole society approach' which is consistent with the progressive social model of disability (INFINITE AC #2). Based on this rights based, whole society approach the next set of criteria are user-focused, as outlined below.

	Scores ranked from 1 (not likely) to 5 (very likely) to achieve goal	**1** ☹	**2**	**3** 😐	**4**	**5** ☺
	Overall Approach / Philosophy					
1	Will promote all human rights & fundamental freedoms for people with a disability, including respect for their inherent dignity					
2	The model is closely aligned to a ‘whole of society’ approach					
	User focussed					
3	Will promote dispersed independent housing within the community					
4	Scope to ensure access to primary care and multidisciplinary team specialist services (as required)					
5	Scope for individualised funding throughout the lifecycle					
6	Will promote positive risk-taking					
7	Will enable an environment to promote trust in the end user					
	Process					
8	Scope for an easy, informative & transparent national access route					
9	Will easily integrate a national individualised, needs-led resource allocation assessment					
10	Will separate those planning, supporting and delivering services					
11	Scope for a reconfiguration plan within each organisation contracted by the HSE (promoting buy-in)					
12	HSE to agree and revise the structure for local collaborative working					
	Resource issues					
13	Will have training opportunities for staff in skills required to facilitate independence, inclusion & self-determination					
14	Scope to select and recruit appropriately skilled workforce					
15	Will have key supports available for promoting ‘valued social roles’					
16	Will have facilitative administration available					
17	Need for additional funding during the transitionary phase					
18	Expertise and resources available to ensure quality in HSE funded services					
	Sustainability					
19	Scope for stakeholder evaluations based on carefully designed research and data collection processes and procedures					
20	Likelihood of a smooth transition between traditional and new funding models					
	Overall Score					

Figure A3.7.1 – INFINITE Scorecard

A3.7.1.2 User focussed (Criteria 3-7)

The third recommended criterion to be included in the framework relates to the fact that Ireland was recently identified, by the 'European Association of Service Providers for Persons with Disabilities', as one of six underperforming countries, mainly due to delays in its process of de-institutionalisation (Fleming, McGilloway, et al., 2016a). Therefore, in line with the 'Moving on from Congregated Settings' Report (2011), it is desirable that any new model ensures that "All those moving from congregated settings should be provided with dispersed housing in the community, where they may:

o Choose to live on their own

o Share with others who do not have a disability

o Share their home with other people with a disability

o Live with their own family or opt for long-term placement with another family." (HSE, 2011b, p. 132) INFINITE (AC #3):

To facilitate this transition to the community, the next two criteria are based on recommendations from 'New Directions' (2012). These include: "….ensuring access to primary care and multidisciplinary team specialist services" (INFINITE AC #4); and "…facilitating continuity of support throughout a person's lifecycle" (INFINITE AC #5).

The transition to the community also requires a shift from a traditional paternalistic approach to one of trust, particularly in the abilities of the person with a disability (Fleming, McGilloway, et al., 2016c; Fleming et al., (2017 - under review)) (INFINITE AC #6). More specifically Priestley (2007) encourages implementers of individualised funding initiatives to trust the end user to be willing and able to honestly manage funds. By so doing , a balance between 'accountability for public funds' and the 'control over funds for the person with a disability' will lead to a simplified system rather than one that is overly complex and administratively burdensome (Chopin & Findlay, 2010). Changes within the current governance structures should ensure trust, flexibility and cooperation underpins the relationship between funding body and end user. (INFINITE AC #7). This leads us onto the next set of criteria, which relate to process.

A3.7.1.3 Process (Criteria 8-12)

The evaluative research of the four Genio funded pilots in Ireland related to facilitators of successful implementation at the early stage. One of the key recommendations from this research and international experience, was the need for an easy and transparent national access route (Fleming, McGilloway, et al., 2016c; Fleming et al., (2017 - under review)), a governmental promise expected to be delivered by the end of 2017 (Department of the Taoiseach, 2016) (INFINITE AC #8). To facilitate ease and transparency:

1. Information about access routes, funding mechanisms and allocation processes and, indeed, all aspects associated with individualised funding needs to be carefully considered and designed specifically for people with a disability and their support network. (Fleming, McGilloway, et al., 2016c; Fleming et al., (2017 - under review)). Laragy, David and Moran (2015) describe a framework for information provision which includes:

- accessible and diverse in mode, format, source, location;
- personalised and targeted – appropriate for audience and purpose;
- accurate, consistent, timely;
- from a trusted and independent source;
- culturally appropriate;
- proactive for 'hard to reach' groups;
- gender appropriate.

