

It's not just about the support:  
Exploring the ways in which family  
members and people with disabilities  
evaluate their self-directed / self-  
managed arrangements

Project Report

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## **Disclaimer**

The information contained within this report is based on a consultative process with a number of family members and people with disabilities who are currently self-directing or self-managing their support arrangements, or have an interest in doing so at some future point.

The opinions, comments and/or analysis expressed in this document are those of the author or authors and do not necessarily represent the views of the Minister for Disability Reform and cannot be taken in any way as expressions of government policy.

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## ***EXECUTIVE SUMMARY***

### **Introduction**

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) is examining ways in which care and support can be provided to people with disabilities through an insurance approach. Through the Practical Design Fund (PDF) initiative, this project was commissioned to explore the ways in which people with disabilities and family members evaluate self-directed / self-managed arrangements. This report provides findings about the literature related to this field, as well as information acquired from semi-structured interviews with people with disabilities, family members and significant other people who are currently self-directing / self-managing arrangements, or who have expressed an interest in doing so at some future time. The report also considers the implications regarding evaluation practices, and draws together implications for future consideration for the DisabilityCare Australia national disability insurance scheme.

### **Background**

This project had five main aims which included conducting a literature review on content related to maintaining, monitoring & evaluating self-directed / self-managed arrangements over time; consulting with a number of people who are currently self-directing / self-managing support arrangements or who wish to do so at some future time; developing, trialing and refining simple English tools that may assist people to manage the evaluation process in self-directed / self-managed arrangements beyond the lifespan of the project; making recommendations related to sustaining self-directed / self-managed practices over time that could be incorporated into the broader development of the NDIS; and preparing the project report within the nominated time frame and within available resources. The project was conducted across five Australian states over a three month period.

### **Study questions**

The study was operationalized by asking the following research questions:

- What are the reasons for considering self-directed / self-managed arrangements?
- What supports facilitate the implementation and establishment of an effective self-directed / self-managed arrangement that can be maintained over time?
- What level of monitoring are family members and people with disabilities prepared to accept with managing self-directed / self-managed arrangements over time?

- What are the critical success factors for monitoring and evaluating self-directed / self-managed arrangements?

## **Project findings**

The project achieved its objectives regarding the literature review, with an examination of a number of journal articles, reports, and other documents referring to what is known about self-directed / self-managed practices that incorporate flexible funding approaches, the impacts of these arrangements on individuals, concerns arising from this approach, and the implications related to monitoring and evaluative strategies over time. While these arrangements are not new, considerable interest has been placed over the years on specifying what self-direction and flexible funding means to government, service structures and individuals. While this has traditionally been achieved through the use of specified budgets that people use to select, purchase and manage their own supports within an established framework of guidelines, over time people with disabilities have progressively become active citizens who have the right to assert and exercise control over their supports and life, instead of being a passive recipient of pre-purchased services.

Through the use of self-directed, flexible funded approaches, increased satisfaction levels for people who have undertaken these arrangements have been noted by a number of researchers. However, these arrangements require diligent attention with the practical aspects of monitoring the daily, weekly, monthly, and quarterly requirements. While this requires attention on paperwork, there are also practical elements associated with staff management practices that require attention. At the same time, it has been noted that many models of self-direction currently in place throughout a number of countries rely quite extensively on the person acting as a direct administrator of their own support (Kendrick 2006).

Concerns about self-directed flexible approaches also mean that there is a requirement for balancing the safeguards & mechanisms to protect vulnerable people with the entitlement to have individual control, choice and flexibility and ensuring monitoring processes to prove accountability in the use of government funds (Craig & Cocks 2009). Another concern raised by researchers refers to the pressures associated with audit processes. While research indicates that the inclusion of different stakeholders, including people with disabilities, has long been an important consideration for evaluation practices (Jacobson et al 2013; Orr 2010), limited attention appears to have been placed on the ways in which family members

and people with disabilities may be supported to successfully evaluate their arrangements and contribute to continual improvement processes, or even if there is a need for this to be considered, based on the paperwork involved in managing a self-directed / self-managed arrangement. How such strategies are implemented, including the practice principles that guide implementation and the level of resources, will determine whether the pitfalls associated with a free market model are adequately addressed (Fawcett & Plath 2012). This will be the challenge for the future and follows on from the Australian Government Productivity Commission Report (2011) which proposes that the quality of services would be monitored and addressed by a national data collection system and the publication of outcome results for consumers to appraise.

