

Implications for family carers when people with psychosocial disability have individualised funding packages – literature review

Commissioned by Mind Australia

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Foreword

As carers, we have been both excited and worried about the introduction of the National Disability Insurance Scheme. There has been much talk on the individual focus of the funded items and news coming out of the trial sites. In commissioning this research, we wanted to find out how carers experienced similar schemes when they were introduced internationally.

In setting out, we didn't know what to expect, and to be honest we thought the findings might be less than positive! We, were mostly relieved by the findings which give us optimism in stepping forward. For us, the literature revealed new understandings of how the lives of families and carers can be improved with adequate support to their family member or friend. It also provided learnings that may assist as we move to the NDIS together. In particular, they highlight that as carers we must be prepared, supported and involved.

The report purposefully stays in the remit of a literature review. We wanted to look deeply into, and present, the literature - to share what we found. For this reason, it does not interpret the literature or make recommendations. We hope however, that this is a useful contribution to the knowledge base and keeps a focus on the important role and contribution of carers.

We want to thank Mind Australia for pursuing this research, and the researchers, particularly Dr. Carmel Laragy for her persistence in digging for the literature that focuses on families and carers.

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Executive summary

This literature review examined the impact of individualised funding on family carers of people with psychosocial disability. It was conducted in the context of the National Disability Insurance Scheme (NDIS) being rolled out across Australia as individualised funding is becoming the dominant funding mechanism in disability and aged services. This executive summary provides an overview of the key themes and findings and a detailed account of the review follows.

Outcomes dependent on system design

There is no simple answer to the question about the impact of individualised funding on family carers of people with psychosocial disability and the outcomes achieved. The answer depends on:

- how programs are structured
- whether the level of information and the support provided match the level of responsibility expected of people who manage funds and purchase services,
- the adequacy of funds, and
- the availability of supports and services.

Individualised funding programs resulted in better outcomes compared to traditional block funded service provision for carers and participants and had no adverse effects when conditions were conducive. However, they presented challenges to family carers when carers had to ‘fill in the gaps’ and provide support when funding was inadequate or when they were expected to shoulder the burden of managing administrative responsibilities without adequate support.

Individualised funding – diverse models

There are many models of individualised funding programs and this makes it difficult to systematically compare outcomes. For example, England has approximately 150 local authorities and each authority manages its individualised funding programs differently. Despite these differences, the impact of programs on family carers was distinguished by a number of features. Some programs allowed self-management which gave participants full administrative responsibility for recruiting and directing support workers, managing taxation and insurance requirements, finding services and activities and acquitting financial accounts. Within these programs, some provided all the necessary support to enable participants to do this, while others offered little or no support and expected participants to source private providers to manage these tasks if they did not want to do it themselves.

Another distinguishing feature was the adequacy of funding. Australia has looked to the United Kingdom (UK) and other countries when designing the NDIS. However, recent austerity measures in the UK resulted in the removal of information and administrative support services and individual funding allocations were reduced. These two factors combined have reduced the potential of English individualised funding programs to address people’s needs. Australia has made a commitment to funding the NDIS and support systems are being developed. It is hoped that this review will contribute to the NDIS developing effective support mechanisms to achieve its aims, especially those in regard to maintaining the health and wellbeing of carers.

Funding for family carers

Individualised funding programs typically assess a person's needs and this assessment determines their allocated funding. The NDIS has a commitment to supporting carers and items designed to maintain the carer's health and wellbeing can be included in the NDIS participant's plan¹. In contrast, family carers in England have a legal right to an assessment of their needs and the potential for funding to be allocated independent of their family member. However, in practice this opportunity is rarely taken up. The reasons for this appear to be a combination of staff not being aware of carers' needs, family carers either refusing the offer or not asserting their rights and asking for an assessment, and carers not knowing this opportunity existed. With or without an entitlement to an assessment and allocation in their own right, it seems that family carers need education about assessment processes and planning meetings so that they can use these processes effectively for the benefit of their family member and themselves.

Positive outcomes

A range of benefits was identified for family carers involved with individualised funding when outcomes were compared to traditional service provision:

- Carers benefitted when individualised funding provided more choice, control and flexibility with services and supports.
- Even though carers generally did not receive allocated funding in their own right, they often benefitted when their family member's quality of life improved. For example, they gained respite when their family member had activities or a holiday, and when they shared the same residence and domestic assistance was provided.
- In addition, carers had 'flow-on' benefits when their family member had improved outcomes such as spending less time as a psychiatric inpatient, having fewer criminal justice contacts, being less stressed, gaining confidence and getting a job.

Concerns

Studies identified that many carers and participants found the administrative responsibilities onerous when they were required to recruit and direct support workers, manage taxation and insurance requirements, find services and activities and acquit financial accounts. This discouraged some carers from promoting self-managed programs or the use of individualised funding to their family member when they were optional. Coupled with this concern was that of not having sufficient funds. This resulted in people being unable to purchase necessary supports and services or purchase administrative assistance when required. Austerity measures in some countries have cut people's budgets and left them with insufficient funds to purchase necessary supports. These cuts are particularly concerning in individualised funding programs because there are no disability services with block funding available to support people in times of crisis.

1. <http://www.ndis.gov.au/families-carers/information-families-and-carers>

Summary

Key factors in individualised funding programs that impacted on outcomes for family carers were:

- access to information about program policies, spending guidelines, administrative supports and available services and activities
- support to consider their needs and aspirations as well as those of their family member
- sufficient funds for their family member to purchase necessary supports and social participation activities
- staff attitudes that encouraged power sharing rather than being patronising
- support to manage administrative tasks being commensurate with the level of responsibility expected of family carers, and
- availability of appropriate services and activities to purchase.

Family carers were able to lobby and secure better funding and support for their family member when they had confidence and skills. Peer support through education programs and informal groups was found in the literature to be effective in developing these abilities in carers. The findings indicate that governments can maximise positive outcomes for people with a psychosocial disability and improve the quality of life of family carers by financing and facilitating peer support programs to develop carers' abilities.

Glossary

Direct payments

Payments paid into the bank account of the person with disability or their representative. Although programs vary in design, they usually require the participant to recruit and support workers, manage taxation and insurance requirements, find services and activities and acquit financial accounts.

Individualised funding

Individualised funding is the generic term used in this paper to encompass all versions of individual payments.

Participant

A person with disability receiving an individualised funding payment.

Respite

Services that provide a short-term and time-limited break for families and other voluntary caregivers. They can be in the person's home, a holiday, at a centre, with a host family respite/peer support respite.

Support workers

Staff employed to provide personal and social support.

Literature review

This section presents detailed analyses of academic articles and reports that examined individualised funding programs and shows their impact on the family carers of people with a psychosocial disability. The family member is referred to as the ‘participant’ in the individualised funding program.

Introduction

Individualised funding packages² are allocated to people with all types of disability and to the elderly when they need personal, clinical and social support. In individualised funding programs, government funding that was previously allocated to block funded services has been redirected and allocated to people on an individual basis after an assessment of their needs. This is a major transformation in service delivery. The focus on the individual with the disability also changes the allocation of funding. For example, funding was previously allocated to respite services to assist family carers. In individualised funding programs the person with disability is allocated the funds to purchase services and supports, including activities and holidays. Sometimes this provides respite to family carers. While the main focus of individualised funding is on the person with disability, this literature review considers the direct and indirect impacts on family carers. In Australia, family carers do not have an assessment of their needs and they are not allocated their own budget. At this point in time, the available evidence on the full impact of individualised funding on carers and their access to support is not clear.

Individualised funding differs from previous block funded services in that public money is allocated to an individual instead of to an agency. Within specified guidelines, the person can choose how and where the funds are spent. Sometimes funds are held in an account that can only pay specified bills and it is not available for discretionary spending. Across the globe individualised funding programs

have various names and many variations. They use different terms to refer to the allocated budget, they have different assessment criteria and spending guidelines, a variety of ways of allocating funding, and differences in the provision of information and support, level of administrative responsibility expected and accountability requirements. Throughout this review efforts are made to identify the configuration of the program reviewed and the research methods used to assess outcomes because each of these factors has an impact on potential outcomes and the reliability of the findings. A nuanced approach is taken that attempts to identify what factors contributed to the outcomes reported.

Few studies were found that focused explicitly on the impact of individualised funding on family carers of people with a psychosocial disability. This review is an important contribution because it does directly review the impact on carers. It includes literature showing the impact of individualised funding on carers with a family member having any type of disability or in the context of aged care with the aim of exploring whether there are any factors common to all family carers. The review also briefly considers the impact of individualised funding on participants because of possible flow-on effects to carers.

Overall, the findings show that individualised funding programs result in better outcomes for the person with disability and they have no adverse effects compared to traditional block funded service provision as long as conditions are conducive. Conversely, there are poor outcomes for participants when insufficient funds are allocated and people are expected to assume responsibilities they cannot manage. These positive and negative outcomes flow on to family carers. They benefit directly by having more respite when their family member is purposefully occupied, and indirectly if family member has improved mental health, new housing opportunities and greater social participation.

2. The term individualised funding will be used throughout this report without repeating the word ‘package’.

This literature review is divided into the following sections:

- Aims and key questions
- The background to the review
- An overview of Individualised funding
- The literature review method
- The findings
- Conclusion

Aim and key questions

The aims of this literature review were:

- To review national and international evidence showing the impact of individualised funding programs on family carers of people with a psychosocial disability; and
- To provide an evidence base to assist in informing debate and policy development.

It is hoped that the information provided will contribute to learning and maximise positive outcomes for family carers and their ability to support their family member. This review was conducted as the National Disability Insurance Scheme (NDIS) was being rolled out across Australia and individualised funding was becoming a dominant funding mechanism in disability and aged services.

The key question that guided this review was:

- What are the impacts on family carers of people with a psychosocial disability when their family member has individualised support funding ?

