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# Optimising self-directed funding for the long-term disabled

Briefing Document

February 2015

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**The National Trauma Institute (NTRI) Forum:** The NTRI Forum is a three-year project that aims to improve the care of brain, spinal cord or other major traumatic injuries. The NTRI Forum's model involves defining the major challenges through consultation with key stakeholders to understand the issues and complexities; gathering and summarising from publications and further consultation the information necessary to properly consider each challenge; convening stakeholder dialogues to connect this information with the people who can make change happen; and briefing the organisations and individuals who can effect change about their role in developed strategies. For more information visit [www.ntriforum.org.au](http://www.ntriforum.org.au)

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# Table of Contents

Executive Summary ..... 4

Background..... 6

Aims and Terms of Reference .....10

Overview of evidence for self-directed funding .....12

Questions for Deliberation .....21

References.....22

Appendices .....24

## Executive Summary

People with long-term disabilities have become increasingly frustrated with the inadequate support services provided by the disability sector. In particular, people with long-term disabilities want to have support services which met their needs as well as greater choice and control in the decisions around them. Over the last five years the popularity of self-directed funding has increased significantly. In 2011/12 the Australian Government made a commitment to implement a National Disability Insurance Scheme (NDIS) as advised through an inquiry by the Productivity Commission to have full rollout country wide by 2018. Self-directed funding is used as a mechanism to promote self-determination and empowerment in people with long-term disabilities and to facilitate their living in the community independently. Self-directed funding can be provided by an individual package held by a provider, by an individual budget held by the person to spend through providers or by direct payments to spend on the open market.

The implementation of self-directed funding models has been implemented in various forms over the past couple of decades, including the piloting of small scale programs and the introduction of larger scale programs by government bodies or departments in specific disability groups. Self-directed funding models are strongly established in the UK, USA and Western Australia. The inclusion of infrastructure supports such as independent brokers, financial intermediaries and ongoing support for clients are beneficial features of established models, particularly for people with complex needs. Despite their popularity, there is a lack of evidence about the effectiveness of self-directed funding models in practice, and no evidence comparing different models. No single model has been demonstrated to be superior to another, likely in part because the cultural and political context in which a scheme is introduced has a strong influence on its design, implementation and outcomes. Despite this, there are consistent indications that offering flexible and creative options within models is the best approach for ensuring people with more complex and potentially unmet needs, have an opportunity to take up self-directed funding successfully.

There are limited studies of the feasibility and impact of self-directed funding for people in the compensable sector with catastrophic injuries. Qualitative studies using interviews or questionnaires reveal that, generally, people with long-term disabilities recognise that self-directed funding should be one option among the range of options for receiving necessary support services; however, there is variability in the stated willingness to take on self-directed funding themselves. A lack of awareness of what is involved in self-directed funding and how it can be managed has been reported. In addition, it has been suggested that not all people have the skills, education or experience to manage self-directed funding, hence training and information sessions that are understandable and comprehensive are likely to be necessary in order to encourage uptake.

This NTRI Forum aims to consider the factors which influence the uptake of self-directed funding by the long-term disabled.

Two questions were identified for deliberation in a Stakeholder Dialogue:

1. What are the barriers and facilitators to optimal implementation and uptake of self-directed funding in Australia and New Zealand?

2. How can knowledge of barriers and facilitators be used to address these challenges?

An accompanying document (Dialogue Summary) will present the results of the deliberation upon these questions.

## Background

Funding for the provision of care and support services to people with long-term disabilities has not been optimal to facilitate their independence and empowerment within the community. Block funding (or the traditional approach) – in which government agencies or service providers who manage or control the provision of services for people with disabilities - is no longer the most common or widely accepted as the only available approach. A new approach is emerging as being widely accepted amongst those in the disability sector. This consumer-directed or self-directed approach allows a person with a disability to have control and choices in how their disability support funding is spent. No longer are people with disabilities seen to have a passive role in the choice and management of their care and support.

This change in approach is said to have started during the 1970s with ‘the community or independent living’ movement in which people with disabilities (or their families) went against large-scale institutional accommodation as being the only available option to meet their care and support needs (deinstitutionalisation)<sup>1</sup>. During this time the term ‘normalisation’ was used to promote the change, although people with disabilities still did not have the right to make their own support decisions. The United Nations (UN) published a document in 1975 known as “The United Nations Declaration of the Rights of Disabled Persons” which laid the foundations to end segregation occurring for people with disabilities<sup>2</sup>. Following this, the International Year for Disabled Persons (1981) was declared, and the rights of people with disabilities to have personal assistance and live independently were strongly promoted. Less than 10 years ago the UN convention mandated governments worldwide to enable people with disabilities the opportunity to use their rights to have a say in the services and supports that they receive<sup>3</sup>.

### **Context for self-directed funding**

In the last couple of decades, several countries have committed to and promoted a consumer-directed or person-centred approach to service delivery for people with disabilities - Canada, the United Kingdom, Sweden, Germany, the United States of America (USA), and Australia more recently.

#### *Internationally*

Canada first started its approach to self-directed funding in 1982 with a program for people with developmental disabilities (Special Services at Home, SSAH)<sup>4</sup>. Sweden and the USA were next to introduce and promote a consumer-directed approach. In Sweden, two Disability Acts were written into policy in 1993 for people with acquired brain injury, permanent physical or mental impairments and severe intellectual disability or autism - the “Support and Service for Persons with Certain Functional Impairments Act (LSS)” and the “Personal Assistance Act (LASS)”<sup>3</sup>. In 2006, there were more than 17,000 people reported to be receiving the care and support they needed and wanted.

A project was initiated in 1996 in New Hampshire (USA) to commence ‘self-determination funding’<sup>4</sup>. Pilots in Florida, New Jersey and Arkansas known as the “Cash and Counseling Demonstration and Evaluation (CCDE)” were also conducted as initial efforts in the sector. Also in 1996, the “Community Care (Direct Payments) Act in the UK was enacted allowing small, restricted disability groups to have control in managing their funds and employing

support workers directly. This model is now available to all people with disabilities in the UK (Health and Social Care Act, 2001) and has also been mandated in Scotland (Health and Community Act, 2002)<sup>3</sup>. Although both countries enacted these Acts in close succession, the uptake of the program in Scotland was not as fast as that observed in the UK.