The consultative process encompassed conducting semi-structured interviews with people who are currently self-directing / self-managing their arrangements, or are interested in doing so at some future time. The target of meeting with a number of people currently undertaking the responsibilities associated with managing these arrangements, as well as with a number of people who were interested in this approach was achieved, with forty-eight (48) people self-selecting into the project. This included nineteen (19) people with disabilities as well as twenty one (21) family members or significant other people who are involved in self-managed / self-directed arrangements, as well as six (6) of people with disabilities and four (4) family members who were interested in this form of support but had not commenced at the time of this project. The results of these interviews indicate that a significant number of people living in the Eastern states of Australia had experienced unresolved problems with their service provider, which often was the precursor for commencing self-directed / self-managed arrangements, whereas people living in Western Australia had not had similar experiences.

The interviews also reviewed the extensive levels of monitoring activities that these people are doing on a regular basis, with numerous examples provided of the ways in which tangible differences have occurred in the life of the person with disabilities since starting this form of support. At the same time, several people who had expressed an interest in self-directing / self-managing their arrangement indicated that they were aware of these monitoring responsibilities, whereas other people had very limited understanding of what would be involved. Participants considered that people who want to embark on the self-directed / self-managed path would need good information and practical tools in place before starting; an

awareness of the personal implications associated with managing these arrangements while at the same time carefully monitoring routine practices; and other broader implications to make these arrangements work over time.

The implications on the individual who has the primary responsibility for maintaining the arrangement – whether this is the person with a disability or a family member or significant other person – emphasized the need to withstand negative attitudes from funding bodies, government staff members as well as from their local service providers about taking on the responsibilities associated with the self-directed/self-managed arrangement. These responsibilities were sometimes countered with problems associated with poverty, being seen to be the ‘lynch pin’ holding the arrangement together, and being emotionally exhausted because there were very limited external supports provided to people in this situation. In fact, there were examples provided where people who could not receive respite support because they were self-directing / self-managing their arrangement.

During the semi-structured interviews, it became apparent that evaluation is not a generally defined consideration or expectation within self-managed or self-directed arrangements. This meant that when participants were asked about evaluative processes, five (5) out of forty (40) people who are currently self-directing / self-managing stated they believe evaluation is a component of formal audit processes that they undertake. This showed a level of confusion about what the differences are between audits, evaluations, and to some degree, monitoring practices. Similarly, there were questions raised about why family members have to do an audit for the company they had established solely for their son / daughter / sibling, whereas people with disabilities who self-manage are not required to undertake audit processes at all. While several participants with disabilities expressed an interest in having their arrangement monitored, as a way of these people feeling assured that they are meeting the necessary requirements associated with their funding, broader acceptance of the inclusion of evaluation strategies into the realm of having these arrangements audited was not evident throughout this project process.

Participants provided an overview of the types of questions that could assist broader evaluation reviews. However, the development and implementation of easy-to-understand evaluation tools was hindered by the fact that participants did not currently incorporate evaluation into the underlying philosophy of their arrangement, and there were some strong

negative reactions towards the role of government wanting to obtain more information about what people are doing with their arrangements, and why. Similarly, it was unclear what evaluation framework would be implemented by DisabilityCare Australia, and whether this framework would encompass the voice and lived experience of people with disabilities, family members and significant other people who are involved in managing self-directed / self-managed arrangements, or not.

The report concludes with a number of recommendations pertaining to the development of a robust monitoring and evaluation framework that can be incorporated into the future of DisabilityCare Australia national disability insurance scheme.

**It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements**

**REPORT**

**1.0 BACKGROUND**

The Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) is currently involved in examining ways in which care and support can be provided to people with disabilities through an insurance approach over a long period of time. One such initiative is the Practical Design Fund (PDF), which involves identifying practical methods to prepare people with disabilities, carers, family members, the disability sector workforce and disability sector organisations to transition into the National Disability Insurance Scheme (NDIS). Projects funded through the Practical Design Fund provide individuals and organisations with the opportunity to contribute towards the transition to self-directed and/or individualized funding, support people with disabilities to exercise choice and control, support the growth and skilling of the disability workforce, and assist disability organisations to transition into the NDIS environment. Most projects funded through the PDF are expected to be completed by 30 April, 2013.

This project, “It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements”, provides insight into the ways in which self-directed / self-managed arrangements are monitored and maintained over time. In particular, this project focuses on the practical elements associated with successfully maintaining arrangements, and considers the critical requirements for achieving long-term outcomes and benefits associated with self-directed / self-managed processes.