A subsidiary questions was:

- Can the experiences of family carers of 'other service users' using individualised funding inform our understanding of the impact on carers of people with a psychosocial disability? 'Other service users' referred to those with different types of disabilities and the elderly.

To answer these questions the literature reviewed considered the outcomes reported, what factors contributed to these outcomes and any risks compared to traditional block funded supports.

Background

This section presents a profile of the number of people with disability and their carers, clarifies the interpretation of psychosocial disability used, presents general information about individualised funding and details of the National Disability Insurance Scheme (NDIS).

In Australia, an estimated 321,531 people used disability support services under the National Disability Agreement (NDA) in 2013–14. Of these, 86% lived with an informal carer, most often their mother; 54% lived with their family; and 12% used respite (Australian Institute of Health and Welfare 2015).

Psychosocial disability

The term 'psychosocial disability' is used in this review because it is used by the NDIS in their policies and public statements. The NDIS Act 2013 (Commonwealth of Australia 2013) uses both this and the term 'psychiatric conditions'. The NDIS has indicated that it wants to bridge the gap between the medical model of disability – which tends to treat the symptoms of mental ill-health, and the social model of the disability which considers the social context (Bonyhady 2014). This context includes location, socioeconomic status, poverty, homelessness, social isolation, ethnicity, family, gender and religion (Oliver and Barnes 2010, Kipling 2014).

People with psychosocial disability in some other countries have been slow to take up individualised funding opportunities. Only 2% in Scotland took up the option to use 'self-directed support' (Ridley, Spandler et al. 2012), and 9% in England (Royal College of Psychiatrists and Association of Directors of Adult Social Services 2013). It was thought that these low figures resulted because the programs were not well designed to attract and meet the needs of people with psychosocial disability (Williams and Smith 2014). Further,

it was suggested more broadly, that when services systems are designed to meet the needs of people with psychosocial disability, the numbers using individualised funding will increase (Ridley, Spandler et al. 2012, Williams and Smith 2014).

Family carers – profile

Family carers are defined as those who provide informal help or supervision to a family member needing help with core activities of mobility, self-care and communication, and this help is likely to be for at least six months (Australian Government 2010, Australian Bureau of Statistics ABS 2012: Carers Key Findings). However, it is widely reported that many people providing this help do not identify with, or like this term. One English study found that half of all carers did not identify with the term ‘carer’ because they offered their support as part of their commitment to family relationships (Larkin and Milne 2014).

The economic contribution of informal care to family and friends in Australia during 2015 was estimated to be \$60.3 billion, as assessed by the replacement value if services were to be purchased from formal service providers (Deloitte Access Economics 2015). This is reportedly equivalent to 3.8% of gross domestic product and 60% of the health and social work industry.

Caring for a family member has been found to provide family carers much satisfaction in terms of enhancing their relationships through shared mutual love and support, meeting perceived responsibilities, and giving them enhanced self-esteem (Savage and Bailey 2004). However, family carers also face challenges and disadvantages in terms of reduced income and wellbeing. Carers have lower labour force participation rates and lower incomes (Australian Bureau of Statistics ABS 2012). As the majority of carers are female, 70% of primary carers and 56% of carers overall, the ABS reported that women are most acutely disadvantaged.

A number of concerning findings have been reported about the wellbeing of Australian carers. Cummins, Hughes and Tomyn

(Cummins, Hughes et al. 2007) have conducted extensive wellbeing surveys of different groups and they found that carers had the lowest collective wellbeing of any group surveyed. Specific findings included:

- Carers on average were moderately depressed.
- Sole parents were the most disadvantaged.
- Female carers had lower wellbeing than male carers.
- The majority of carers received no treatment for themselves because they lacked time and money.
- Carers were more likely than others to: experience chronic pain; carry an injury which reduced their wellbeing; and have financial concerns.

Having low household income was a double jeopardy for carers. Their average household income was lower than the general population, and their wellbeing was depressed due to low income. These findings indicate that carers make considerable contributions, often at great cost to themselves.

Both the rewards and demands of caring were found to be similar across the globe in a survey of carers in 22 countries conducted by the *European Federation of Families of People with Mental Illness* (EUFAMI 2015). The findings showed positive outcomes for carers such as sometimes feeling closer to family members and gaining satisfaction from contributing to the recovery of their family member or reducing relapses by being involved in treatment plans. Despite these positive findings, overall the survey confirmed the negative impacts caring can have on family carers. At a personal level many experienced drifting apart from their families and isolation, social prejudice and exclusion from society, and being unable to cope with the constant anxiety of caring. At a systems level many were dissatisfied with the level of information available and being excluded from meaningful involvement with healthcare professionals.

Family carer rights

The rights and needs of family carers are promoted in Australia's *Carer Recognition Act 2010*. According to the Act carers should be: supported to enjoy optimum health and social wellbeing and to participate in family, social and community life; acknowledged as individuals with their own needs within and beyond the caring role; supported to achieve greater economic wellbeing and sustainability; and, where appropriate, should have opportunities to participate in employment and education (Schedule 1). Notably these ambitious sentiments are not supported by any specific actions or government resource allocation.

The Commonwealth Government has plans for a *National-carer-gateway* to provide information for all carers (Fifield 2015). The press release says "Hard-working, time-poor carers will have a single phone number and website with a service finder where they can quickly find relevant information about the services available to them". However, it is not clear if this information service will be designed to meet carer's own needs or to find services for the person they support. The NDIS Act 2013 acknowledges the *Carer Recognition Act 2010*, although it clearly focuses on the person with disability and the carer is seen as an adjunct. This is evident when it says:

- Where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant (S31.c).
- Where possible, strengthen and build capacity of families and carers to support participants who are children (S31.d).
- If the participant and the participant's carers agree—strengthen and build the capacity of families and carers to support the participant in adult life. (S31.da).

Taking a stronger stand in support of carers than Australia, the UK has the *2004 Carers (Equal Opportunities) Act*. This gives carers the right to an assessment of their needs

separate to the needs of the family member they support. However, despite their legal entitlement, few carers in the UK have their own needs assessment (Moran, Arksey et al. 2012, Glendinning, Mitchell et al. 2015).

As shown by the EUFAMI survey (2015), the needs of carers in many countries are not being addressed and their rights are not being upheld. The reasons for this are complex. Contributing factors are thought to be: difficulties of separating user and carer legislation: the absence of a clear carer/cared-for dichotomy because of the interdependent and reciprocal nature of caregiving relationships: and unresolved debates about whether policies that support carers perpetuate disabled and older people's dependence (Larkin and Mitchell 2015).

Individualised funding: an introduction

- Individualised funding programs have existed in countries other than Australia for over 40 years.
- They have many different names and configurations.
- They were introduced to Australia with the intention of providing more service options and improved outcomes for people with disability.
- Australia's National Disability Insurance Scheme (NDIS) commenced in trial sites in 2013 and it will be progressively rolled out across the country.
- Eligibility for the NDIS is having a permanent impairment that substantially reduces functional capacity.
- While carers are generally not eligible for an assessment and funding allocation in their own right, their needs can be considered in their family member's

Individualised funding will be briefly described before considering its impact on family carers. Individualised funding is money allocated to a person to address their needs resulting from their disability or because they are elderly and frail. It is important to note that individualised funding is only a funding mechanism or ‘technical lever’. This mechanism provides more flexibility and it is designed to give them more choice and control over the services and support they use, and ultimately their lives (Larkin and Mitchell 2015).

Individualised funding programs use a plethora of terms such as ‘direct payment’, ‘personal budget’, ‘individual budget’ and ‘cash and counseling’, and each program has different guidelines and requirements. The shared characteristics of individualised funding programs are that people know how much money is allocated to them and they can choose where it will be spent (Duffy 2005). Funding is portable and participants can move from one service provider to another and in some instances self-manage the funds.

Individualised funding is usually allocated following an assessment of need and in some, but not all jurisdictions, funding is tied to a plan that specifies how it can be spent (Laragy 2010). Depending on the program’s guidelines, funds are held by the person or their representative, a service provider or a financial administrator (Purcal, Fisher et al. 2014).

Individualised funding for disability supports reportedly commenced in the 1970s in a number of countries. In Canada the Woodlands Parents Group in British Columbia was allocated funding to move their children with intellectual disability from a disability institution to community living (Power, Lord et al. 2013); in the United States (US) Vietnam veterans with disabilities in Berkeley received funding to purchase supports to live in the community (Yeandle and Ungerson 2007); and in Germany people with physical disabilities gained funding to live in the community instead of institutions where they had been dominated by paternalistic professionals (Junne and Huber

2014). All groups held and managed the funds and had the option to purchase support from general community services or a disability service provider.

Many European and North American countries have used individualised funding to provide disability and aged care support for many years (Hutchison, Lord et al. 2006, Yeandle and Ungerson 2007). Western Australia was the first Australian state to extensively use individualised funding to support people with disability when it commenced in 1988 (Bartnik and Chalmers 2007). Other states subsequently developed small scale programs (Purcal, Fisher et al. 2014). The Productivity Commission (Productivity Commission 2011) encouraged a national individualised funding program after reviewing disability services and finding that Australia’s traditional disability service system was “underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports” (p.2). The Productivity Commission proposed that the limited disability funding could be used more efficiently if people had more choice and control, and service providers had to compete in an open market. However it remains to be seen if individualised funding will be more efficient and effective. Some writers are sceptical after their experiences in the UK (Slasberg, Beresford et al. 2012, Spicker 2013). Disability advocacy groups have generally been positive and have encouraged the introduction of individualised funding because they considered that it offers people with disability more choice and control and better outcomes (Victorian Disability Advocacy Network 2008).

Models of individualised funding

Different designs of individualised funding models across the globe appear to lead to different outcomes. Two features that are particularly relevant to family carers are the level of administrative responsibility participants are expected to carry, and whether the funds provided are adequate to meet people’s needs. The impact of inadequate funding and austerity measures is discussed

below under the heading 'Austerity'. Examples of programs requiring different levels of administrative responsibility are discussed here.