### *Australia*

Western Australia was one of the first states or territories in Australia to initiate a self-directed funding program on a large-scale, commencing in 1988<sup>5, 6</sup>. The rationale for the program was in response to the recognition that people with disabilities who lived in rural and remote locations found it difficult to obtain the required support services. The program was offered to people with intellectual disabilities and was seen to be a successful example of the self-directed funding approach worldwide<sup>4, 7</sup>. The state of Victoria has also been an early adopter of providing self-directed funding with the commencement of several programs based on this approach to funding: Futures for Young Adults program<sup>8</sup>, the Victorian Support & Choice program (2003) and HomeFirst (attendant care program)<sup>3</sup>. The current models available in Australia will be discussed in more detail in the section “Overview of the evidence” of this report (pg.12).

The Australian Government recently requested the Productivity Commission to undertake an inquiry into the National Disability Long-term Care and Support Scheme to “examine the feasibility, costs and benefits of replacing the current system of disability services with a new national disability care and support scheme” (Productivity Commission report, pg.3, 2011)<sup>9</sup>. The Productivity Commission held hearings in June and July 2010 and found that “the current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments (pg.2)”<sup>9</sup>. The Productivity Commission recommended that a new national scheme be formed – the National Disability Insurance Scheme (NDIS) – “whose benefits will outweigh the costs involved”<sup>9</sup>. It is hoped that this scheme will provide people with more choice through “so-called ‘individualised funding’ or ‘consumer-directed’ care” whereby “people receive an annual funding entitlement that they can spend on the services they want or can exercise greater control over the services they receive” (pg. 22-23)<sup>9</sup>. The Productivity Commission also recommended “a no-fault National Injury Insurance Scheme, comprising a federation of individual state and territory schemes, would provide fully-funded care and support for all cases of catastrophic injury. It would draw on the best schemes currently operating around Australia. State and territory governments would be the major driver, developing a comprehensive scheme by 2015” (pg.3)<sup>9</sup>.

The Productivity Commission’s paper is recognised as a significant landmark in the history of the Australian disability sector. It is a key step towards achieving equity, inclusion and fairness for all people with disabilities and a better system that is more efficient and cost-effective<sup>9</sup>.

### **What is self-directed funding?**

Self-directed funding is an approach in which “a particular person is allocated a defined package of funding to spend on disability support services of their choosing including the disability support type and who provides the support”<sup>8</sup>. There are many terms that are utilised by and within different countries to refer to self-directed funding (Table 1, overleaf). This does create some complexity but is also reflective of the contextual factors and the stage/s of implementation that help to shape each model.



**Table 1 – Differing terminology utilised for self-directed funding**

Country	Terminology
USA	Self-determination Cash and counseling schemes Personal assistance schemes Consumer-directed care
UK	Direct payments Cash-for-care (individual/personal budgets) Personalisation
European countries	Direct payments
Canada	Self-directed care Self-managed contracts
Australia	Self-purchasing Self-directed funding Individualised funding National Disability Insurance Scheme (NDIS)

The underlying principle of self-directed funding is the same across all countries and states; a person with a disability is directly allocated support funding to use for their care and support provision.

As mentioned, self-directed funding varies based on the cultural and political context in which it is implemented. The way in which it is organised changes according to -

1. The person that holds the funds, i.e. the client, the service provider, or financial facilitator/intermediary,
2. The portability between service agencies,
3. The disability support types the funds are utilised for (e.g. accommodation, respite, community services and management support), and
4. Providers the funds can be spent with.<sup>8</sup>

These components are affected by several factors including the person’s capacity, their preferences and whether they utilise informal support, the availability of support from single or multiple provider types, and legal requirements, policy and program definitions<sup>8</sup>. To ensure that an individual’s preferences are considered in their self-directed funding package, mechanisms include an individual needs assessment, goal setting, planning, flexibility, selecting and purchasing support services.

**Types of self-directed funding**

In Australia, the main approach adopted for self-directed funding is to allocate a portable package of funds to an individual, which is held by a single service provider (except in Western Australia where an individual has total control of the package)<sup>8</sup>. In the former type of package there are restrictions such as the use of only one disability support type, e.g. accommodation support, inadequate funding, and software designed for bulk or block payments only<sup>4</sup>. There are two further options for types of self-directed funding packages: an individual (budget) package held by the person with a disability which can be spent through approved providers; and a direct payment to a person with a disability, their family or a facilitator whereby their funding can be spent through the open market. This latter approach

can be easily tailored to meet the person's preferences and is suited for purchasing non-traditional disability support types<sup>8</sup>. In the former approach there can be a financial or fiscal intermediary who manages the package on behalf of the person with a disability.

There is limited evidence about the experience and outcomes of self-directed funding models. Outcomes used in the evaluation of the effectiveness of self-directed funding in people with disabilities typically include: levels of satisfaction, personal wellbeing, physical and mental health, social (or community) participation and quality of life. One study analysed the social participation outcomes in Sweden, England, Scotland and Australia for clients using self-directed funding programs<sup>3</sup>. It was reported by Laragy (2010) that social participation is a key objective of flexible funding programmes and is “the 'glue' that contributes to a viable and sustainable society and a means to citizens having a good quality of life (pg. 130).”<sup>3</sup> The findings of the study were that flexible funding allows for greater access to social activities (e.g. shopping, employment, education, physical recreation, socialising) and therefore participation; however, the resources within the community need to be adequate otherwise people with disabilities could remain isolated at home. Of all the four countries investigated, Sweden was considered to have “the most supportive and flexible policies” due to their strong commitment to equality; that people with disabilities should be able to follow the same lifestyles as those without. The UK was considered the next most supportive scheme, followed by Scotland and Australia. Laragy argued that the values and expectations of countries their political context and available resources has a strong influence on the experience of self-directed funding for a person with a disability<sup>3</sup>.

## Aims and Terms of Reference

This NTRI Forum focuses on models of self-directed funding for the long-term disabled. It will take account of long-term disabilities in a broad sense, with a specific focus on people with catastrophic injury where evidence is available.