2. Information should also provide clear guidance for disability managers around eligibility for individualised funding and the mechanisms to assign and actively facilitate a needs-based budget to interested individuals.

A standardised national resource allocation system will also be necessary to determine individual budgets, as recommended by the 'Value for Money and Policy Review' (2012):

"*a common assessment method should be developed or adopted by the HSE and implemented by disability service providers on a national basis to determine the services that are required by an individual*". Such assessment tools have been piloted by the NDA and integration of the chosen tool into existing service structures will be vital for individualised funding to work. This provides the basis for criterion number 9. (INFINITE AC #9).

Another process related measure is derived from the 'Moving on from Congregated Settings' report (2011) which recommends that in-home[16] and inclusion supports[17] are delivered separately as illustrated by the following: *"Governance, management and delivery of residential supports should be separate from provision of inclusion supports, to ensure that the person with a disability has maximum choice of support providers and maximum independence."*(HSE, 2011b, p. 107). This recommendation, also flagged within studies included in the systematic review (Study Three), can be extended to all types of supports including, for example: a separation between the financial intermediary service and those facilitating the life choices / person-centred planning for the person with a disability, (whether they are centre or community based) (Emslie et al., 2005); or those conducting outreach and enrolment vs. administrative support (Phillips et al., 2006). This requirement to separate the planning, support and delivery of services is captured by criterion 10 (INFINITE AC #10)

New Directions (2012) recommended procedures to facilitate the organisational restructuring required to change how services are delivered. Among those was "a reconfiguration plan within each organisation contracted by the HSE" with HSE guidance and approval for each individual reconfiguration plan and the timeframe for delivery (INFINITE AC #11). It also encouraged the "HSE to agree and commission or revise the structure for local collaborative working" which requires willingness of all stakeholders to participate in the structure. The importance of these collaborative relationships featured heavily in Study Three (Chapter 6) (INFINITE AC #12). These were the basis of criteria 11 and 12.

This need for service provision restructuring will undoubtedly affect staff, with organisation and staff buy-in integral to successful implementation, as highlighted in Study Three (Fleming et al., (2017 - under review)). This leads to the penultimate set of criteria for the INFINITE scorecard.

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[16] "In-home supports are those forms of support that enable the person to live independently and safely in their own home. As well as support provided by paid staff, Smart Technology (technologies used to support people to remain independent in their own homes) should form part of the new model of in-home support."(HSE, 2011b, p. 8)

[17] "Inclusion supports are those supports aimed at facilitating each individual to develop active linkages and relationships with services and people in their own locality and local community." (HSE, 2011b, p. 8)

A3.7.1.4 Resources (Criteria 13 – 18)

The availability and quality of human resources were consistently highlighted in Study Three (Chapter 6), including such things as staff attitudes, skills, access to training and ultimately their understanding of individualised funding (Fleming et al., (2017 - under review)). This latter point formed the basis of a key recommendation in the 'Moving on from Congergated Settings' (2011) report, suggesting that available 'manpower' require a "*different skill mix, different skills and ethos… Staff roles in a community setting will be defined differently, with a greater emphasis on promoting independence and facilitating inclusion*" **(HSE, 2011b, p. 95)**. Thus, any new model should be assessed in terms of the extent to which staff have the necessary skills or their need of / access to training in the facilitation and support of independence, inclusion and self-determination (INFINITE AC #13).

The importance of staffing is also highlighted by Fixsen, Blase, Naoom, & Wallace (2009) who present the core components to implement and sustain the effective use of human service innovations such as evidence-based programs, for example, individualised funding (Figure A3.7.2). One of the core elements also relates to staffing whereby: 'Staff selection and recruitment' must be carefully considered, particularly where skills are difficult to teach in training sessions such as common sense, sense of social justice, ethics, willingness to learn, willingness to intervene, good judgment and empathy (INFINITE AC #14). (D. L. Fixsen et al., 2009) Staff recruitment and retention were highlighted as key challenges for people with a disability who were self-directing their supports. As such, the availability of training, support and resources (such as a centralised database of skilled workers) need to be considered when assessing INFINITE AC 14.