While expert opinion was obtained from people who are currently undertaking self-directed / self-managed arrangements, as well as from people who are seeking to do this form of management, the project acknowledges the underlying policy frameworks across states that currently enable this form of support to occur. Moreover, from an international perspective, the frameworks associated with self-directed / self-managed arrangements are not new. In fact, evidence associated with trials and implementation activities have been recorded since the late 1990s in a number of countries, including England, Scotland, Sweden, and the United States of America. Observations have been made about the satisfaction levels associated with

these activities, and a number of researchers have commented on the risks. However, limited attention has been placed on the practicalities associated with maintaining these arrangements over a number of years and decades. This highlights an apparent void within policy systems, with uncertainty about how to support people who are currently self-directing/self-managing or who have yet to enter the self-directed / self-managed realm to be aware of what it takes to make these arrangements work over time.

The purpose of this report is to present a review of the literature related to self-directed / self-managed arrangements, and to summarise the ways in which these arrangements are monitored and evaluated. When looking at the broad area of self-directed arrangements, an explanation is provided of the escalating global interest in self-directed / self-managed arrangements for people with disabilities, as well as the ways in which global commentators view the potential changes and issues arising from implementing these arrangements. Some of the pervasive assumptions regarding the success and risks related to the management of these arrangements are explored. Comments from people who are currently self-directing / self-managing their arrangement, or anticipate to be doing so in the near future, provide an overview of what people consider to be essential monitoring activities, and are also included in this report. The final section of the report describes some approaches that could be considered in determining the way forward with embedding monitoring and evaluative strategies within self-directed / self-managed arrangements over time.

## **2.0 AIMS**

The aims of this project focused on:

- 2.1** Conducting a literature review on content related to maintaining, monitoring & evaluating self-directed / self-managed arrangements over time
- 2.2** Consulting with at least thirty (30) people with disabilities and/or family members who are currently self-directing / self-managing support arrangements, as well as consulting with at least fifteen (15) people who have expressed an interest in undertaking these practices at some future time.
- 2.3** Developing, trialing and refining simple English tools that may assist people to manage the evaluation process in self-directed / self-managed arrangements beyond the lifespan of the project.

- 2.4 Making recommendations related to sustaining self-directed / self-managed practices over time that could be incorporated into the broader development of the NDIS.
- 2.5 Preparing the project report within the nominated time frame and within available resources

### 3.0 **METHOD**

This section outlines the research design and methodology utilised for this project. A detailed discussion of the methods, study period, recruitment process, research questions, consultation processes as well as the methods used to analyse the acquired data are presented. The criterion for the literature review includes a glossary of terms. Challenges, ethical considerations, issues relevant to insider research, and limitations are integrated and explained in the discussion.

#### 3.1 **STUDY PERIOD**

This project encompassed a review of existing literature as well as a consultative process conducted over a three-month period with a number of people with disabilities, family members and significant other people. The consultation process encompassed semi-structured interviews conducted with people where they live, and included locations such as Brisbane, Sunshine Coast, North Queensland, New South Wales, Sydney (including western suburbs and nearby locations), Melbourne, Adelaide, Perth, and Canberra.

#### 3.2 **STUDY POPULATION & SAMPLE**

Participants were recruited with the assistance of several agencies and key informant individuals located throughout Australia. The sample included people with disabilities and family members who have a lived experience with directing or managing their support arrangements over a period of time, or who had expressed an interest in doing so. These people self-selected into the project by approaching the consultant for more information and were subsequently provided with details of the project (*see Appendix 1: Participant Information Pack*).

The project submission estimated that the participants involved in this study would be in the vicinity of thirty (30) people who have been self-directing / self-managing these arrangements, and fifteen (15) people who have not commenced this form of support as yet.

For the purpose of this study, the actual numbers remained flexible to accommodate previously unknown interest in the topic and to continue until saturation point was reached (Siedman 2006). This meant that participant recruitment ended when the full range of ideas about the current status of self-directing and self-managing support arrangements had been captured and no further new information was gained.

For this project, participants included both people with a disability who have assumed responsibility for their self-directed / self-managed arrangement, or a family member or significant other person who has assumed responsibility on behalf of a person with a disability. Forty-eight (48) people self-selected into the project. This included nineteen (19) people with disabilities as well as twenty one (21) family members or significant other people who are involved in self-managed / self-directed arrangements, as well as six (6) of people with disabilities and four (4) family members who were interested in this form of support. The age of the reference person with a disability who was being supported through the self-directed / self-managed arrangement ranged from 18 years to 60+ years of age. While the majority of participants receive funding from government sources, two (2) participant spoke about self-direction within a compensable framework and a another one (1) participant spoke about support from a combined non-Government organisation and compensation framework. One (1) participant spoke from her experiences as the key supporter of a person with disabilities to whom she was unrelated.