### Aim of the Forum

This NTRI Forum aims:

- To consider the factors which influence the uptake of self-directed funding by the long-term disabled.

### Terms of Reference

This NTRI Forum will address the following specific questions:

1. What models exist for self-directed funding for the long-term disabled? What is the experience of self-directed funding by the long-term disabled? *[Focus of Briefing Document]*
2. What are the barriers and facilitators to optimal implementation and uptake of self-directed funding in Australia and New Zealand? *[Focus of morning discussion at the stakeholder dialogue]*
3. How can knowledge of barriers and facilitators be used to address these challenges? *[Focus of afternoon discussion at the stakeholder dialogue]*

### Context of this NTRI Forum

NTRI Forum topics are identified through liaison with a broad range of neurotrauma research networks and organisations. All potential NTRI Forum topics are submitted to the Victorian Neurotrauma Advisory Council (VNAC) for approval. VNAC is an expert body representing key stakeholders in the Victorian neurotrauma community including the Transport Accident Commission (TAC) and government, health and community services, researchers, and patient advocacy groups. Further information about VNAC can be found at:

<http://www.ntri.org.au/research/vnac>

The topic for this NTRI Forum was identified through liaison with the TAC. This program is funded by the Transport Accident Commission (TAC) and Workcover through the Institute for Safety, Compensation and Rehabilitation Research (ISCR). Online available outputs from this NTRI Forum could be utilised by researchers and other stakeholders to inform or develop projects in related areas. This NTRI Forum topic was approved by VNAC in February 2014.

### **Aims of the briefing document**

This briefing document is directed towards researchers, service delivery and advocacy organisations and other stakeholders with experience and expertise in the provision of self-directed funding people with long-term disability. The aims of the briefing document are to:

1. Provide the background (history) of how self-directed funding came about worldwide and what types of approaches are available
2. Provide an overview of the literature related to self-directed funding models and the experience of people with long-term disabilities
3. Present questions for deliberation at a Stakeholder Dialogue to inform considerations on strategies for self-directed funding approaches, in particular for people with catastrophic injuries [*Outcomes of the Stakeholder Dialogue will be presented in the accompanying Dialogue Summary for this NTRI Forum*]

### **Background and Scope**

This briefing document was prepared to inform a structured stakeholder dialogue of which research evidence is one of many considerations. The dialogue aims to connect the information from the briefing document with the people who can make change happen, and energise and inspire the participants by bringing them together to address a common challenge. This use of collective problem solving can create outcomes that are not otherwise possible, because it transforms each individual's knowledge to a collective 'team knowledge' that can spark insights and generate action addressing the issue.

## Overview of evidence for self-directed funding

A variety of searches were conducted to identify the evidence for self-directed funding programs or models, and the experience from people with long-term disabilities (Appendix 1). The search yielded a total of 2205 citations. Following screening of titles and abstracts, a total of 86 full text articles were retrieved and reviewed against the inclusion/exclusion criteria (Appendix 1). There were 15 relevant full text articles identified. A grey literature search was conducted on Google Scholar using a variety of key terms, e.g. self-directed funding, individualised funding, + people with disabilities, resulting in seven relevant reports. There was one other report that was provided by an expert in the field. This resulted in a total of 23 documents which inform this section of the report.

From the 23 documents identified, there were –

- 3 systematic narrative reviews<sup>10-13</sup>;
- 7 literature reviews<sup>4, 8, 14-17</sup>;
- 3 program/model evaluations<sup>18-20</sup>; and
- 8 primary studies<sup>8, 17, 21-26</sup>.

The topic of self-directed funding support for people with long-term disabilities is a social, public policy topic for which no systematic reviews exist. Therefore, this report draws mainly from systematic *narrative* reviews (SNRs); however, when models have not been included due to scope of the SNRs, literature reviews will be used to supplement the evidence.

### Overview of evidence from the most up-to-date systematic reviews, reviews and primary studies

Three systematic narrative reviews (SNRs) were identified for this report relating to self-directed funding models. One SNR analysed self-directed funding models for people with any type of disability in the United Kingdom (UK), the United States of America (USA) and Australia<sup>10</sup>. The authors identified 52 documents - 7 studies of which were on the Cash and Counseling program run in the USA, 1 on the Individual Budgets program run in the UK and 3 studies programs run in Australia. One SNR analysed 17 studies of people with learning disabilities, specifically in the UK. They were only able to identify 2 studies that were specific to people with learning disabilities<sup>11</sup>. One SNR of which was not directly relevant as it investigated the barriers and facilitators of self-directed funding in the UK models<sup>12</sup>

### International models

*United States of America – Cash and Counseling, Consumer-Directed Personal Assistance Services (CDPAS)*

The USA has two different models of self-directed funding – the Cash and Counseling program and Consumer-Directed Personal Assistance Services (CDPAS).

The CDPAS is highly variable from state to state in the USA. In Michigan, Texas, Maryland, and Washington State there was high satisfaction amongst older people using the CDPAS; however, in California the satisfaction with preferences, choice and unmet needs of older

people were lower. The authors concluded that the lower satisfaction of older people's rapid and fluctuating changes in health<sup>13</sup>. It should be noted that the population is older people and presence of disabilities were not reported. Another study conducted in Washington DC (2008)<sup>27</sup> that was identified in a literature review<sup>4</sup> found that families who participated in a self-directed funding program had high levels of satisfaction with their level of involvement in the decision making process. Interestingly, families also reported that fewer services were received when they had greater control, however they were still satisfied with the quality of the available services.

The Cash and Counseling programs are "designed to provide counselling assistance to support decision making, planning, and fund management" (pg. 567)<sup>13</sup>. Crozier et al. (2013) reported that the funding for these programs was mostly utilised to purchase "workers for assistance in personal care, routine health care needs such as taking medications, housework, and transportation assistance (pg. 459)."<sup>10</sup> Evaluations of the Cash and Counseling programs for people with mental health disabilities reported a positive effect on their personal care and wellbeing, as well as clients having "greater satisfaction with support arrangements and fewer unmet needs"<sup>28</sup>. Crozier et al. (2013) reported that the Cash and Counseling programs are appropriate for people with physical disabilities, mental health problems, children with representatives, the elderly, and non-elderly adults<sup>10</sup>.