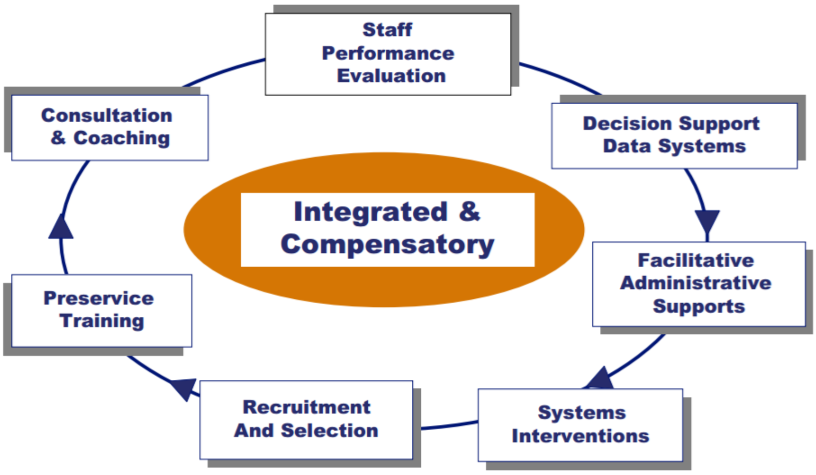

Figure A3.7.2 – Core Implementation Components

(D. L. Fixsen et al., 2009, p. 534)

Studies Two and Three, in line with national policy (HSE, 2012b) outline a number of essential supports required for people with a disability transitioning from traditional settings to innovative, community based initiatives. This network of support can be paid or unpaid, or most likely a combination of both, and is integral to successful implementation. Upskilling and ongoing information provision will promote 'valued social roles' as reflected in criterion number fifteen within the framework. (INFINITE AC #15). Specific resources, to facilitate the realisation of valued social roles, particularly in relation to paid support, may include: person-centred planning, advocacy, support for community inclusion, in-home supports, community-based primary care and specialist supports, and work/further education Support" (HSE, 2011b, p. 106).

To complement the skilled workforce and community based resources, outlined above, the end-users themselves may also require upskilling, in order to move on from 'learned passivity' (for individuals with a disability), or paternalistic behaviours (from their informal support network). These should include, but are not limited to: training and real-life opportunities around decision-making for individuals with a disability; and a discovery process framework that includes: facilitating decision-making; people management skills; and facilitating behaviour change. (Fleming, 2016b; Fleming, McGilloway, et al., 2016c; Fleming et al., (2017 - under review))

Facilitative administration is also a core component of implementation, providing leadership and support to frontline staff and wider support networks. Within the pilot initiatives in Ireland and across the international literature (Studies Two and Three), the use of existing centralised administrative structures was seen to be very beneficial, given the limited resources. Facilitative administration can also utilise data and evidence to carefully consider and develop policies, procedures, structures, culture and climate, elements which transcend many of the earlier criteria captured in the framework (INFINITE AC #16). (D. L. Fixsen et al., 2009)

Apart from human resources, additional funding may be essential during the (time limited) transitionary period, a requirement found necessary in the economic sustainability element of the Health Research Boards recent evidence review (Pike et al., 2016). (INFINITE AC #17) Such transitionary costs are inevitable, as highlighted recently by HSE Director General, Tony O'Brien, in relation to primary care transitional costs: "Need to accept that "decisive" shift to primary care requires significant transitional funding to make it possible" (T. O'Brien, 2016). Furthermore, an investment recommended by New Directions (2012) relates to ongoing monitoring and evaluation "….ensuring quality in HSE funded adult day services" which is dependent on “specialist expertise in monitoring and evaluation functions of the quality system” (INFINITE AC #18). This leads to the final two criteria, embedded in implementation science.

A3.7.1.5 Sustainability (Criteria 19-20)

Fixsen, Blase, Naoom, & Wallace (2009) identify monitoring and evaluation as core elements of implementation science. Staff evaluations are intended to measure the use and outcomes of skills related to: staff selection, training and coaching. Evaluations can also highlight where service delivery models are being locally tailored. Since individualised funding is a policy initiative rather than a ‘tightly defined intervention’, the emphasis on implementation fidelity is less applicable. However an adherence to the principles of effective individualised funding, informed by international evidence and experience is vital. Indeed, the evaluative research in Ireland highlighted the importance of flexibility in terms of successful implementation (Fleming, 2016b; Fleming, McGilloway, et al., 2016c). In order to measure the effectiveness (and the elements that impact effectiveness) it will be essential to capture reliable, valid, timely and measurable outcomes for people with a disability, paid and unpaid support network, and data relating to organisational adherence to the core principles of self-determination, as highlighted in INFINITE scorecard, whether that relates to traditional services or individualised funding interventions. INFINITE AC #19. Such research activities will inform the Decision Support Data Systems, another core component of implementation (Figure A3.7.2).