The United Kingdom (UK) programs *Direct Payments* (Homer and Gilder 2008) and *Individual Budgets* (Glendinning, Challis et al. 2008) are examples of programs that required high levels of administrative responsibility while offering little support. These programs were optional alternatives to agency managed supports. Despite the lack of support provided in the programs, two-thirds of the participants with all types of disability chose individualised funding and had funds paid directly into their bank account and they self-managed (Cheshire West & Chester Council 2010).

In contrast to English programs, the United States (US) *Cash and Counseling* program provided advice and support for all administrative requirements at no cost to the participant (Shen, Smyer et al. 2008). This program was provided across 15 states and it has been extensively evaluated. It gave participants the opportunity to employ whoever they wanted as their support worker, including family members, except their spouse or the person acting as their program representative. Participants had the option to use fiscal intermediaries to handle bookkeeping and payroll services on their behalf, and almost all clients used these free services. This US program aimed to make individualised funding a viable option for people of all ages and with all types of impairment, including those with a psychosocial disability. Features that enabled this inclusivity were allowing family carers to be the person's nominated representative and providing them with the necessary administrative support. In some states family members were allowed to be the paid support worker.

Other countries have options that sit between the two ends of the spectrum existing in the UK and the US. For example, participants in Sweden had a choice of options regarding the level of administrative responsibility they

wanted to take, and they could employ family members. It is interesting to note that only 3% of Swedish participants chose to manage all their employer and financial accountability responsibilities, while many others retained executive decision making while delegating administrative tasks to services or cooperatives (Laragy 2010).

The National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) commenced in 2013 (Commonwealth of Australia 2013), following recommendations from the Productivity Commission (Productivity Commission 2011). The existing Medicare levy was raised by 0.5% in July 2014 to finance this initiative³. Eligibility for the NDIS is defined as having a permanent impairment that substantially reduces functional capacity in one or more of the following activities: i) communication; ii) social interaction; iii) learning; iv) mobility; v) self-care; vi) self-management; vii) social and economic participation (S.24). The NDIS aims to give people with disability greater choice and control so that they can choose support that is consistent with their cultural, religious and personal preferences. The intention is that by giving people with disability more choice their rights will be promoted and they will have increased independence and better outcomes, including enhanced social and economic participation.

People with impairments that vary over time are eligible for the NDIS if their underlying condition is assessed as being permanent, including people with a psychosocial disability. However, the requirement for people with a psychosocial disability to be diagnosed as having a permanent impairment has caused much controversy in the mental health field (Slade and Longden 2015, Brophy 2015 In press). The 'recovery' paradigm, which emphasises hope and the possibility of recovery, is prominent in the psychosocial disability field. Conceptual tensions exist between this paradigm and the NDIS's

3. <http://www.ndis.gov.au/news/media/disability-scheme-supports-everyone-week>

concept of permanent disability. Nicholas and Reifels (2014) outlined these tensions and reviewed the definition of ‘permanent’ disability in Australian and international policy documents. They found that ‘permanent’ is defined variously as two or three years across Australian legislation and guidelines, and other countries often avoid a tight definition by using terms such as ‘permanent’, ‘persistent’ or ‘prolonged’ disability related to mental illness (p.8). This is an area needing further clarification with regard to the NDIS and psychosocial disability. A potential issue is whether NDIS staff have the necessary skills to assess psychosocial disability, especially if the person appears relatively well or stable at the time of assessment⁴.

The NDIS Act 2013 recognises the importance of family carers when it refers to the *Carer Recognition Act 2010* (S3.3), and by including the following references:

- The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected (S4.4.12).
- People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime (S4.4.3).
- Strengthening the sustainability of informal supports available to the person, including through building the capacity of the person’s carer (S25.1.C).
- Planning should:
 - where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant (S31.c)
 - where possible, strengthen and build capacity of families and carers to support participants who are children (S31.d)

- if the participant and the participant’s carers agree—strengthen and build the capacity of families and carers to support the participant in adult life (S31.da).

The NDIS provides a vision of disability support that is radically different to previous block funded disability services. KPMG (KPMG 2014) conducted an initial review of the NDIS implementation and reported that “there is commonality of vision across stakeholders as to the outcomes desired from a future market. However, the detailed design required to achieve this vision has neither been agreed, nor fully conceptualised, by all stakeholders” (p.8). Problems identified that need to be addressed include:

- Policy is driving the implementation without sufficient feedback from those implementing the scheme.
- It is not clear what supports will be provided to people with disability assessed as being ineligible for the NDIS.
- The market that is supposed to provide services is underdeveloped.
- There is insufficient data to inform market modelling to determine pricing and service provision.
- The interface with mainstream services such as health, criminal justice, education, childcare and child protection is not clear.
- There is insufficient data to inform workforce modelling, especially workforce capacity and skills and peer workers, which is a model developing in mental health care.

Despite the good intentions of the NDIS, there are concerns about its ability to provide appropriate and adequate support to people with psychosocial disability (Williams and Smith 2014).

4. <https://mhaustralia.org/civicrm/mailling/view?reset=1&id=368>

These concerns include:

- The possibility of a gross underestimation of the number of people with psychosocial disability eligible for the scheme and consequently available funds being inadequate.
- Whether the scheme has the flexibility to respond to the fluctuating disability support needs of people with a mental illness of an episodic nature.
- Whether access to early intervention psychosocial support will be available given the challenge of predicting ‘permanent’ impairment as required by the NDIS eligibility criteria.
- The readiness of the workforce and service providers to adjust to this fundamental change in service delivery.
- How states and territories will respond to the support needs of the many people who are not eligible for, or choose not to access, the NDIS scheme.
- The difficulty in defining the boundaries between services and whether they are the responsibility of the health system or the NDIS.

Some of these concerns are shared by other individualised funding programs. For example, a Swedish study found that one of their biggest problems was determining eligibility criteria for people with psychosocial disability (Askheim, Bengtsson et al. 2014).

The NDIS also shows a commitment to carers when it says on its website that supports to maintain a carer’s health and wellbeing can be included in NDIS participant plans⁵. This support may include participation in a support group or a special interest network. However,

there are qualifications to this support when the NDIS says that it will take into account what it is reasonable to expect families, carers, informal networks and the community to provide when deciding whether to fund or provide a support. It is not clear what the NDIS will expect family carers to provide before offering assistance.

The Federal Government is intending to support all carers with their proposed National-carer-gateway (Fifield 2015). This information ‘gateway’ will provide information to all carers, including family carers of people with a psychosocial disability receiving NDIS support. However it is currently uncertain what support and information will be provided.

5. <http://www.ndis.gov.au/families-carers/information-families-and-carers>

Method

The method used to find and analyse relevant literature can be described as a ‘critical interpretive synthesis’ (Carey 2012). While evidence was systematically sought consistent with a ‘systemic review’, a broad approach was taken that considered opinions and case studies which fall outside the scientific rigour required for a formal systemic review.

When relevant literature was identified, it was reviewed for themes, narratives and complexity. Analysing complexity was consistent with contemporary ‘realism’ theory (Dalkin, Dalkin et al. 2015). This theory recognises complexity and goes beyond asking whether something works. It focuses on what works, how, in which conditions and for whom, and it considers the context, the mechanisms used and the outcome configurations. In essence, realism looks at the total system and its interconnections. This approach was considered appropriate for reviewing the impact of individualised funding on family carers because of the complexities involved.

Five strategies were used to locate relevant literature from the period 2006 to 2015.

1. The *Scopus* data base was used to source relevant references. Because this data base is comprehensive, no additional data base was used to avoid duplication of results. An initial search using the terms [‘disability’] and [‘personalisation’ or ‘personal budget’ or ‘cash’ or ‘funding’] identified 2,284 documents. Thirty-five subsequent searches were conducted using a combination of the terms: individualised funding, personal budget, cash and counselling, personalisation/ personalization, cash for care, consumer directed care, carer, social care, mental health, mental illness, psy*, disability, Australia, USA, Canada, Europe, United Kingdom, England, Sweden, Norway, Netherlands, Germany, Ireland and New Zealand. When thirty or less articles were identified in a search, each abstract was read for relevance. When more than thirty

articles were identified, a further filter was applied using one of the terms listed above.

2. A Google search was conducted using the terms mentioned above.
3. The author’s EndNote data base was searched using the terms mentioned above.
4. Social policy and disability conference proceedings from Australia and the UK were reviewed using the same search terms .
5. Articles and documents identified in the above searches included numerous references to other papers. When these appeared to be relevant, they were sourced, read and evaluated. For example, Webber et al.’s 2014 paper reviewed eleven UK and four US studies that reported on the effectiveness of individualised funding for people with a psychosocial disability (Webber, Treacy et al. 2014). Items that predated the 2006 search period were included when they had particular relevance and importance.

Few references were found that focused specifically on carers of people with a psychosocial disability using individualised funding packages. Consequently, the search was broadened to include: i) references showing the impact of individualised funding packages on carers of people with all types of disability; and ii) outcomes for people with psychosocial disability and other types of disability when a ‘flow-on’ effect for family carers was indicted. Additionally, the literature review included references that gave a profile of all carers and the contributions they make to provide contextual information.

Of the 91 references included in this literature review, approximately one-quarter were sourced through the Scopus data base searches using the terms noted above, and a further one-quarter were sourced from the list of suggestions Scopus provided showing other articles from the authors listed and additional papers on related topics. Approximately one-fifth of the references came from the author’s EndNote data base. The remaining references

were found through the other methods noted, with the most effective strategy being to follow the trail of references listed in articles and documents.