### *Canada*

Self-directed funding has long been in operation in Canada. It started in the province of Alberta in the mid-1980s and at present most, if not all provinces employ a self-directed funding approach<sup>15</sup>. A detailed overview of all models and programs in Canada is reported by Chopin and Findlay (2010)<sup>16</sup>. One of the programs in Ontario – the Individualised Quality of Life project – found that it is important to ensure that allocation and administration of self-directed funding be separated from planning and service delivery. It was observed that where provinces first implemented the program at a trial site prior to province-wide implementation there was some loss of flexibility, regional variation, unclear policies (Choices in Supports for Independent Living program, British Columbia) and inadequate monitoring of supports by brokers (Ontario's Choices program). The programs within Canada have been found to be cost-effective in comparison to the traditional block funding<sup>16</sup>.

### *United Kingdom (England and Scotland)*

The most recent model of self-directed funding in the United Kingdom (UK) is the Individual Budgets Program (Direct Payments). These programs started in 1996 in young people with disabilities to promote their independent living in the community. This program allows people with disabilities to "decide how they would receive their allowance, with options including direct payments, payments into joint accounts, or having a local authority manage the money (pg.459)"<sup>10</sup>. As a part of the process, the person must undertake a needs assessment in which the level of funding is decided. The person then makes decisions on the level, type and provider of services, as well as carrying out administrative tasks<sup>4, 8</sup>. A senior manager assesses and approves the person's plan before they can spend the budget on their required care and supports.

All of the systematic narrative reviews in this report included the UK model. One study in particular considered experiences of people with learning disabilities and physical disabilities, as well as older people<sup>29</sup>. This study evaluated the program in 13 pilot sites in the UK and was considered to be a robust study as it included a 'quasi-randomised control trial'.<sup>11</sup> People with physical disabilities were satisfied with the support services they purchased and the quality of the support was perceived to be higher than those who did not self-direct. People with learning disabilities found self-directed funding to have a positive impact on their lives by giving them more control<sup>29</sup>.

### *European countries*

France, Sweden, The Netherlands, Austria, and Italy all have self-directed funding approaches; however, there are limited studies that have evaluated how current models and programs impact on people with long-term disabilities. The most formalised approaches are present in The Netherlands and in France<sup>30</sup>. In the Netherlands, people with disabilities are offered a direct payment that is provided monthly. The model is flexible and provides great control to people with disabilities to use their funding to employ a combination of both formal and informal care supports<sup>4</sup>. Approaches in Austria and Italy are not well-regulated and there are cases of funding being used to employ support care workers whilst paying them low wages 'off the books'<sup>4</sup>.

### **Australian state models**

There are several different funding approaches employed in states and territories of Australia (Table 2). Most have implemented a version of self-directed funding, with the most typical being small-scale pilot projects that undergo evaluation for their effectiveness for consideration of implementation on a larger scale<sup>4, 8, 15</sup>. Western Australia (WA) was one of the first states to provide people with a self-directed funding approach. At present, all funding is self-directed with the exception of particular types of respite and therapies<sup>8</sup>. WA is considering providing the shared management model or microboard to all people with disabilities. The microboard model was developed and has been used in the USA since 2001 (Table 2). A microboard is a "small group of committed family and friends that join and form a non-profit society around a person with a disability who has particular needs for support" (National Council on Disability, 2005)<sup>15</sup>.

Queensland adopted Local Area Coordination (LAC) in 1988; however, it also has individual packages which are held by a provider and currently has introduced hybrid funding models (Table 2). Hybrid funding incorporates "block funding for the service provider to deliver shared accommodation support and individual funding for the person to provide for additional individual care needs and community access (pg. 20)."<sup>8</sup> This type of funding model has been piloted with people who need more support hours.

Tasmania, like Victoria, has implemented Individual Support Packages (ISPs) and provides the person with a disability up to 34 hours/week of personal care and respite<sup>8</sup>. The person is not provided with funds directly; however, they can choose their service provider. Prior to the ISP, Tasmania used the model of group homes for people with intellectual disabilities. Currently Tasmania are trialling direct funding offered to a person through a contract with a non-government organisation (NGO) so they can hire their own staff whilst paying an administration fee to the NGO (Table 2).

The Northern Territory has two types of funding models – ISPs and Disability Case Coordinators and Case Managers<sup>8</sup>. The ISPs are portable, but it may not always be feasible in the Territory's health system, due to the short supply of support organisations and providers. Funds can be used to purchase support from a service provider or the open market. Funding is provided quarterly and requires the person to provide an acquittal form (Table 2).

New South Wales offer two types of funding models: a portable package held by a service provider and direct payment to the person to spend on the open market (Table 2). Some of the programs that are available include: Attendant Care Program (ACP), Extended Family Support program, Community Participation – Self Management Program, Family Assistance Fund (FAF) and the NSW Younger People in Residential Aged Care (YPIRAC) program<sup>8</sup>.



The Australian Capital Territory (ACT) also has adopted the ISP model and has recently started offering Quality of Life grants which are a type of direct payment approach in which small, one-off grants are provided to people to use in the open market<sup>8</sup>. South Australia offers individual portable funding held by a service provider and operates under a brokerage model to registered providers (Table 2)<sup>8</sup>.

#### *The Victorian context*

Victoria has followed suit from WA in committing to self-directed funding since the early 1990s. In 2008, the Victorian Department of Human Services (DHS) created Individual Support Packages (ISPs) for people with disabilities to be able to manage their own funds and choose support services and providers that meet their needs.

An audit of the effectiveness of ISPs was conducted by the Victorian Auditor-General in 2011<sup>31</sup>. The audit found that access to ISPs was time consuming and a difficult process for people to understand. The person's capacity was found to be a strong factor in completing an application, as well as knowing where to go and who to contact to assist them in filling out the application. For people with cognitive disabilities, this could be difficult due to their reduced capacity and may result in them not completing an application.