The types of disabilities represented in this project varied significantly and included learning disabilities (n=16), psychiatric disability (n=2), diverse physical disabilities (n=16), acquired disabilities (n=12), and sensory / speech disabilities (n=2).

Twenty (20) interviews were conducted in Queensland, five (5) in New South Wales, two (2) in the Australian Capital Territory, three (3) in Victoria, ten (10) in South Australia and eight (8) in Western Australia over a ten week period. This process included telephone interviews for people who expressed an interest in participating in the project, but who lived in areas outside the main interview regions or where the times for face-to-face interviews did not suit them. When telephone interviews were provided, the participants were asked similar questions to those asked in the face-to-face interviews.

### 3.3 INCLUSION CRITERIA FOR LITERATURE REVIEW

In order to meet the requirements of this project, it was necessary that the literature met the following criteria:

- A central focus on self-directed / self-direction, self-managed / self-management, and/or individualized budgets;
- Literature that may have been academically refereed, or contained within text, grey and electronic literature;
- Reference to trends, issues and concerns related to self-directed / self-managed support;
- Reference to disability included any form of long-term, permanent disability, and encapsulated people of all ages and abilities, regardless of whether they were directly involved in self-directed / self-managed practices or not;
- Reference to other people included family members, siblings and significant other people who have a defined interest in any aspect of conducting self-directed / self-managed support arrangements;
- Discussion about the implementation of self-directed / self-managed arrangements or individualized budgets, regardless of country of origin;
- Reference to methods that could be associated with facilitating, monitoring, and evaluating arrangements for people with disabilities over time;
- Literature needed to be in English, and published between 1990 and 2013.

A variety of methods was used to source and obtain reports, literature, grey literature, as well as refereed articles. These methods included web based searches using Google and Google Scholar, as well as through a number of mainstream databases.

The following definitions are used to guide the project, and refer to commonly used terms in the literature:

#### 3.3.1 Glossary of Terms

**Direct payment:** Provision of a direct payment to a person with disabilities instead of services provided through a designated service provider to that person.

**Self-directed:** Funding is provided to an organization & subsequently acquitted by them to the government. The person with disabilities or family

members and significant other people direct the required types of services & supports, and report directly to the organisation.

**Self-managed:** The person with disabilities or family members and significant other people manage the all aspects of the funding, and provide financial acquittals and reports directly to the funding body / government, or do so in consultation with an agency.

**Shared management:** This approach is based on an agreed sharing of supports / funding management responsibilities between the individual and/or their family and a Support Organisation.

**Audit:** Audits are conducted on a person, organization, project, product, or primarily for the purpose of verifying compliance with established rules, procedures, regulations, mandates and standards. Quality audits assess efficiency of management systems, and are used to obtain certification, which addresses the efficiency of the system, the ability to reach target levels as well as the effectiveness of being able to address problems while at the same time, striving towards improvement of the system.

**Monitoring:** Routine, systematic collection, recording & analysis of information mainly for the purpose of checking progress & implementation against pre-determined goals, plans, objectives, and check compliance to established standards. Monitoring helps to identify trends and patterns, adapt strategies being used, and provide information for program management. This involves the establishment of indicators that focus on inputs, activities and, to some extent, outcomes:

- Inputs e.g. funding; staff time; policies & procedures; standards; feedback; questions focus on determining if finances, personnel and materials are available on time and in the right quantities and quality.
- Activities e.g. community activities; personal care; employment practices; regular financial management; questions focus on determining if activities are being implemented on schedule and within budget, as well as if the activities are leading to the expected outputs.
- Outputs e.g. staff, day-to-day management practices, training; questions focus on determining if outputs are leading to the achievement of outcomes.
- Outcomes e.g. changes, differences as a result of outputs; risk assessment & controls; cost, efficiency, compliance, consistency; questions flow across into an evaluation process, mainly because they require a longer timeframe to measure.

**Evaluation:** The systematic & objective assessment of a process or program, including its design, characteristics, implementation, outcomes & results that determine the merit or worth of a specific program. There are two main types of evaluation: formative & summative. Evaluation refers to the episodic assessment of change & is designed to ask questions on whether the process or program has achieved what it aimed to achieve. For example:

- Did we deliver what we said we were going to deliver?
- How well are resources used?
- What difference did it make?
- Are we meeting the identified need?
- How well did we need expected outcomes?
- What have we learned?
- What impacts have we seen?
- What can we take from this approach & use to inform future decisions?