Milne and Larkin (2015) categorised studies of carers into two groups. One group, *Gathering and Evaluating*, focused on quantitative evidence such as the extent of care-giving, who provided care to whom and the tangible outcomes reported. The authors argued that this category of research dominated public perceptions about caring and had a strong influence on policy decisions. The second group, *Conceptualising and Theorising*, explored the experiential nature of caring. These studies aimed to understand care as an integral part of human relationships with consideration of interdependence and reciprocity. They concluded that elements of both groups should be integrated into research. Consistent with Milne and Larkin's assertion, most of the literature found for this review fell within the definition of their first group. However, this review is mindful of the importance of relationships and includes findings about this dimension when available.

Findings

Key themes and findings from the literature reviewed regarding the impact of individualised funding on carers of people with a psychosocial disability are presented under the following headings: i) family carer benefits; ii) family carer concerns; iii) benefits to people with psychosocial disability; iv) benefits to people with other types of disability; v) critical factors; and conclusion. The division between the benefits for family carers and those they supported is blurred with family carers reporting that they benefitted when their family member's quality of life improved. Consequently, a brief summary of the benefits to participants in individualised funding programs is included.

General themes in the literature reviewed have been identified. However, it is not possible to directly compare findings from all studies because they examined different variables. These included different program designs, varying funding allocations and support arrangements, and participants with different types of disability. It seems likely that people with a psychosocial disability, physical disability or intellectual disability will have different program needs. Because the type and rigour of the methodology affects the validity of the findings and the conclusions that can be drawn, the methodological details of key studies are included in text boxes throughout this section.

Carers experiences of individualised funding in the Australian's NDIS trial in NSW, based on anecdotal accounts from carers, encapsulates many of the findings from national and international research studies (Carers Australia - NSW 2014, Carers NSW 2015). A summary of the NSW findings, including positive outcomes and issues of concern, is presented first because it is local, current and representative of wider findings. This summary is followed by a detailed review of research studies using headings identified in the research.

Positive outcomes for carers in NSW in the NDIS (Carers NSW 2015)

- Greater choice and control
- Funded supports directly supporting their caring role, e.g. domestic assistance, respite, family therapy
- Positive working relationships with NDIS planners
- 'Flow-on' benefits for carers when the NDIS gave their family member improved quality, value and flexibility of disability support, e.g. ability to return to work, less stress, less financial pressure

Individualised funding was reported to provide 'flow-on' effects for family carers when the family member's needs were met, as shown in the following quotes:

"David cares for his adult son Gary, who recently went through the NDIS planning process with the support of his Dad and his service provider. They had a very helpful planner and were very happy with the process. David now gets four times as much respite as he did previously and Gary has sufficient therapy, personal care and domestic help for the first time."

"Recently we opted for direct payment and direct employment of support workers and this is FANTASTIC. A little bit of work to set up but assisted by a bookkeeper who also does payroll of support workers. We promoted one support worker to co-ordinate the support arrange rosters and verify time sheets. We have more choice and control, support is totally tailored to my son, support workers undertake the training we want and we get more bang for our buck."

"Able to access to the therapies required without putting a financial strain on family income."

"Allows me to perform part time work." (p.11).

Issues of concern for carers in NSW in the NDIS (Carers NSW 2015)

As well as positive outcomes, carers in the NSW NDIS (Carers NSW 2015) identified issues of concern. These were:

- The NDIS is not sufficiently focussed on meeting carers' needs.
- A separate conversation between the planner and the carer is only a possibility, not a formal entitlement for carers.
- Many carers struggled to understand and embrace the NDIS due to limited and inconsistent information.
- Not all carers had access to capacity building opportunities.
- Many carers felt unprepared when they attended planning sessions.
- The ability of NDIS planners varied and some did not take the carers perspective into account.
- Many carers found that the NDIS created more administrative work for them.
- Many carers found NDIS plans difficult to understand and implement.

Some family carers did not feel that their needs were being addressed as shown in the following quote:

“Sylvia supports carers in the Hunter trial site. Some carers she has spoken to have had positive experiences with planners, but mostly their experiences have been negative, with some families being told quite rudely that “it’s not about them”. One carer Sylvia spoke to was thrilled with the amount of financial support offered to her son, but was upset that nobody asked her at any time how she was coping.” (p.17)

Some carers had concerns that they would be worse off under the NDIS. They feared that the NDIS does not focus on carers' needs, and because existing state funded services will or might close down and people ineligible for the NDIS might be left with no support.

Personal budgets for carers

In Australia, family carers of people with disability do not have an entitlement to an assessment of their needs or an allocated budget to meet their needs. As noted above, the UK *2004 Carers (Equal Opportunities) Act* gives UK carers the same entitlement to an assessment and an allocated budget as the person they support. However, despite their legal entitlement, UK studies reported that carers rarely had their own assessment or received an allocated budget (Moran, Arksey et al. 2012, Hatton and Waters 2013, Glendinning, Mitchell et al. 2015).

In the Hatton and Waters survey of carers in the UK, only 2.8% of carers reported receiving individualised funding in their own right. However, having their own allocated budget may not be entirely beneficial for carers. It could transfer more responsibility to them for the care of their family member and increase their administrative responsibilities, which is a problem discussed below. Block funded supports for carers can also continue without them receiving individualised funding, hence they might be less attracted to individualised support.

Family carer benefits

- Individualised funding programs provided carers with greater choice and control over services and supports.
- They resulted in better outcomes for family carers and participants compared to traditional block funded service provision with no adverse effects when conditions were conducive (support with planning, adequate funding).
- To achieve positive outcomes the program needed to ensure that the level of information and the support provided matched the level of responsibility managed, there were adequate funds and there were supports and services to purchase.
- Family carers had respite when their family member had appropriate activities and holidays, and some carers returned to work.
- There were ‘flow-on’ benefits for carers when their family member spent less time as a psychiatric inpatient, had fewer criminal justice contacts, was less stressed, gained confidence or got a job.
- There were mixed findings when family carers were employed as paid support workers; some welcomed the opportunity because of the income and it improved their status, while others found that it created tensions in the relationship and they were less appreciated.

This section presents research findings showing the positive benefits of individualised funding to family carers and issues of concern and challenges are presented below. Where possible family carers of people with a psychosocial disability are identified. However, studies did not always distinguish this group from carers in general.

Choice, control and flexibility

A consistent finding in individualised funding studies around the globe was that family carers welcomed and benefitted from having more control and choice of services. They benefitted by being able to organise supports and services to suit their preferences and those of the family member and they had new opportunities. Examples of these were being able to specify what time the support worker attended, and their family member going on a holiday (Bogenschutz, Hewitt et al. 2010, Stevens, Glendinning et al. 2011, Moran, Arksey et al. 2012, Laragy, Fisher et al. 2015). Having control over the money gave people using individualised funding more power and control. As one person in an English study noted, “I’m the piper, I pay the money” (Leece 2010) (p.196).

However, these writers also noted that having choice in individualised funding programs was linked to a wide range of personal and structural factors and potential challenges, which are discussed in a later section. Before people could have choice and control they needed the capacity to make decisions or assistance when required, access to information, adequate funds, services to select, systems to manage administrative responsibilities if they did not want to self-manage or did not have the capacity to do this themselves, services responsive to their needs in a market economy with a profit motive, and the willingness of professionals and staff to share power and control.

Positive outcomes

In the US, the *Cash and Counseling* program was conducted across many states and it was carefully evaluated using comparisons to others receiving agency support. One of their evaluations is of particular note because it included ‘informal caregivers’, nearly all being family members (Brown, Carlson et al. 2007). They found overwhelmingly that individualised funding had a positive impact on caregivers. Caregivers of people using individualised funding were: less likely to report emotional, physical, or financial strain; more satisfied with their life; more satisfied with the care they provided to their family member; and less worried about their family member. Family carers could be paid to work as support workers in this program and this may have contributed to some positive carer feedback as they were compensated for previously unpaid work.

Participants with disability receiving individualised funding were also more likely to report positive outcomes compared to those in the control group. They gave higher ratings for having their needs met and satisfaction with their support workers. The range of their needs studied included daily living activities, help around the house, and routine health care. However, it is noted that the study did not focus on social activities.

Among the UK studies that reported positive outcomes for family carers when their family member used individualised funding was the recent study by Larkin (Larkin 2015).

Larkin, 2015. England. *Developing the knowledge base about carers and personalisation: Contributions made by an exploration of carers’ perspectives on personal budgets and the carer-service user relationship*. Qualitative. Semi-structured interviews with 23 carers of people receiving a personal budget from 11 English local authorities. Type of disability and duration of use of funding unknown. Compared the carer-service user relationship before and after the introduction of personal budgets.

This study illustrates both the range of benefits and concerns mentioned in other studies. Three quarters of the carers reported positive outcomes such as having more control over their lives, more free time, doing more exercise, feeling happier, healthier and being less stressed. Some resumed interests they had dropped such as attending football matches and playing golf because of their caring responsibilities. Just over half felt that their relationship with their family member had been enhanced. Comments included:

“... it’s freed my life up”

“... before ... I felt much more trapped and almost resented it and I don’t anymore’. (p.37)

Interestingly, a third of the carers said their increased happiness was due to the person they cared for being happier. This sentiment was summed up by a carer who said: “Well, if he’s happy, I’m happy. It rubs off, doesn’t it?” (p.37).

Carers in this study also noted a range of concerns. The major concern of over half the carers was the burdensome administrative requirements, especially recruiting and managing staff which was required in the UK program.

Annual surveys of people using individualised funding and their carers have been conducted in England (Hatton and Waters 2011, Hatton and Waters 2013).

Hatton C. and J. Waters. England. Conducted the annual *Poet Surveys of Personal Health Budget Holders and Carers*. POET means Personalisation Outcome Evaluation Tool. Findings came from people using *Individual Budgets* in 2011 and people using Personal Health Budgets in 2013 (Hatton and Waters 2011, Hatton and Waters 2013). Surveys were distributed to participants and carers. The 2013 Personal Health Budgets survey included people managing physical health problems as well as those with psychosocial disability or intellectual disability. Surveys were widely promoted and distributed through some local authorities. The 2011 and 2013 surveys had 434 and 117 carer respondents respectively (not necessarily all family carers).