People who have successfully obtained an ISP have reported it to be 'life-changing' (pg.viii)<sup>31</sup>. The audit concluded that, although many people are interested in what ISPs can do to promote individual choice and independence, there are issues with accessing them due to convoluted eligibility criteria and demand exceeding supply. A total of 1439 people were waiting for their ISP in March 2011, and it was found that some people were waiting up to an average of just under 1.5 years, a problem for those who are may find themselves in a crisis situation without any support funds.

The audit also reported an issue with inconsistencies in prioritisation following assessment of applications by service provider staff or notional amounts of funding not being indicative of the need and urgency of a person. The audit also identified problems arising from inconsistencies in the quality of contracted facilitators, including differences in training and monitoring procedures between internal and external providers.

The audit raised concerns about the quality of monitoring systems in place and reported the model caused significant financial pressures for service providers, with issues related to the inaccurate estimates of unit prices for ISPs. The audit also concluded that certain people did not have access to certain services due to their complex situation or geographical location.

The audit concluded that DHS should provide "clearer policy and guidelines, better resource infrastructure, staff training and monitoring, suitable information systems, and develop a customer-focused culture to help people understand and use the system" (pg.viii). Part of DHS' response to the audit has been to develop a resource allocation tool that can be used in the assessment process to support appropriate allocation of funding<sup>8</sup>.

#### *The compensation environment - Victoria*

In Australia, people with catastrophic injuries such as traumatic brain injury or spinal cord injury are categorised as compensable and non-compensable clients. A model of self-directed funding is available to compensable clients operated by the Transport Accident Commission (TAC) is available to compensable clients and is known as Self-Purchasing<sup>15</sup>. This model is intended to allow clients more independence, choice and control of the



supports and services they receive. An initial assessment is made by the TAC when the client expresses an interest to take up the option of self-directed funding. An agreement is entered into by the client or their substitute decision maker with the TAC in which they can receive a direct payment allocated monthly to purchase services. A broker can also be agreed (by the TAC and the client) to assist in the purchasing of TAC funded support services. A review is conducted as part of the agreement to make sure the client is satisfied and is managing their funds to best support their needs<sup>15</sup>.

**Table 2 – Summary of funding models for states and territories in Australia (adapted from Fisher, K et al, 2010)<sup>8</sup>**

State	Initial model	Individual package held by a provider	Individual budget held by the person to spend through providers	Direct payments to the person to spend on the open market	Future model (beyond 2008)
Western Australia	Local Area Coordination (LAC) Program (1988)	✓	✓ My Place (accommodation support)	✓	- Range of individual funding approaches (including microboards) - Shared management model to be offered to all people with disabilities
Victoria	Portable funding held by a provider	✓ ISPs	✗	✓	Resource allocation tool for improved equity and access to ISPs
Queensland	Local Area Coordination (LAC) Program (1988)	✓	✗	✓	Less emphasis on specialised disability support
Tasmania	Group home model	✓ ISPs	✗	✗	- Direct funding trials with non-government organisation - Provide more funded hours rather than current capped 34 hours
Australian Capital	ISPs	✓ ISPs	✗	✓ (one-off individual grants)	Same as initial
New South Wales	Not reported	✓	✗	✓	Currently undergoing evaluation of models and plan to implement 4 pilots with SDF
South Australia	Not reported	✓	✗	✗	Introduction of a 'self-managed' approach

Northern Territory	ISPs and Local Area Coordination (LAC) Program (2000)	✓ ISPs	x	x	Introduce a more equitable approach
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\*Shaded boxes denote main type of funding model utilised

### National Disability Insurance Scheme (NDIS)

In response to reports that the disability system is fragmented, inadequate, underfunded and inequitable, the Productivity Commission was asked by the Australian government to undertake an inquiry. This inquiry resulted in the production and release of a comprehensive report advocating for the formation of a National Disability Insurance Scheme (NDIS)<sup>9</sup>. At the end of 2011, the government committed itself to planning and implementing this scheme using an advisory group. It is important to note that the new scheme will occur alongside existing compulsory Motor Vehicle Accident Insurance and Workcover Schemes, but the Productivity Commission also recommended a second scheme be created for people with catastrophic injuries – the National Injury Insurance Scheme, NIIS<sup>32</sup>. Several NDIS trial sites have commenced around Australia, however the full rollout of the scheme will not occur until 2018. At present, there is limited information available on the status of the NIIS implementation strategy and timeline for its rollout in Australia but is thought to occur following the completion of the NDIS.

The NDIS is composed of three tiers with most of the funding directed at Tier 3, which is for people with ongoing, permanent (long-term) disabilities that have significant impact on their lives requiring high care and support. As part of this Tier, people undergo an assessment followed by planning of their ‘care package’ or support program. The person is able to choose formal or informal providers and utilises a voucher system to purchase their supports. If a person has a strong desire they can have their package ‘cashed out’ to control their own care and support in a way that they feel is most appropriate to their needs (self-directed). There is also an option for people who cannot manage their care package, are not able to choose providers themselves (due to cognitive impairment), or do not have a suitable carer to be provided with an independent broker by the NDIS. Two other options exist that specifically for people with disabilities who find themselves disadvantaged due to their geographic location or exist in marginalised groups such as Indigenous Australians are the assessment process and local area co-ordination (LAC). The local area co-ordination approach involves local based authorities (coordinators) that operate in conjunction with the central government to build strong partnerships and collaboration with people with disabilities, their families and the community. It operates through a natural and community support approach hence there are no specified prescribed supports<sup>14</sup>. The coordinator works in a defined geographical location that may include several different types of disabilities and age groups. Western Australia and Scotland both have the LAC program approach available and New South Wales and Queensland have also applied this approach to certain rural/remote locations. This approach is thought to be cost-effective as it makes use of limited resources available in the community<sup>32</sup>.

The Productivity Commission proposed that Allied Health professionals undertake the role of assessors in the NDIS. Allied Health professionals, particularly social workers, are seen as appropriately trained to be involved in brokerage, local area co-ordination and assessment roles due to their professional competencies such as personal engagement and relationship building. Training is intended to ensure a standardised, equal approach can be applied for all people with disabilities so everyone will have access to the same entitlements (pg.14)<sup>9</sup>.