Finally, ‘systems interventions’ are various strategies to align new interventions (for example, individualised funding) with external systems (block grant funding). Ensuring a smooth transition between the two was a particularly important point which arose from the evaluative research in Ireland. (Fleming, 2016b; Fleming, McGilloway, et al., 2016c) INFINITE AC #20

A3.7.2 Implementation Options

Various implementation options will now be outlined in detail. These options can be scored against the INFINITE scorecard to determine which will be most likely to succeed. The options are categorised as follows:

1. No change to the status quo
2. Incremental approach (each stage of the incremental approach will be scored separately using the INFINITE scorecard)
    - Cohort 1 - School leavers

- Cohort 2 - Those currently availing of traditional services
    - *Cohort 2a – Adults availing of services*
    - *Cohort 2b – Children availing of services*
- *Cohort 3 – People with severe or profound impairments*
- *Cohort 4 – Older people with age related disability*

A3.7.2.1 No change to the status quo (the 'do nothing' option)

In line with current HSE service plans, all existing disability services will continue to be funded, increasing day centre places, respite and personal assistant services, as envisioned by the Minister of State for disability issues (McGrath, 2016). Alongside the traditional services the current individualised funding option in operation in Ireland today, albeit not readily available, will continue.

Unfortunately, this option is economically unviable in the long term, particularly if the current level of traditional services is maintained in addition to the roll-out of personalised budgets. Furthermore, it is not particularly progressive in terms of meeting international best practice and attendant policy recommendations. In fact, it has been acknowledged that the disability services in Ireland are not meeting the recommendations of the Committee on the Rights of Persons with Disabilities (**CRPD**) (Inclusion Ireland, 2013). Remaining with the status quo is also likely to face many implementation challenges already encountered by the pilot programmes. Similar to the early adopters such as the US, Canada, the UK, Australia and New Zealand, attempts to fit a new model into pre-existing systems and organisational structures is likely to limit the benefits of self-directed support both to the person and the health system in particular, leading to a more expensive system overall. Therefore, it is recommended that lessons are taken on board from the findings of research on current pilot approaches (Fleming, 2016b; Fleming, McGilloway, et al., 2015b, 2016c, 2016d), adopting successful elements, but utilising an incremental approach whereby existing services have time to adjust and transition, while emerging services have time to put the necessary systems, resources and skill base in place.

A3.7.2.2 Incremental implementation

An incremental approach is one potential mechanism for rolling out personalised budgets gradually, giving time for people, systems, organisations, cultures and budgets to adapt to the new service model. One way to achieve incremental implementation is by adopting what has been called a 'cohort approach', a preferable option among many people involved in the Irish evaluative research. This focuses on specific groups (e.g. of different ages) at different stages including, for example, school leavers, adults etc. Further details are provided below:

Cohort 1 - School leavers

There is a growing number of children and teenagers with a disability availing of mainstream education - growing from just 10,400 in 1996 (8,000 in primary schools and 2,400 in post-primary school) (NDA, 1996) to over 48,000 in 2016 (25,647 students in mainstream primary and 22,777[18] students in post primary schools)(NCSE, 2016). Evidence suggests that the transition from school to adulthood can be a time of great stress for families due to the uncertainty related to the loss of support and respite provided by schools (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2016). Indeed, the evaluation of the four pilots in Ireland indicated potential setbacks for young adults moving to a segregated 'day service' from a dynamic mainstream school setting where students were fully integrated into their community (Fleming, McGilloway, et al., 2016d). The first vignette illustrates how one individual experienced this transition prior to participating in one of the pilot initiatives.