Carers reported both benefits and challenges, with benefits outweighing the challenges. In the 2011 and 2013 surveys respectively, percentages of carers who reported improvements are show below:

60% and 70% - quality of life;

67% and 69% - support to continue caring;

60% and 52% - finances;

53% and 53% - physical and mental wellbeing;

58% and 44% - choice and control over their own lives;

54% and (no data) - relationships with paid support

The English evaluation of *Individual Budgets* (2008) found that individualised funding led to improved relationships for some family carers and the family member they supported. The team conducted a number of separate studies and produced a number of papers. One study of participants' experiences reported that individualised funding had a positive impact on them and it improved family relationships (Glendinning, Challis et al. 2008).

Glendinning, Challis et al., 2008. England. *Evaluation of the Individual Budgets Pilot Programme*. Randomised control design. 500 participants using 'Individualised Budgets' and 500 receiving traditional support services. Participants could choose the level of administrative management they wanted to undertake and 51% took a 'Direct Payment' which required full self-management. A family member managed the support in over 40% of instances. A limitation was that interviews were conducted only a few months after the program commenced. Consequently, many findings were speculative about what might result rather than reports of what had happened.

Participants were pleased to be able to make financial contributions to activities and outings such as paying for a meal or a bus fare. Although only modest amounts of money were involved, this had a big impact on participants feeling less of a burden on their family because they could 'pay their way'. This study also reported that coordinators who assessed needs and allocated funding spent significantly more time assessing carers' needs compared to those in the control group even when the carer was not having an assessment in their own right (Glendinning, Challis et al. 2008).

Another of the *Individual Budgets* studies interviewed 24 family carers about their experiences of individualised funding (Moran, Arksey et al. 2012).

Moran, Arksey et al., 2012. England. *Personalisation and carers: whose rights? Whose benefits?* Part of Individual Budgets Evaluation Network (IBSEN). Qualitative and quantitative. Telephone interviews with 'lead officers' supporting carer in Local Authority N= 12; face to face or telephone interviews with carers in the 'intervention group' N = 60, and 'control group' N = 69. An additional 24 interviews were conducted with a sub-group of carers. A limitation was that interviews were conducted 3-6 months after program commenced when systems were still being developed and outcomes were unclear.

Carers with a family member using individualised funding were significantly more likely: to have higher scores on the single-item quality-of-life measure; be fully occupied in activities of their choice; have no outstanding needs for social participation and involvement; and feel in control of their daily lives. Although not statistically significant, carers of people using individualised funding compared to those in the control group had lower levels of need, had higher self-perceived health, and were more likely to appraise their care-giving role positively. Overall, the key benefits that carers identified were:

- having greater choice, control and use of their time
- improved quality of life for their family member receiving support, and
- enhanced family relationships.

Positive examples included being able to employ a support worker to do work that family carers had previously undertaken, and their family member using funding to develop independent living skills and relationships with people outside the family.

Several carers reported that contributing to their family member's assessment of need gave them the opportunity to request and receive the supports needed. Although the services and supports allowed were not always what they wanted, having greater choice resulted in more opportunities. For example, one carer said:

“... when [my daughter] used to go away to respite and she hated it, there was a guilt element to sending her . . . because I was tired, or because I needed a break. Whereas now, if she goes away to [selected service] for three days, and I recharge and I have a fantastic time, I know that she's also having a fantastic time, it takes that guilt element, so you're more likely to do it (Parent of daughter with intellectual disability)” (p.473).

Flow-on benefits for family carers

When there were benefits for a person using individualised funding it often appeared that there were benefits for family carers as well. A later section will report on benefits to the person receiving support and this section presents findings from two studies that explicitly recorded benefits to family members.

The English study by Larsen et al. (2015) is of particular interest because it focused on outcomes for people with psychosocial disability using individualised funding (personal budgets) and it commented on expected outcomes for family carers even though none were interviewed.

Larsen et al., 2015. England. *Outcomes from personal budgets in mental health: service users' experiences in three English local authorities*. Qualitative interviews. Convenience sampling recruited 47 people with psychosocial disability using 'personal budgets' in three English local authority areas. Family carers were not interviewed.

The majority of participants (34 out of 47) reported improvements in their mental health and emotional wellbeing when using individualised funding and they spoke about feeling more relaxed, more positive, more confident, less stressed, less depressed and having a better quality of life. These improvements were attributed to having more control and using their funding flexibly. They structured daily routines to build social relationships and had more participation in activity groups, joined a gym, accessed vocational training which led to employment, paid for childcare so they could attend psychotherapy sessions which improved their confidence and for some this resulted in employment, and one person had a support worker provide personal hygiene instruction at home which eliminated infections and other physical health problems. Of particular note is that many participants thought their positive

outcomes had a positive 'knock-on' or impact effect to the lives of family and friends.

Another English study reported similar findings (Cheshire West & Chester Council 2010).

Cheshire West & Chester Council 2010. *Findings from the personal budgets survey*. England. Purposeful sample, all types of disability including psychosocial disability. Questionnaires were sent to participants with a separate sheet for their family carer. 31 % response rate and 203 questionnaires completed. The proportion of sample with a psychosocial disability was not recorded, nor the number of family carers who responded.

This study is of interest because it sought the views of family carers. However, their responses are not clearly distinguished from the participants in the program. The sample included, but was not restricted to people with a psychosocial disability. People with disability using 'personal budgets' reported similar benefits to those described above. Over half said their 'quality of life' and 'respect from those who support them' had improved, they liked having greater choice and control and being able to use the funds flexibly, they had increased leisure and social activities, which included seeing friends and family, shopping, gardening and having social interaction. Forty-four per cent said their relationships with family and friends had improved compared to two percent who said they were worse. Most thought that the flexible arrangements took pressure off their family carers and allowed them to have a break. The major concern mentioned was the administrative burden of managing direct payments.

Employing family carers

A feature of some individualised funding programs is that family carers can be engaged as paid support workers, either employed directly by the family member or through a support agency. This is controversial with both advantages and disadvantages being identified. Findings from a number of international studies are presented below.

A study in the Netherlands that examined payment to family carers conducted an extensive literature review before collecting their data (Grootegoed, Knijn et al. 2010).

Grootegoed, Knijn and Da Roit, 2010. Netherlands. *Relatives as paid care givers: How family carers experience payments for care*. Qualitative. Interviewed 17 female paid family carers with at least six months experience of being paid for their support work.

The literature review showed both positive and negative outcomes for family carers, with some findings being all positive and others being predominately negative. Positive findings included family carers benefitting from the income, the recognition of the value of the work they had previously provide for free, and giving them the opportunity to care for a family member when they needed to work for an income. The negative findings included reducing altruistic attitudes, increasing the duration of family obligations, losing the appreciation that was previously given, and empowering the care receiver at the expense of the care giver. Concerns were raised about the lack of subsidiary employment rights such as holidays and days off.

Grootegoed et al.'s (Grootegoed, Knijn et al. 2010) study of paid carers excluded those caring for relatives with a psychosocial disability. The reasons for this exclusion were not explained. Possibly the authors thought that family carers of people with a psychosocial disability may have different working conditions to other family carers. The findings showed mixed and partly contradictory responses. Most care givers liked the payment as it recognised and raised their status as carers. Some also found that that the formal contract helped manage strained relationships by enabling a clearer differentiation of care tasks from affection. On the other hand, some carers felt a greater obligation to provide high-quality care, and found that they were thanked less often and received fewer tokens of gratitude. These findings suggested that being a paid family carer suited some people in certain circumstances and not others. However, the authors overarching concern was that family carers would be “led into a cul-de-sac of reduced labour-market value and limited employment rights” (p.486).

In the US *Cash and Counseling* program described above, one of the evaluations compared the impact on participants when supported by a paid family member with support from a non-family support worker (Simon-Rusinowitz, Mahoney et al. 2005).

Simon-Rusinowitz, Mahoney et al., 2005. USA. *Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation*. Part of series of qualitative and quantitative randomised control design evaluations of the *Cash and Counseling* program involving thousands of participants in 15 states across the country. This paper reported on an Arkansas study with sample of 417 paid family workers and 99 paid non-family support workers. Surveys were conducted nine months after people commenced the program.

The study identified few differences for participants, although some had better outcomes when employing a family member. For example, those with a paid family support worker had fewer respiratory infections, bed sores or pressure sores and their overall satisfaction rating was 99% compared to 91% for non-family support workers. While concerns were raised by the authors about family caregivers being overburdened and losing respect, family caregivers reported high levels of satisfaction with the care arrangement overall.

Another US *Cash and Counseling* program evaluation confirmed the positive aspects of employing family carers (Simon-Rusinowitz, García et al. 2010).

Simon-Rusinowitz, García et al. 2010. USA. *Cash and Counseling evaluation. Qualitative*. Interviews conducted with 15 and 16 paid family carers in two (unidentified) states respectively.

Participants liked receiving support from a family member, and the paid family carers found the work satisfying. It was advantageous to them not having to choose between paid work and caring for a relative, especially those in low-income families. However, one concern raised was that paid family carers needed more information about policies and guidelines regarding payments.

A further study from the *Cash and Counseling* evaluations found that family members receiving payment generally liked this arrangement. However, it was noted that many spent the funds on goods and other services for their family member (Norstrand, Mahoney et al. 2009). They received few direct benefits themselves.

In New Zealand, providing an option to pay family carers has been hotly debated. The Government initially had a blanket policy of not paying family carers. However, in 2000 seven parents and two people with disability took a complaint to the Human Rights Commission (HRC) and argued that family carers had the right to be paid (Bookman 2012). They eventually won their case after appealing to the High Court and the Court of Appeal (Ministry of Health v Atkinson and Others). In 2012 the Government began a series of consultations to determine the content and implementation of new policies to pay family carers (Ministry of Health 2012). Carers New Zealand (2012) have campaigned strongly for full time carers to be paid a wage commensurate with that paid to agency support workers for 40 hours of work per week, and for this income to be treated favourably in terms of tax and benefit assessments.