### *Self-directed funding program/model evaluations*

Following the reports of Fisher et al. (2010)<sup>8</sup> and Kirkman, M (2011)<sup>4</sup>, three other reports were identified which have evaluated pilots of self-directed funding models in South Australia (SA)<sup>19</sup>, New Zealand<sup>20</sup> and the Saskatchewan province in Canada<sup>18</sup>.

In 2009, Community and Home Support South Australia commenced the Phase One of their Self-managed funding initiative. The Department for Communities and Social Inclusion (DCSI) commissioned an evaluation of the initiative by Jenny Pearson & Associates in January 2011<sup>19</sup>. A total of 62 participants were enrolled at the time of the evaluation with 56 having signed a self-managed funding agreement. Participants were able to choose a financial intermediary and host organisation as well as having a Facilitator provided in their self-managed agreement. Once a person has put together a plan with their facilitator it is presented to a Self-managed Funding Panel who make recommendations for approval. An agreement is signed with the person and the DCSI. Surveys (9 months post-commencement) and focus groups (2-3 months post-commencement) with participants in the program were undertaken to understand the experience of self-managed funding and report outcomes of the program to consider in further phases.

Qualitative data analysis revealed that participants found the program provided them with greater control, choice, independence, decision making, well-being, empowerment and flexibility than to before taking up self-managed funding<sup>19</sup>. All participants (except one who had a package held by a host organisation) took up the option of receiving direct payments to use to purchase support services from service providers. Participants also reported that the increased number of hours and sessions of support that they needed were possible and the range of types of services was increased with self-managed funding. Most participants felt that self-managed funding had met their expectations. The information that was provided was felt to be easy to understand, useful and adequate; however, the amount of information was 'big' and 'daunting' (pg. 14)<sup>19</sup>. The use and ongoing availability of facilitators was highly valued by participants. Participants also reported that some agencies were either unaware of, not willing or not ready for the self-managed funding initiative. Administration of funding on a day to day basis was reported to work well.

An evaluation of self-directed funding in New Zealand, termed individualised funding (IF), was commissioned by the Ministry of Health in 2011. The evaluation involved over 40 interviews with people who had IF, host providers and Ministry of Health staff. In 2008 there was only one host provider for IF (Manawanui in Charge) providing IF to 130 people and this increased in 2011 to more than 10 host providers providing IF to over 1000 people<sup>20</sup>. In both 2008 and 2011, people with IF reported feeling satisfied, empowered and in control. However, there was limited flexibility in options within IF, such as specified hourly rates and types of services available to purchase. For some people it was felt that IF brought a range of financial risks that in most cases related to the employment of support workers, e.g. redundancy payments and a lack of appropriate training. The evaluation also revealed that although more people are taking up IF, service utilisation remained stable.

In 2010, families in several provinces around Canada asked the Government to provide them with self-directed funding for disability care and support. In Saskatchewan, Canada, the Ministry of Social Services, Community Living Service Delivery (CLSD) offered self-managed contracts to families of young people with intellectual disabilities<sup>18</sup>. A study evaluated the impact of self-managed contracts on people with intellectual disabilities and their families using interviews, and also investigated the reason some families prefer to remain with traditional block funding rather than take up self-managed contracts. Overall, people with self-managed contracts reported that this option should be made available with all other service options, however they did recognise that they are not suited or appropriate for

everyone<sup>18</sup>. The self-managed funding contracts are reliant on clients or their families having time, energy, resources (money and creativity), and this may not be manageable for some people or families. The evaluation found that people described their experiences of services before self-managed contracts as poor, inadequate, unstable, made them feel isolated, insecure, stressed, worried and concerned about the effects on other family members. The previous service model was group homes and often involved moving people from one residence to another.

In terms of the process of obtaining a self-managed contract the evaluation reported mixed reactions among people. Some people found the process to be ‘strenuous’ but, due to their education and employment background, were able to continue through it. There were others who found the process difficult, as they had less education and experience in writing applications; they reported receiving no assistance or support<sup>18</sup>. Most people reported that the duration of the process took ‘many years’, making them feel insecure. They also felt undermined by staff in terms of their knowledge and competencies in handling the application process. Some people reported that the level of funding on self-managed contracts was still inadequate for their needs and said they felt high levels of anxiety that they would lose the funding they had, so did not want to discuss it with other people. The evaluation concluded that further improvements need to be made so that more people will see the benefits that self-managed funding contracts can provide.

#### *Features of effective self-directed funding models or programs*

Chenoweth and Clements (2009) reviewed international and local models of self-directed funding and identified common features that are needed for models/programs to be effective<sup>15</sup> –

- A good system for allocation of individualised funds, linked to person-centred planning for support needs;
- Allocation of some block funding to build capacity of services, when implementing IF and self-directed support;
- Local area coordination, so that local needs and preferences shape local services;
- Implementation in phases
- Provision of Infrastructure supports ( e.g. service brokerage; fiscal intermediaries; and case managers) separate from the service system;
- Minimising bureaucracy;
- Alternative quality systems to those based solely on organisational frameworks;
- Increased access to mainstream services, and increased capacity of mainstream services to respond to specialised needs;
- Best practice approaches underpinning the system and models of service delivery; and
- Blended formal and informal supports.

The profile of individuals in Australia most likely to take up self-directed funding are “people of working age with low support needs, male and non-Indigenous service users, people with one disability and people without informal care networks. This applies across disability types and disability support services (pg.v)”<sup>8</sup>.

#### **Primary studies**

There were a total of 8 primary qualitative studies identified which were not included in the systematic narrative reviews – 5 studies involving interviews<sup>8, 21, 23, 25, 26</sup>, 2 studies involving a survey<sup>22</sup> or questionnaire<sup>8</sup>, 1 cohort study<sup>24</sup>, and 1 case study<sup>17</sup> (1 study did interviews and questionnaires<sup>8</sup>). A summary of the study findings and their conclusions are provided in Table 1 (Appendix 2).