Vignette 3.7.1

Participant in pilot: *When I finished school I went to (day service) … It didn't really work out for me. (**Researcher:** OK why was that?) Because I couldn't find my future, where I'm meant to be, (it) blocked me away from my future. (**Researcher:** OK. And how, why did you feel like that? How were you feeling blocked?) Eh... You ever feel like you are being left behind…*

This participant's mother elaborated this point when she joined the interview in the latter half:

Mother: *She was in mainstream primary and secondary school and then she left school and there wasn't really any options, em except the rehabilitation training course, in (day service), so she started on that but after, I'd say, short as three months, it wasn't really challenging her or she wasn't moving on (**Participant:** That's what I was trying to say)*

Interviewees from evaluative research of pilot 4

Careful consideration needs to be given to this critical transitionary juncture when individualised supports can have a real and lasting impact on peoples futures (R. L. Morgan & Riesen, 2016). Information dissemination, educational programmes and training should commence for disabled people and their support network well in advance of this transition

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[18] Approximately 10,000 of these students have a borderline or mild general learning disability or a specific learning disability

taking place. This will allow for a more fully informed population that can freely choose the life options that best suits the disabled individual and their support network.

Anecdotal evidence from the feasibility studies conducted by the National Disability Authority of various resource allocation systems (NDA, 2015), suggests that the FACE toolkit has been rolled out to school leavers during 2016. Although there is no evidence to suggest that the results from these assessments are currently being used for allocating resources, it would suggest that perhaps this cohort approach is being considered by government for national roll-out.

The availability of a a personalised budget at this stage in a person's life (i.e. , before they enter traditional adult services), means that money can be allocated in an individualised manner before it gets 'tied up' in the block grant mechanism. As such, current service provision will continue as normal, except personal budget holders can freely choose to avail of none, some, or all of the services on offer from traditional providers. Alternatively, they may source needs-based services from existing options within the community, supported by formal and informal supports, such as their circle of support or brokerage / intermediary services (Fleming, 2016b; Fleming, McGilloway, et al., 2016c, 2016d).

Approximately 611 eighteen year olds have a disability in Ireland (1.2% of the total disabled population), based on figures from NIDD and NPSDD and 2011 census figures [including 3.7% increase between 2011 & 2016 census]) (CSO, 2011, 2016; Doyle & Carew, 2015; Hourigan, Doyle, & Carew, 2015). According to practitioners, in the Irish evaluative research, between €14,000 and €16,000 was available to new entrants, in order to fund a 'Rehabilitative Training' place. Such a training course is intended to develop personal core competencies, life skills, social skills, and basic work skills to a level consistent with that individual's capacities (Fleming, McGilloway, et al., 2016a). Upon completion of this course, the funding reportedly drops to between €10,000 to €12,000 for long-term users of day services, when people are meant to use their newly acquired skills to progress onto a full life involving for example employment, further education and community integration:

> "*there's been a defined rehabilitative training amount when the school leaver's going into services, which is a grant of between 14,000 and 16,000, depending on their needs.*" (Staff member – CS4)
>
> "*You know how much it costs [annually] for you through the [training centre] five days a week? €14,000*" (Staff member – CS1)

> "*Somebody who has been in a service provider, gone through the RT training which is normally 14, 15, it generally drops back anyhow to 10-12,000, if somebody's staying in a service provider long term.*" (Staff member – CS4)

Based on the above figures, and taking the average annual cost of day services in Ireland (€13,000), the projected total cost of day services would be €7,943,000 for all 611 eighteen year olds (representing school leavers). This amount of funding could be redirected from traditional services to offer personalised budgets. Alternatively, the €7.5m earmarked for 'new initiatives' (HSE, 2015) could be used to implement the first stage of this cohort approach (i.e. school leavers), with no immediate impact on existing services.

Cohort 2 - Those currently availing of traditional services

Clearly, the 'school leaver' approach (outlined above) would not cater for all the people currently enrolled in traditional services. As of 2015, 27,733 people with an intellectual disability (98.7% of the total population registered on the NIDD[19]) and 5,021 with a physical or sensory disability (22.0% of total population registered on the NPSDDA[20]) were in receipt of services (Doyle & Carew, 2015; Hourigan et al., 2015). These figures included children and adults. Therefore, for purposes of the incremental implementation of personalised budgets, this cohort could l be further divided into adults and children.

Cohort 2a – Adults availing of services

In 2013, 18,275 adults with an intellectual disability were using day services in Ireland (Fleming, McGilloway, et al., 2016a) and approximately 3,382 adults with a physical or sensory disability were in receipt of services in 2015. Of these, 1,745 were in receipt of 'day services', as defined by the NPSDDA. The majority were using 'open employment' (524) or day activation services (424). In addition to 'day services', 'personal assistance and support services' were utilised by 1,643 adults on the NPSDDA, the majority being home help (458, 9.1%), personal assistant (401, 8.0%) and peer support (370, 7.4%) (Hourigan et al., 2015). It should also be noted that in 2015, 7,724 of people on the NIDD were also in receipt of full time residential services (Doyle & Carew, 2015).