One English study of *Direct Payments* interviewed support workers and found that almost half had been providing support informally to their employer (the person with a disability who was the participant in the program) prior to their employment (Leece 2010).

Leece, 2010. England. *Paying the Piper and Calling the Tune: Power and the Direct Payment Relationship*. Compared those using individualised funding and those receiving agency based support. Qualitative and quantitative. 32 interviews: individualised funding participants with physical disability N=8; traditional agency based home care recipients with physical disability N = 8; individualised funding workers N=8; traditional agency based home care workers N= 8. Two questionnaires to measure stress and job satisfaction.

The study concluded that individualised funding may benefit informal carers who receive payment for work that was previously unpaid.

Family carer concerns

- Administrative responsibilities were a concern to many, but not all carers, when they were required to recruit and direct support workers, manage taxation and insurance requirements, find services and activities and acquit financial accounts without adequate support.
- Accessing information about policies and program guidelines was often difficult.
- Family carers were left to 'pick up the tab' for hidden costs or when funding was inadequate.

Many of the factors that led to positive outcomes listed above also had a 'flip side' with aspects that were potentially negative and needed to be managed. Although greater choice, control and flexibility were widely welcomed, they also brought concerns and challenges. This section will present concerns and issues that were entwined with, and accompanied the positive aspects.

Administrative demands

A major concern for many people was the administrative burden of self-managing individualised funding when no or little support was designed into the program. This was a particular burden for family carers of people with a psychosocial disability when they struggled with the paper work in individualised funding programs (Hamilton, Szymczynska et al. 2015). The administrative tasks included recruiting and directing support workers, managing taxation and insurance requirements, finding services and activities and acquitting financial accounts. As noted above, there were programs that provided this administrative support free of charge, with some making its use mandatory. In other programs administrative support could be purchased either from within the program or from an external agent. Many people used these supports when they were available because they did not want to self-manage all requirements (Moran, Arksey et al. 2012). However, it needs to be noted that some people wanted to manage these tasks, especially when they had previous business experience and self-management resulted in them having more funds available to purchase support (Moran, Arksey et al. 2012). In Australia when Carers NSW Australia surveyed its members, 57% want to self-manage their allocated funds if this option becomes available (Broady 2014).

Many family carers who were obligated to manage these administrative tasks found them onerous (Glendinning, Challis et al. 2008, Norstrand, Mahoney et al. 2009, Cheshire West & Chester Council 2010, Larkin and

Milne 2014). These difficulties were often exacerbated when systems and guidelines were complex and difficult to understand (Norrie, Weinstein et al. 2014). These tasks and responsibilities were stressful for many carers and sometimes caused tensions in relationships between couples (Moran, Arksey et al. 2012). There are also many 'hidden' costs that are usually not adequately remunerated.

The administrative pressures are captured in the following quotes

“What if I overspend?’ ‘I don’t want to owe people money.’ ‘What if I don’t fill the form in right?’ ‘What if there is no money left?’ ‘What if they cut my budget?’ ‘I can’t recruit anyone!’” (Glendinning, Challis et al. 2008) (p.73)

“My husband, who has his own health problems, does his best to help me in the absence of my PA (personal assistant) and does paperwork such as time sheets, account sheets, holiday sheets, logs all monies in and out, and all of this is unpaid which if an outsider was doing this would be paid. Why this difference because he is a family member? This is not physical but it is time consuming and somewhat costly paper, ink, disc etc. for computer.” (Cheshire West & Chester Council 2010) (p.19)

Utilising family resources

The intent of individualised funding programs is to use funds flexibly, which includes merging public funds and private resources to maximise opportunities (Glendinning, Challis et al. 2008). The literature provided examples of where this can be difficult for participants and their families because they can be under pressure to 'top up' the allocated funds when they are inadequate.

Are family carers' rights being upheld?

Australia's *Carer Recognition Act 2010* recognises the rights of family carers. However England's 2004 Carers (Equal Opportunities) Act gives carers the right to an assessment of their needs, but this appears to rarely occur. In the study of carers conducted by Moran

et al. (Moran, Arksey et al. 2012) described above, their in-depth interviews with 24 family carers found that none had an assessment of their needs or resources allocated to them. The aspirations of family carers were not considered. Notably, the carers did report 'flow-on' benefits when their family member gained better supports through individualised funding, especially when the planner took a holistic approach and considered the carer's needs. However, their rights and needs were not directly addressed.

One of the studies conducted as part of the *Individual Budgets* program evaluation raised similar concerns (Glendinning, Mitchell et al. 2015).

Glendinning, Mitchell et al., 2015. England. *Ambiguity in practice? Carers' roles in personalised social care in England*. Qualitative. Three part study consisting of: i) separate interviews with a selected sample of carers and the older person they supported (N=4), and carers and the person with an intellectual disability they supported (N=11); ii) an online survey of 16 adult social care departments about policies; and iii) interviews with administration staff in three councils.

This study examined whether carers in the UK had their needs assessed as distinct from those they supported. They began with the premise that the needs and priorities of family carers are not always aligned with the family member they support. Overall the study identified that carers' needs were not being addressed as the legislation had intended. A small number of carers did have their own assessment meeting and those that did valued the opportunity to talk in private about their needs. A few others declined the offer as they felt they did not need a meeting. However, none were asked about their wider aspirations related to employment, learning and leisure, as required by the 2004 Act. The usual practice was for only one assessment meeting to occur and this focused on their family member's needs.

Carers were often reluctant to discuss their needs in the presence of their family member, and they resented being asked if they were “willing” to continue providing support in a way that assumed they could and would. The study concluded that implementation practices tended to restrict carers’ rights and prioritised the needs of those they supported. These practices included staff perceiving carers primarily as a resource and interpreter of needs of the person they supported, and staff not asking carers about their support needs. As found in the Moran et al. 2012 study, carers sometimes had ‘flow-on’ benefits from their family member gaining better supports through individualised funding. However, the study concluded that

carers often facilitated the empowerment of their family member at the expense of meeting their own needs, and carers needed a separate assessment meeting separate to the person they supported.

In the Australian context, the dilemmas of separating the rights and needs of carers of a family member with intellectual disability were discussed by Fyffe et al. (2015). The authors argued that by referring to the development of respite programs to give the primary carer a short-term ‘break’ it reinforced the solely negative dichotomy of overwhelmed carers and dependent people with disabilities. They concluded that new policies and practices are needed to better integrate the perspectives of family carers and those they support in ways that both parties can benefit from.

It is often assumed in Australia that family carers will provide care and sometimes accommodation for the whole of their lives (National Rural Health Alliance Inc. and National Disability and Carer Alliance 2013). The human rights of both the carer and the person with a disability are seen to be violated by this unspoken assumption. A study undertaken by the National Rural Health Alliance Inc. and National Disability and Carer Alliance found that people with disability wanted to become independent

of their parents similarly to people without disability. They concluded that the human rights, developmental needs and life goals of both the people with disability and their carers should be accepted and facilitated by policy and program delivery.

Further evidence that family carers are often taken for granted by policy makers and researchers is shown in reports that overlooked and excluded them. One example is the *A WAY FORWARD: Equipping Australia’s Mental Health System for the Next Generation* report (Hosie, Vogl et al. 2015). This report examined the “financial costs to the individual, government and society” (p.23) of psychosocial disability. It considered the financial costs of psychosocial disability in terms of health costs, unemployment and disability payments as well as “out-of-pocket expenses incurred by patients and their families, such as travel, co-payments and expenditure in the home” (p.24). However, it did not consider the life time financial impact on family carers who are often disadvantaged by reduced income as detailed by the Australian Bureau of Statistics and discussed above (Australian Bureau of Statistics ABS 2012).

People with disability

- People with a psychosocial disability who participated in individualised funding programs benefitted in terms of less time in psychiatric hospitals and criminal justice settings and a better quality of life.
- They had no adverse outcomes when given appropriate support.
- Having greater control over spending and a wider range of flexible support arrangements resulted in positive outcomes.
- There were positive ‘flow-on’ effects to their family carers.

While the focus of this report is on family carers, a brief summary of the benefits of individualised funding for people with psychosocial disability is included because of the likely ‘flow-on’ effects to their family carers.

A study of people with a psychosocial disability using individualised funding in the US was conducted by Shen et al. (2008) using a control group.

Shen, Smyer et al. 2008. USA. *Does Mental Illness Affect Consumer Direction of Community-Based Care? Lessons From the Arkansas Cash and Counseling Program*. Qualitative & quantitative. Randomised controlled design. ‘Experimental group’ using individualised funding N = 109; ‘control group’ receiving traditional agency support N = 119. Extensive range of quantitative measures analysed. A feature of the program was providing at no cost support and advice (referred to as counseling), assistance with hiring and managing support workers, and a bookkeeping service to fulfil fiscal responsibilities. Participants had the option to nominate family members or a friend to make decisions on their behalf. The monthly budget was used to purchase goods or employ support workers, and family or friends could be employed.

The participants using individualised funding gave statistically significant higher scores on most measures compared to those who received agency support. They gave higher ratings to their perceived quality of life, their overall care arrangement, service delivery time and reliability and satisfaction with their support workers. Importantly, the statistical analysis found no significant differences between those using individualised funding and the control group with regard to adverse events and general health status. The authors

concluded that individualised funding can provide benefits to everyone with no additional risk as long as appropriate supports are provided. This included people with a psychosocial disability who had better outcomes and no adverse effects. Three factors were identified that contributed to the positive outcomes:

- The option to appoint a representative (a family member or friend) to help with decisions.
- Consultants to provide information and support.
- The assistance of a bookkeeping service to manage the fiscal responsibilities.

A second study of people with psychosocial disability in the US found that the introduction of individualised funding led to participants spending significantly less time in psychiatric inpatient and criminal justice settings and they showed “significantly better functioning” (p.600) (Cook, Russell et al. 2008).