Overall, the primary studies revealed several features of self-directed funding models –

- There are mixed reactions to taking up self-directed funding models. Some individuals are enthusiastic about them due to their greater control and choice in support services, whilst others are satisfied with traditional models and providers managing the services for them. There is increased responsibility in taking up self-directed funding which can be stressful for some people, particularly those who do not have the education level or experience to manage them. In general, people want to have the option of self-directed funding available in conjunction with other service options.
- People who take up self-directed funding have to develop skills to manage their care such as accounting and negotiation of services ‘shrewdly’. It is important to have ongoing support available for clients, particularly as the disability sector changes with time.
- There appears to be a lack of awareness about what is involved with self-directed funding; therefore, providing public information sessions or making information widely available that is easily understood whilst comprehensive is beneficial.
- A case study design involving clients in the compensable sector explored different arrangements made for managing funds. They reported that employment of family members by clients was not optimal rather funds managed by people external to the family unit who have the skills to do most things on their own and are prepared to put the person’s needs first were more successful. The establishment of a company structure was also considered a worthy approach to management of self-directed funding particularly from multiple locations, and it is essential that the person with the disability and the fund managers have a trusting relationship.

## Summary

In summary, there is great variation in self-directed funding models, in part due to the differences in the socio-political context across countries, states or jurisdictions. Available evidence indicates that not all models/programs are suitable for every type of person with a disability. There needs to be flexibility and/or options within models/programs for more complex situations, and to be able to access more specialised ‘non-traditional’ disability support services in the community. There also needs to be creativity applied to self-directed funding models in rural or remote areas where services are limited, i.e. microboards or local area coordination (LAC).

It is hoped that the National Disability Insurance Scheme (NDIS) will be a key step forward in providing greater access to needed supports, higher satisfaction and independence for people with disabilities in Australia. Evaluation studies of small scale models/pilots provide in-depth insights into the effect of self-directed funding programs from the perspective of the person with a disability. This information is valuable for informing the components of larger scale models, for development of more effective processes and to increase the satisfaction of people with disabilities.

## Questions for Deliberation

1. What are the barriers and facilitators to optimal implementation and uptake of self-directed funding in Australia and New Zealand?
2. How can knowledge of barriers and facilitators be used to address these challenges?

*An accompanying document, the Dialogue Summary, presents results of deliberation upon these questions from the Stakeholder Dialogue.*



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## Appendices

### Appendix 1

#### Box 1 - NTRI Forum search methods to identify self-directed funding models for the long-term disabled

##### Search methodology

- Comprehensive searches of the following databases from January 2009 until August 2014 were undertaken: MEDLINE (search strategy below); All EBM; CINAHL Plus; PsycINFO; APAIS; Proquest; Embase; Scopus and Sociological Abstracts.
- Google was also searched using the terms “individualized or self directed funding” combined with “people with disabilities” with the date restriction from 2009 -2014. The first 100 results were screened.
- Reference lists of included studies were also scanned to identify further relevant references.

##### Inclusion/Exclusion Criteria

**Patient group:** People with long-term disabilities (i.e. physical, cognitive etc.)

*Exclusion* – People *without* long-term disabilities

**Intervention:** Self-directed funding programs or models, and the experience of these from people with long-term disabilities or their carers/families

**Phase of care:** Community

*Exclusion* - None

**Study type:** All study types (systematic reviews, organisational reports, e.g. TAC, MAA, NZ ACC if available), primary studies not included in systematic reviews, case studies, reviews (literature, historical)

*Exclusion* - None

**Date Range:** 2009 - Current

**Language:** English

##### **Example of search strategy (Medline) –**

1. Financial Management/
2. Health Resources/ec [Economics]
3. (disabled or disability).ti,ab.
4. or/1-3
5. ((self directed or self-directed or individual or individualised or individualized or self or person or person-centered or direct) adj3 (payment\* or financial support\* or funds or funding)).ti,ab.
6. Self Care/
7. or/5-6
8. and/4,7
9. limit 8 to yr="2010 -Current"

**Appendix 2, Table 1 - Overview of primary studies of the experience of self-directed funding for the long-term disabled**

Study/ Country	Design/Methodology	Participants/type of disability (n=?/total)	Findings	Conclusion
Rees, K, 2014  Australia	Case study	Person with a disability (originally a compensation settlement) (n=1)	<p>A number of components have contributed towards the success of a self-directed approach:</p> <ul style="list-style-type: none"> <li>• Establishing the frameworks within a company structure so that the support could be managed from a range of locations.</li> <li>• Not to employ family members but instead employ people who are expected to operate as adults and to assume responsibility for organising their own work, managing small budgets and selecting new team members.</li> <li>• Writing a handbook which contains information related to supporting the person with a disability.</li> <li>• Establishing an external team who will provide information, support, guidance as well as reality checks.</li> <li>• Continuing to ask: whose needs are being served?</li> </ul>	Successful outcomes have occurred where there is a sense of partnership between trust fund managers and compensable individuals and their supporters, with attention being placed on ensuring the funds last for as long as possible while at the same time being managed in innovative and individually responsive ways.
Inoue, M et al, 2014  USA (West Virginia)	Cohort study	Individuals, who participated in the self-directed care program within the Medicaid Aged	<ul style="list-style-type: none"> <li>• People with disabilities are interested in and able to save for the purchase of goods/services that enhance</li> </ul>	Incorporating budget authority in long-term care delivery system would be one way to enhance the

		and Disabled Wavier (ADW) Program, called Personal Options and filed applications for a purchase of goods/services under this program between Sep 2009 to Aug 2011 (n=181)	<p>their welfare.</p> <ul style="list-style-type: none"> <li>• Items related to improvement in personal functioning and household equipment were requested the most.</li> <li>• Reveal needs that were unmet under the traditional Medicaid HCBS program.</li> <li>• Creating programs with greater potential to effectively respond to these needs may be important for people with disabilities.</li> </ul>	capacity of people with disabilities to better meet their needs.
Junne and Huber, 2014 Germany	Interviews	Individuals involved in direct payment schemes; n=14 budget users (disabled people), n= 11 care assistants, n=9 employees of care providers, n=3 administrators or local authorities/n=37 (total)	<ul style="list-style-type: none"> <li>• Direct payments created new liabilities for service users. Once they had accepted direct payments, they became responsible and liable for the appropriate use of that money.</li> <li>• In this study, no evidence that direct payments was being used to cut the overall cost of care.</li> <li>• Users responded to 'risks' through a form of anticipatory self-control and self-management and normalised behaviour.</li> <li>• As a result (of these risks), budget users and their assistants needed to have or develop skills that were not required under former care regimes: such as the</li> </ul>	The very freedom granted by direct payments requires users to subject themselves to an entrepreneurial economic rationale which has effects far beyond questions of care.