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[19] National Intellectual Disability Database

[20] National Physical and Sensory Disability Database

Although these are the official figures from the two national databases, the findings from the research conducted on the pilot programmes would suggest that money assigned for individuals continues to be allocated to a service provider over a number of years regardless of whether the person is attending that service or not and this is particularly true for day services (Vignette 3.7.2).

Vignette 3.7.2

Talking about money tied up in traditional services -

Anybody I'm working with, a number that I'm working with have actually chosen to be outside the (day or residential) service for two or three years, and the service was still getting the funding, so at that point they were really looking for the funding so that they could actually do something constructive with it.

Talking about getting money released from residential service –

… it's been a very difficult road for some people. We're actually having a meeting tomorrow with a disability manager and a service provider, actually sorry … the person (with a disability) themselves doesn't want the service provider in the room because it has kind of blocked his move a lot, and it's been, it's causing a lot of stress at this stage. He's nearly two years down the road since we started with him. Money still hasn't been taken out or freed up from the service. And what they have actually offered is, €1,700 as his care needs, supported for a full year, which is absolutely appalling

Paid support from evaluative research of pilot 4

Furthermore, the data from a 15 year trend study of day services for people with an intellectual disability showed a sharp decrease in younger people availing of day services, with no indication of what alternatives these young adults were using (Fleming, McGilloway, et al., 2016a). This non-attendance at day services suggests a growing dissatisfaction with day services amongst the people who use them. Furthermore, this does not represent value for money and arguably therefore, a mechanism needs to be put in place to transfer an individual's total allocation from the traditional service provider to the individual, if they wish to adopt a personalised budget.

One possible way to achieve this is to amend service agreements with current providers of disability services so that a proportion of their allocated funds are moved to personalised budgets. This amount could start as a very small proportion of the budget that increases progressively each year until the bulk of the budget has moved to a personalised configuration. These personalised budgets would be offered to existing users of the service. A business plan should accompany such service agreements outlining how services will adapt to offer a variety of needs-based options that people can then choose to spend their budgets on, without being tied into availing of other activities that do not interest them. In this way, the person can choose to spend funds from the personalised budget on community based services and activities outside of the congregated setting. The business plans should also incorporate essential implementation plans, such as training opportunities for disabled people, family and staff, in addition to accessible, transparent information.

Finally the business plan should carefully outline the service provider's financial plan for transitioning existing funds to personalised budgets. This financial plan should be tailored to meet each service provider's unique position, but with the guarantee that at least 25% of funds are personalised within five years. This should then increase to 50%-75% within 10 years.

Cohort 2b – Children availing of services

Leap, an NGO in Ireland[21], is calling on the government to extend personalised budgets to all people with a disability, regardless of age or 'level' of disability. As indicated by the evidence review conducted by the Health Research Board, four of the six jurisdictions reviewed did not have a lower age limit, except for the UK (18 years) and Canada (19 years in 3 of 4 provinces reviewed) (Pike et al., 2016). Of the 5,021 people on NPSDDA, 1,639 were under the age of 18. 704 children were in mainstream primary school (43.0%) and 382 were in secondary school (23.3%), accounting for the majority of these all day services recorded on NPSDDA (38.4%). Although mainstream schooling offers many benefits for young people with disabilities, it does not cater for after school hours or for the 7,500 children enrolled in 'special schools' (NCSE, 2016). A further 210 children with physical or sensory disabilities avail of personal assistance and support services (12.8% of 1,639), the vast majority utilising peer support (n = 71, 4.3%), home help (n = 51, 3.1%) or a home care assistant (n = 33, 2.0%) (Hourigan et al., 2015).

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[21] With a vision of: 'Children and families living their lives to the full and enjoying a good life, relationships, belonging and socially valued roles (www.leapireland.com)

For children younger than school going age, assessment and early intervention options could be purchased by a personal budget, to ensure the best start is provided at the earliest possible stage. For school going children, many of the support needs are catered for during school hours, however additional resources are required for after school hours. For both groups, a needs based assessment could be used to assess what services are required and funded accordingly. This cohort is not likely to require a substantial proportion of the national personalised funding budget, due to their needs being met in a number of other state funded health, social and educational services. As such, it is the intention of the government to limit personalised funding to adults during the initial implementation phase. However, this should not lead to an oversight in terms of the needs of children with disabilities and their families. As such, explicit plans should be put in place, by the strategy taskforce, to cater for this cohort in later phases of implementation.