Cook, Russell et al., 2008. US. *Economic Grand Rounds: A Self-Directed Care Model for Mental Health Recovery*. Case file audit examining qualitative and quantitative factors. N = 106. Method of sample selection is unknown. Individual data records were examined in the year before using individualised funding with those after its commencement.

In England, when individualised funding was initially introduced few people with a psychosocial disability took up the opportunity. Consequently a pilot program was created to encourage their use. The evaluation of this program found that individualised funding was being used creatively to assist participants with domestic and other practical matters so they could live independently, as well as assist with their education, work, personal relationships and social life (Spandler and Vick 2006).

Spandler and Vick 2006. England. *Opportunities for independent living using direct payments in mental health*. Qualitative interviews evaluated pilot program for people with psychosocial disability using individualised funding. Interviews with ‘direct payments’ recipients with psychosocial disability N = 27; interviews with interviews care coordinators, local authority ‘leads’ and support workers N = unspecified.

One woman said:

“...having a PA (personal assistant) I can say ‘I want to go to London next Saturday, can you come with me?’ This gives you that bit of independence that you can go and do something. All right you’re taking somebody with you, but it’s on a different relationship ... The dynamics are different and you’re the one that is in control ... so it’s like being on my own in a way and having that freedom.” (p.111)

The UK evaluation of *Individual Budgets* discussed above (Glendinning, Challis et al. 2008), which had ‘intervention’ and ‘control’ groups, reported that participants with psychosocial disability using individualised funding had statistically significant higher quality of life scores. The contributing factors were thought to be having higher levels of control over spending and the wider range of flexible support arrangements available.

A range of benefits for people with psychosocial disability using individualised funding in England were reported above under the heading ‘Flow-on benefits for family carers’ (Larsen, Tew et al. 2015). These included employment and social activities and a better quality of life.

The studies above focused exclusively on people with a psychosocial disability. The following studies include people with a

psychosocial disability along with those who have other types of disability and the elderly.

Interestingly, the Glendinning et al.(2008) study which was described above, found that people with a psychosocial disability had the most positive outcomes in terms of overall well-being compared to all others in their study. Participants had many different mental health diagnosis and levels of severity and it was concluded that the flexible funding allowed a greater range and flexibility of support arrangements than were available to others to meet their needs.

A Germany study of individualised funding focused on risk and found legal liability for the use of funds poses the greatest risk to people self-managing in individualised funding programs (Junne and Huber 2014).

Junne and Huber, 2014. Germany. *The risk of users’ choice: exploring the case of direct payments in German social care*. Qualitative interviews with participants receiving ‘direct payments’ (N=14), support workers, care assistants, plus staff from disability service providers and local authorities (N=23). The study included people with a psychosocial disability amongst others.

A detailed discussion of risk is presented below. In addition, they found the greatest benefit to participants was having more control over support services. People appreciated being less dependent on service providers and having increased self-determination.

The US *Cash and Counseling* evaluation, which is described above, reviewed data gathered across numerous states and reported many examples of participants using individualised funding in flexible and creative ways (Norstrand, Mahoney et al. 2009). Their examples included purchasing home exercise equipment when wintery conditions made it difficult to leave the house and attending physical therapy sessions.

In summary, opportunities from using flexible individualised funding included the following examples:

- Purchasing a hot tub to decrease pain from arthritis
- Paying for a dog service to provide mobility assistance and cognitive and psychological support
- Repairing a specially modified van to access the community
- Purchasing home exercise equipment when wintery conditions made it difficult to leave the house to attend physical therapy sessions

Critical factors

- Choice and control over funding that could be used flexibly
- Information about program policies and spending guidelines and available services
- Planning support to consider needs and aspirations and plan services accordingly
- Support services to manage administrative responsibilities when required
- Support and oversight to manage risks
- Organisations and staff working from empowerment principles who were willing to share power and control
- Adequate funding
- Availability of appropriate services to purchase

Factors that contributed to positive outcomes in individualised funding programs in the studies reviewed are summarised in the box above. Additional factors that impacted on family carers as well as the family using individualised funding are noted below.

Information and support

Information is essential before people can make informed choices and take control of their support services in individualised funding programs (Laragy, David et al. 2015). Access to information was identified as critically important in numerous studies. Examples of studies that emphasised the importance of accessing information and support were:

- The Australian study conducted by *Carers NSW* which found that carers' highest priority was accessing information (Broady 2014). Carers wanted information about services, finances, legal issues and access to respite.
- The German study on risk which found that participants who did not have adequate information sometimes inadvertently transgressed the rules and had to repay funds (Junne and Huber 2014).
- The English study from the *Individual Budgets* evaluation team (Baxter, Glendinning et al. 2008).
- The US study from the *Cash and Counseling* team which found that programs were compromised and ineffective when carers, participants, case managers and other staff did not understand program guidelines (O'Keeffe 2009).

In response to the need to develop new information strategies, an Australian website called *Clickability*⁶ was launched in the NDIS Barwon region with plans to expand nationally. This is similar to the *Trip Advisor* website in that it lists services, and it gives service users and service providers the opportunity to post comments and provide feedback. Currently there has not been an evaluation of this initiative so it is not possible to comment on its effectiveness.

6. <https://clickability.com.au/>

Closely linked to the need for information in individualised funding programs is the need for participants and their family carers to have appropriate support to negotiate the complex rules and regulations that govern the program, and manage administrative responsibilities as discussed above.

An English study that focused on people with a psychosocial disability and their family carers (Hamilton, Szymczynska et al. 2015) found that family carers played an important role in helping their family member access information, navigate the system and negotiate funding.

Hamilton, Szymczynska et al., 2015. England. *The role of family carers in the use of personal budgets by people with mental health problems*. In-depth qualitative interviews with 18 family carers and 12 people with a psychosocial disability using individualised funding. Three local authorities purposively selected the sample to achieve maximum diversity of geographical spread. The study explored experiences of family involvement in accessing and managing personal budgets for a person with mental health-related social care needs, but not outcomes.

Carers often heard of individualised funding opportunities through carers' events or groups.

The study also found that family carers who had been recruited through peer networks were better informed and more proactive than other carers. The study indicates that peer support is an effective means of disseminating information and supporting family carers.

No single mechanism was identified that provided the necessary information and support in the individualised funding programs reviewed. The level and type of support needed depended upon the responsibilities

that participants and family carers carried. Strategies for providing the necessary support included: peer support (Joseph Rowntree Foundation 2004, Hamilton, Szymczynska et al. 2015); participants and family carers being involved in the development of policies and guidelines (Mahoney, Wieler Fishman et al. 2007); and developing the capabilities of planners, case managers and other staff to provide empowering and not patronising support (Hamilton, Tew et al. 2015).

Programs that provided these supports reported successful outcomes. The US *Cash and Counseling* program for people with a psychosocial disability (Shen, Smyer et al. 2008) is an example of a program that provided these supports without charge to the participant and it received overwhelmingly positive feedback. Participants were allowed to designate family or friends to help make decisions regarding their care; and it offered support and advice (counseling) to hire and manage support workers and manage fiscal responsibilities so that all participants with all levels of ability could use individualised funding. This design overcame the problem of participants often being reluctant to pay for these supports from their allocated funds, especially when their budget did not fully meet their needs .

In the literature reviewed, some but minimal attention was paid to how ethnic and other vulnerable groups in society could access information. Overall, the needs of people from ethnic and minority groups have been overlooked in individualised funding programs and they miss out on possible benefits (Laragy, David et al. 2015). Although one English study tried, it had difficulty recruiting family carers of people with psychosocial disability from ethnic backgrounds (Hamilton, Szymczynska et al. 2015). Little is known about the needs of family carers in these groups. It seems likely that participants and their family carers who are Aboriginal or Torres Strait Islander, from culturally and linguistically diverse (CALD) backgrounds or have low socioeconomic status miss out on information because they do not

connect with mainstream media campaigns. This finding suggests that specially designed communication strategies are needed to reach out to these groups in the community's language and in culturally appropriate ways.

Planning meetings

Australia has followed England's example in designing the NDIS to use formal planning meetings as the hub of their assessment, planning and support process. Notably some other countries such as Sweden did not use planning meetings in this way and instead had a separate assessment of personal needs that determined the person's budget (Laragy 2010). In Sweden, once funds were allocated there was no requirement for them to be acquitted against a plan and people were allowed to use the money flexibly.

There have been mixed findings from England regarding the extent to which family carers have been included in individualised funding planning meetings for their family member. Two papers by Hamilton and colleagues (Hamilton, Szymczynska et al. 2015, Hamilton, Tew et al. 2015) reported that family carers, including family carers of people with a psychosocial disability, were usually excluded from planning meetings and most participants did not expect to have a 'voice' and express their opinions. They also reported that many staff dominated meetings and insufficient time was allocated to address matters adequately.

In contrast to these pessimistic findings, two additional English disability studies and one Australian study from the aged care sector found that most family carers played an active role in planning meetings. The Australian KPMG (KPMG 2012) evaluation of consumer directed care for older people reported that carers, particularly younger carers with prior experience of community care, were proactive in expressing what supports they wanted. The English surveys of carers (Hatton and Waters 2011, Hatton and Waters 2013), found that the vast majority of carers (86.5%) felt that their views were fully included in the support plan of the person for whom they were caring. The English study by Moran, Arksey et al. (2012)

reported that most carers were involved in planning for their family members, although it is not known if they were formal meetings or information discussions. It appears that practices and experiences vary across the local authorities that administer planning in England.