			capabilities to organise their own care, to manage their finances, to keep their accounts, to fight for their right to use the funds autonomously and to negotiate shrewdly.	
Broady, T, 2014 Australia (NSW)	Survey	Carers across NSW - n=878 (45.8%) caring for individuals from the disability sector/n=1916 (total)	<ul style="list-style-type: none"> <li>• 57.1% of carers from the disability sector indicated that they would take the option of managing their own IF should it be made available to them.</li> <li>• Three most common reasons for not wanting to manage their own IF were: too complicated, lack of time and lack of skill.</li> <li>• Most common identified needs were: information sessions, a support person/organisation, financial advice, legal advice and additional respite to allow more time.</li> <li>• Concerns include: service access (whether there would be an impact on either the availability or cost of services), carer burden (felt that they would be forced into taking on additional burdens they perceived with IF).</li> </ul>	The survey results indicate two main issues regarding the introduction of PCAs and IF: 1) carer's awareness and understanding of these concepts is low; and 2) there are specific areas of concern where carers require comprehensive information and education. By understanding specific areas in which carers have expressed apprehension, service providers and governments can better informed as to how to encourage people with disability and their carers to engage with PCA and IF, and how to assist them adequately in negotiating the changing landscape with the disability service sector.
Rees, K, 2013 Australia	Semi-structured interviews	People with a disability who have SDF (n=19), people with a disability without	<ul style="list-style-type: none"> <li>• Through the use of self-directed funding, increased satisfaction levels for people</li> </ul>	The report concludes with a number of recommendations

		<p>SDF (n=6); and Family members who manage SDF (n=21), family members interested in SDF (n=4)</p> <p>Mostly government funded, however 2 participants were in a compensation system and one was in a combined</p>	<p>who have undertaken these arrangements were observed.</p> <ul style="list-style-type: none"> <li>• Critical factors that may encourage long term success of self-directed arrangements: <ul style="list-style-type: none"> <li>○ Have widely available and easily understood information about what is involved.</li> <li>○ Be aware of personal implications such as having pig-headed determination and accepting that not all things are going to be done perfectly.</li> <li>○ Have a careful monitoring of routine practices in place.</li> </ul> </li> <li>• Majority of participants would recommend self-direct arrangements.</li> <li>• Concerns were raised about self-directed approaches not being promoted very well (large number of people have not heard of it).</li> </ul>	<p>pertaining to the development of a robust monitoring and evaluation framework that can be incorporated into the future of DisabilityCare Australia's National Disability Insurance Scheme.</p>
<p>Dew A et al, 2013</p> <p>Australia (Rural NSW)</p>	<p>Focus groups interviews</p>	<p>N=97 service providers and n=78 carers of people with disability living in rural NSW (children 0-6 yrs with specific diagnoses including Autism Spectrum Disorder and cerebral</p>	<ul style="list-style-type: none"> <li>• Benefits of IF include greater access to and choice of therapy providers.</li> <li>• Barriers identified: <ul style="list-style-type: none"> <li>○ lack of information and advice,</li> </ul> </li> </ul>	<p>This study highlights the need for further discussion and research about how to overcome the barriers to the optimal use of an IF model for those living in rural and remote areas.</p>

		palsy)	<ul style="list-style-type: none"> <li>○ limited local service options and capacity (in particular for rural and remote areas),</li> <li>○ higher costs and fewer services capacity (in particular for rural and remote areas), and</li> <li>○ complexity of self-managing packages.</li> </ul>	
Arskey and Baxter, 2012  UK	Semi-structured interviews	<p>Sub-sample of 30 individuals (n=5 young people, n=13 parents, n=12 working-age adults and older people) from a full study sample comprised of 98 participants from the following groups:</p> <ol style="list-style-type: none"> <li>1. young people with life-limiting conditions (e.g. Duchenne Muscular Dystrophy) and their parents</li> <li>2. working-age people with fluctuating conditions (e.g. multiple sclerosis) or the sudden onset of poor health (e.g. stroke)</li> <li>3. older people with fluctuating conditions or the sudden onset of poor health</li> </ol>	<ul style="list-style-type: none"> <li>● It is important that advisers draw attention explicitly to potential long-term consequences of suing direct payments at the outset, in addition to providing information about issues of immediate relevance.</li> <li>● Frustration among recipients predominantly caused by lack of continuing support and clear guidance on use of direct payments.</li> <li>● Authorities to consider giving more flexibility for direct payment users to 'carry over' unspent money which could be drawn on when their needs increase temporarily.</li> <li>● Authorities to recruit 'expert direct payment recipients' to promote direct payments among potential recipients.</li> </ul>	<p>This paper explored the positive experiences and challenges that disabled people of all ages face in using direct payments over an extended period of time. The findings show direct payments recipients need support in understanding long-term issues that might arise, as well as on-going monitoring and advice from knowledgeable practitioners as their situations, needs and capabilities change through time.</p>

<p>Fisher, K et al., 2010</p> <p>Australia</p>	<p>Interviews and questionnaires</p>	<p>People with disabilities/ family members Disability service providers Policy officials (Total n=81)</p>	<ul style="list-style-type: none"> <li>• Overall, people with disabilities and their family members were often-always satisfied with individual funding in Australia (61.7%).</li> <li>• Profiles from CSTDA and surveys show that individual funding is more likely to be used by people of working age with low support needs, by male and non-Indigenous service users, by people with one disability rather than multiple disabilities and by people without informal care networks.</li> <li>• While some people with disabilities believed their individual funding should have a greater scope in what it could purchase and how it could be spent, generally individual funding was viewed as highly flexible.</li> <li>• Some of the difficulties encountered by users of individual funding include lack of administrative support, insufficient information for managing their funding and cumbersome and expensive government accountability processes.</li> </ul>	<p>All people using individual funding said it had improved control, choice, independence and self-determination in their lives. They attributed these positive results to the better control they have over the way they organise their disability support.</p>
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