Cohort 3 – People with severe or profound disability

There is an 'unknown' proportion of disabled people in Ireland who are not availing of traditional services as they are not designed to and, therefore, do not meet the needs of this cohort. They are unknown because registration of the national databases is voluntary and intended to inform service planning (Hourigan et al., 2015) and therefore those who never attended services are not likely to be captured . Historically, this group of people would have remained in institutions throughout the course of their lives. Today, they are reportedly the most underserved in the country; many of whom are cared for by their families, with little or no funding. In other countries this cohort tends to require a higher personal budget due to their increased needs, often 24 hours a day, however evidence suggests the costs for recipients of personalised budgets fall below those of traditional service users over an extended period of time. Furthermore, disabled people with complex needs who have had access to a personalised budget are more likely to remain in the community, compared to those without a personalised budget who are more likely to move into residential care (Field, McGechie, & King, 2015). Personalised funding should be extended to this group of people in the same manner as school leavers, using a standardised resource allocation tool to calculate the budget required. In these cases, a brokerage model, as described in the evaluative research of the four Irish pilots, may be of particular benefit (Fleming, 2016b; Fleming, McGilloway, et al., 2016c, 2016d).

Within this incremental approach there are potential savings for the HSE in terms of reduced numbers of places requiring funding in traditional service provision, i.e. school leavers arranging their own supports with the help of formal and informal supports. While uptake is likely to be low, based on international experience, the available savings will be minimal at first, but over time will grow. Regardless, these savings could be used to partly fund personalised budgets for this cohort of people, in some cases, for the first time.

Cohort 4 – Older people with age related disability

Many older people in Ireland have life-long and age related disabilities, with disabled people living longer lives. While residential services continue to cater for disabled people throughout the life cycle, day services, and the attendant funding, appears to cease after the age of 65 (Doyle & Carew, 2015). At this point people are supported by older persons services, which are the same for disabled people as for the general population. A variety of initiatives cater for the needs of these people including: community care such as home help; home care packages; nursing home support schemes; and residential care. International evidence would suggest that older people are less likely to avail of a personalised budget due to: poorly informed care managers; lack of direct payments support services; lack of enthusiasm among local authorities; poor public information; overly complicated monitoring systems; difficulties with associated responsibilities, for example, feeling less able to use direct payments without sufficient support services; and finally concerns about employment of care workers and the related administration. (Carr, 2013) Despite these challenges, the option should be available for older people who wish to have more autonomy and choice over the services they participate in and how and when their needs are met. Furthermore, those who have been availing of a personalised budget, should not be expected to undergo a disruptive transitionary period, between disability funded services and older people services. Therefore, there should not be an arbitrary cut-off point for the provision of personalised budgets.

APPENDIX 3.8 – POLICY BRIEF: INDIVIDUALISED FUNDING FOR PEOPLE WITH A DISABILITY

POLICY BRIEF

INDIVIDUALISED FUNDING for people with a disability

Context

With the Irish Government poised to introduce new funding mechanisms for persons living with a disability, this policy brief will present: 1) a **background** to the origins of individualised funding; 2) trends from national data relating to **traditional service provision**; 3) findings of evaluative research carried out on **four pilot projects in Ireland**; and 4) international evidence on the **effectiveness of individualised funding** at improving health and social care outcomes. Overall this brief endorses Individualised Funding by outlining the benefits of individualised funding while presenting recommendations focussed on successful implementation.

Freedom - Community Integration

Background

Individualised funding is an umbrella term to describe various models of self-directed supports for disabled individuals and/or their support networks. These models are facilitated by an individual budget. In short it is about empowering the disabled person to decide how they are supported, when they are supported and who supports them. In the past, service providers made these decisions for disabled people by offering a selection of options, usually delivered in a group setting that was separated from the wider community. This was based on professional-led services that were relatively easy to deliver in a group setting. However, preferences change - levels of ability vary – past experiences can dictate future interests.

Individualised funding, since it is based on one persons needs and aspirations, has the flexibility to quickly change and adapt to the changing landscape of a persons life, something that is very difficult, if not impossible, within a group-based setting. Critics of individualised funding have raised concerns about the potential adverse implications of commodifying care and of turning disabled people into consumers of basic life needs. However, the vast majority of evidence available indicates many benefits to individualised funding and self-directed support.