Organisational change

A major barrier to family carers and participants utilising the flexibility and potential benefits of individualised funding programs is the procedural and cultural changes organisations need to make to transition from traditional service provision to individualised funding. This transition is complex and challenging and it requires power and control to be transferred from the professionals and support staff to people with disability and their family carers. Significant system changes are required to provide financial accounts and allow greater flexibility. Numerous studies across the globe have identified that a major barrier to this transition is organisational culture and staff attitudinal changes. Studies indicate that strong leadership and proactive organisational change management strategies are required. This has been identified in Germany by Junne and Huber (Junné and Huber 2014), in the US by O'Keeffe (2009), in England by Glendinning, Challis et al. (2008) and Larsen, Ainsworth et al., (2013), and in Australia by Laragy and Ottmann (2011) and Laragy and Allen (2015).

"We're having to undo many years of people's rigid thinking in terms of service users about, 'I know what's best for you'. And I think that has existed in psychiatry for a long time. And I've heard psychiatrists say, 'But I know what's best for you. I know what you need'. But they don't. It's an arrogant statement. We actually need to point out to service users, 'Maybe the reason we don't want you to do that is because you could get hurt, and we can see it'. But again, it's about risk learning. You know, it's positive risk taking. And we're not good at that. And so that's fear for us." (Care co-ordinator, mental health) (Glendinning, Challis et al. 2008) (p.171)

Risks

Concerns have been raised about risks in individualised funding programs associated with the flexibility, autonomy, choice and control they provide. These concerns include the possibility that vulnerable people with disability might be harmed or exploited (Manthorpe and Samsi 2013), and that the funds might be used inappropriately (Glendinning, Challis et al. 2008). The NDIS (2015) identified two types of possible risk to the person. One was the risk of the person receiving poor quality supports, and the other was that the person could be actively harmed in some way.

The German study by Junne and Huber (2014) described above, concluded that the greatest risk to people using individualised funding was their financial liability and not their personal safety. People faced risks related to transferring money, insufficient liquidity and cash flow, possible sanctions if they violated expectations of ‘appropriate use’ of the funds, and difficulties negotiating with the funders who often delayed payments. Because spending guidelines were not clear in that program, participants sometimes overstepped what administrators considered to be reasonable. One woman spent funds on horse riding therapy which was later disallowed, and a man was declared bankrupt when he was unable to repay funds when requested. It was noted that this situation was exceptional because the man had other debts and he used his disability funds to pay these.

Similarly, a Scottish study by Homer and Gilder (2008) concluded that the biggest risk for participants was their legal duties and obligations as employers when they employed support workers. The report recommended general awareness training and a 24/7 legal telephone advice line to manage these risks. The overall finding in both studies was that people using individualised funding face serious financial and legal risks when the appropriate supports are missing.

Recent Australian commissions demonstrate that vulnerable people, with and without disability, face a range of risks (*Commonwealth Royal Commission into Institutional Responses to Child Abuse*⁷, *Victorian Inquiry into the Handling of Child Abuse by Religious and other Organisations*⁸). Unimaginable emotional and physical abuse has been inflicted on vulnerable people by staff in Australian organisations. It also has to be acknowledged that there is risk of vulnerable people being financially abused by their family. The Law Institute of Victoria’s report showed that Victorians lost \$57 million in 2013-14⁹ through the abuse of powers of attorney, which were usually held by a family member. Clearly individualised funding programs cannot remove risks of physical and emotional abuse by staff and financial abuse by families. The key questions to consider are whether individualised funding increases risks, and how can any risks that do exist be managed to minimise harm.

The large scale US *Cash and Counseling* program evaluation looked for evidence of abuse and exploitation when people managed their funds and found it was ‘nearly non-existent’ (Brown, Carlson et al. 2007). This program provided support and advice without charge and had administrative checks and periodic telephone calls and visits to protect against exploitation. The English *Individual Budgets evaluation* (Glendinning, Challis et al. 2008) received allegations of exploitation and abuse by family and physical abuse including rape by support workers. While this evaluation conducted at the early stage of the program’s implementation could not substantiate these allegations, procedures were quickly tightened to address possible concerns.

Proponents of individualised funding programs argue that giving people greater choice and control will enable them to avoid abusive situations and more research needs to be done to investigate this. The above findings also suggest that having support and monitoring mechanisms will minimise risk.

7. <https://www.childabuseroyalcommission.gov.au/>

8. <http://www.parliament.vic.gov.au/fcdc/article/1789>

9. <http://www.liv.asn.au/Practice-Resources/News-Centre/Media-Releases/New-powers-of-attorney-laws-to-improve-protections.aspx>

Austerity

Austerity measures in the UK resulted in substantial cuts to disability funding and these impacted negatively on individualised funding programs. Family carers were concerned that planning decisions for their family member were determined by efforts to reduce spending (Hamilton, Szymczyńska et al. 2015); and that they are often left to 'pick up the tab' when public funded supports did not meet care needs (Larkin and Milne 2014). The cuts have been so severe in the UK that their commitment to the human rights of people with disability is now in question¹⁰.

Austerity measures have reduced the effectiveness of planning processes because of time constraints on staff. Some staff have: had less time to develop co-productive relationships and explore a range of opportunities; not offered individualised funding if it is likely to place more demands on their time; and offered individualised funding to people with psychosocial disability when they were too unwell to make informed choices or to manage the funds (Hamilton, Tew et al. 2015).

Another negative impact of austerity measures in England was funds only being allocated for essential personal care and not for social or leisure activities. This has resulted in higher levels of psychological ill-health and lower levels of wellbeing (Moran, Glendinning et al. 2013).

One English study examined the impact of austerity measures on the professional / service user relationship in individualised funding programs (Lymbery 2014). The cuts had grievous negative consequences on services because the eligibility criteria were tightened, higher fees were charged, there were staff shortages and excessive workloads. The authors concluded:

“It is hard to be optimistic about the future role of social work with adults, given the particular circumstances of the local government sector within which most are employed. Given that the austerity measures have forced a seismic shift in the organisation and structure of all local authorities, it is difficult to imagine a reversal of the current trend for fewer social workers to be employed in more tightly prescribed settings within local government.” (Lymbery 2014) (p.807)

It is difficult to determine if concerns arising from individualised funding programs result from insufficient funding or service design problems, or possibly both. However there does seem to be recent evidence from the UK that adequate funding is essential.

Market economy

There has been an international trend for countries to move from government provided support services for people with disability and the elderly to a mixed model market economy with a combination of for-profit and not-for-profit services. The models vary greatly and each country has designed a system that reflects its social structure and values (Ungerson and Yeandle 2007). Across Europe, countries that rely on family carers such as Germany, France and Austria funded programs that supported families to employ domestic workers. In contrast, Denmark, Finland, Sweden and Belgium encouraged a more entrepreneurial approach and funded individuals to engage companies to provide these services, even if a company was a single self-managing person (Kvist 2012). Differences were observed between countries in their political commitment to a free market model. Ireland showed a strong political commitment to a market economy while the Netherlands developed a more regulated model (Timonen, Convery et al. 2006).

10. <https://kittysjones.wordpress.com/2014/08/16/uk-becomes-the-first-country-to-face-a-un-inquiry-into-disability-rights-violations/>

In Australia, the Productivity Commission promoted competition and a market model when it proposed the NDIS (Productivity Commission 2011). The private consulting firm KPMG endorsed this approach after evaluating the early implementation of the NDIS (KPMG 2014). Notably, KPMG considered the impact of the NDIS on family carers and concluded that a market model will benefit them by extending choice and opportunities.

A literature review of ‘cash-for-care schemes’ in Scotland looked at the complexity within programs across Europe and the US. It concluded that a market model offers more choice and results in better outcomes as long as there are effective controls to counter open market forces and good management (Rummery 2009). A Swedish study came to much the same conclusion, while raising concerns about the working conditions of support workers who were mostly women, and often from minority ethnic groups (Kvist 2012).

A mixture of opinions about a market economy came from England. Some authors concluded that markets and competition can result in greater flexibility and better outcomes if carefully managed and adequate funds are provided (Glendinning 2012). However, others were more critical, especially in an environment of austerity. For example, Lymbery (2014) was concerned about equity issues and feared the capable will flourish while the most vulnerable will be more disempowered (Lymbery 2014).

Overall, the literature review indicates that the market economy is well entrenched in disability service provision. The challenge is to put mechanisms in place that ensure the most vulnerable participants in individualised funding programs are able to benefit.

Conclusion

This literature review found that the design of individualised funding programs determines the impact on family carers. The carers, and their family member, have more positive outcomes compared to traditional agency controlled services when conditions are conducive. The conditions required to achieve these positive outcomes are access to information, support to match the level of administrative responsibility carers are expected to carry, adequate funds, and access to supports and services. The positive outcomes for family carers are that fewer demands are placed on them, they have reduced stress and more opportunities to undertake activities for themselves. In addition, they have ‘flow-on’ benefits when their family member has improved mental health and a better quality of life. A number of risks for carers have been identified. These are:

1. A risk for carers is the administrative responsibilities of managing and accounting for funds on behalf of their family member when they do not have the necessary expertise. Notably, some programs avoided this risk by providing information and support services free of charge.
2. Another risk is the possibility of inadequate funds being allocated to their family member to meet his or her needs. This leaves the family to ‘pick up the tab’ and provide the necessary support.
3. Family carers from minority groups have additional risks of being overlooked in individualised funding programs. These include family carers who are Aboriginal and Torres Strait Islanders, from culturally and linguistically diverse (CALD) backgrounds, or from low socio economic backgrounds.

Most individualised funding programs did not give family carers their own assessment of need or allocate funding to them in their own right. Even in England where legislation formally gave them this entitlement, it rarely occurred in practice. However, even without funding being directly allocated to family carers, they benefitted when they lobby effectively on behalf of their family member to secure better funding and support. To be able to take this proactive role, family carers often needed support to build their confidence and skills. There was strong evidence for peer support through education programs and informal groups that was found to be effective in developing these abilities. If governments want family carers to have a proactive role in the continued support of their family member, the evidence suggests that governments need to finance and facilitate peer support programs to develop carers' abilities. This will maximise the potential that individualised funding programs offer and improve the quality of life of both family carers and participants.

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