Control – Opportunity - Flexibility

The idea of individualised funding grew from the Independent Living Movement that originated in the US and Canada in the 1960s / 70s. The Community Care Act 1990, followed by the Direct Payments Act 1996, saw the first large scale pilots of individualised funding in the UK. This quickly spread to other parts of Europe, North America, Australia and New Zealand. The UN endorsed Individualised Funding, in 2006, as a means to achieve self-determination for disabled people. Irish policy began to reflect the concept of individualised supports in various policy documents including: Time to Move on from Congregated Settings (2011), New Directions (2012), Value for Money and Policy Review (2012). In 2016, on foot of mounting international evidence and advocacy group demands, the Department of Health committed to assemble a taskforce on the implementation of personalised budgets in Ireland.

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Maynooth University National University of Ireland Maynooth
GENIO
HRB Health Research Board
SPHeRE Structured Population and Health-services Research Education

Method

In order to inform the imminent policy decisions, a body of research was undertaken to:

1) look at day-service trends over a 15 year period by analysing national secondary data;

2) evaluate four pilots of individualised funding in Ireland, specifically focussing on the successes and challenges related to implementation within the Irish context, by a largely qualitative in-depth case study approach ; and

3) synthesise the international evidence on the effectiveness of individualised funding at improving health and social care outcomes, as well as summarising the experiences of participants, by means of a Campbell Collaboration systematic review.

Findings

Study 1) Over a 15 year period, 1998-2013, day services in Ireland did not change substantially and often did not reflect demand. Government funds should support individualised models, more adaptive to changing trends. National databases need flexibility to respond to policy and user demands. Future research should focus on day service utilization of younger people and the impact of rurality on service availability, utilization, quality and migration.

Fleming, P., McGilloway, S., & Barry, S. (2016a). Day Service Provision for People with Intellectual Disabilities: A Case Study Mapping 15-Year Trends in Ireland. Journal of Applied Research in Intellectual Disabilities, 30(2), 383–394. doi:10.1111/jar.12249

Study 2) Exemplified by independent-skills development and community integration, the individualised funding pilots in Ireland have been welcomed as a progressive development beyond traditional service provision, with perceived improvements across a range of organisational, personal, health and social care domains. The research explored the importance of 'natural supports' and how overly protective behaviour may unintentionally act as a barrier to full implementation. The findings also indicate that unnecessarily complex systems can lead to individual burnout. Furthermore, a national resource allocation system working in partnership with existing social care professionals and the wider community is recommended, as is learning from overly simplified, group-based ideologies. Fleming, P., McGilloway, S., & Barry, S. (2016b). The successes and challenges of implementing individualised funding and supports for disabled people: an Irish perspective. Disability & Society, 31(10), 15. doi:10.1080/09687599.2016.1261692

Fleming, P. (2016). *How personal budgets are working in Ireland: Evaluating the implementation of four individualised funding initiatives for people with a disability in Ireland*. In G. Trust (Series Ed.), www.genio.ie, (pp. 24). Retrieved from www.genio.ie/personal-budgets

Study 3) Seven studies with eligible quantitative data were identified, demonstrating statistically significant improvements for people utilising individualised funding in terms of quality of life, satisfaction levels and safety, with fewer adverse effects compared to the control group. Cost-effectiveness data was inconclusive. Sixty-nine studies with eligible qualitative data highlighted the many benefits of individualised funding, in addition to implementation successes and challenges.

Fleming, P., McGilloway, S., Hernon, M., O'Doherty, S. (RIP) , Furlong, M., Keogh, F., & Stainton, T. (2017 – under review). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review Retrieved from http://campbellcollaboration.org/lib/project/350/.

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Recommendations

★ Individualised funding should not be forced to function within existing systems, processes and procedures that were developed for a different time, society, perspective and understanding of disability. It should instead be facilitated by a needs-led, person-focussed, aspirational resource allocation system that is flexible and adaptive to various, dynamic and changing contexts.

★ Introduce individualised funding on an incremental (step-by-step) basis, starting with school leavers and, in time, moving to a whole society approach including disabled children and (where appropriate) adults and older people receiving supports within traditional services.

★ Provide the necessary resources, (human, time and financial) to facilitate the transition from traditional paternalistic model of service provision to one that is truly person-focussed, needs led and focussed on full community integration. This should include training opportunities for all stakeholders.

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