Evaluations can be done internally or externally and provide credible information for use in improving the program or process, identifying lessons learned, and informing decisions about future resource allocation. Evaluations can use quantitative data (such as surveys, questionnaires, checklists, numeric or categorical data, using an experimental or quasi-experimental design), a qualitative approach (such as semi-structured data collection from interviews, focus groups, observation), or a mix of both approaches.

**NOTE:** Evaluation is distinguished from monitoring, but they are interdependent. The information collected for monitoring purposes plays a critical role in the evaluation process.

### **3.4 CONSULTATION PROCESS & DATA COLLECTION PROCEDURE**

#### **3.4.1 Study questions**

The study was operationalized by asking the following research questions:

- What are the reasons for considering self-directed / self-managed arrangements?
- What supports facilitate the implementation and establishment of an effective self-directed / self-managed arrangement that can be maintained over time?
- What level of monitoring are family members and people with disabilities prepared to accept with managing self-directed / self-managed arrangements over time?

- What are the critical success factors for monitoring and evaluating self-directed / self-managed arrangements?

The research questions related to the length of time people had been self-directing / self-managing, reasons for considering this approach, practical aspects of managing and monitoring self-directed/self-managed arrangements over time, critical requirements for successful arrangements, and recommendations about this approach. Similar questions were asked of people who had not commenced this form of support arrangement at the time of the interview.

### **3.4.2 Recruitment of participants**

In order to maximize the likelihood of interested people being engaged in this project, the following strategies were used:

- Initial contact with key individuals who subsequently distributed flyers and email content through their networks.
- Initial contact with key organisations that subsequently distributed flyers and email content through their networks.

Specific inclusion criteria incorporated:

- Individuals who have been conducting daily, weekly, monthly and annual practices within a defined self-directed / self-managed arrangement.
- Individuals who had expressed an interest in undertaking self-directed / self-managed approaches, but who had not commenced at the time of the project being undertaken.

### **3.4.3 Interview procedure**

The consultative approach enabled individuals to provide a range and depth of personal and practical knowledge about what is done on a regular basis to facilitate long-term success with self-directed / self-managed arrangements.

As a result of initial telephone contact with nominated representatives of organisations, the consultant was able to develop relevant written content that was subsequently used through the organisation's existing email networks as well as other social media to broadcast the project and what it aimed to achieve. Following this approach, individuals who felt they could contribute to the project made contact with the consultant, and meeting times were scheduled in relevant capital cities and on particular days and times.

In the event where these days, times and locations did not suit the individual, times for a telephone interview were scheduled. The telephone interview used the same format as the face-to-face interview, and offered people a time to contribute at a time that suited them best. The face-to-face interview included semi-structured interview questions (*see Appendix 2: Semi-structured interview protocol*).

Individual written or verbal consent was obtained from all participants, and consent was also formally recorded before the commencement of each interview. A semi-structured interview schedule was used to guide the data gathering phase. An EchoPen was used to record all interviews, and notes taken in response to the questions asked during the semi-structured interview were analysed for content and themes.

The research design for this project was located within the narrative tradition (Lieblich et al 1998) which enabled the consultant to attend to people with disabilities, family members and significant other people by allowing them to 'tell' their experiences about self-directed / self-managed arrangements. Moreover, this approach encompassed participant subjectivity regarding their experiences and observations about the particular contexts within which they live and operate (Maxwell 2005), as well as the consultant's subjectivity with interpreting each person's experiences (Padgett 1998). The semi-structured interviews, while guided by prompts, were largely unstructured to enable discussion to flow into areas which clearly illustrated people's experiences with self-directed / self-managed arrangements. At the same time, consideration of the practicalities associated with the long-term implications of maintaining these arrangements enabled the broader exploration of a topic about which little is currently known (Padgett 1998; Maxwell 2005).

### **3.5 ETHICAL CONSIDERATIONS**

Conducting ethically informed social research should be the goal of all social researchers (Blaxter et al 2007) and include strategies to ensure that the people involved in the research process are not harmed in any way (Altson & Bowles 1997; McGee 2007). Given this requirement, the purpose and structure of this project indicated that there were a number of issues that needed to be addressed in accordance with the National Health and Medical Research Council (2007), with particular reference to research involving humans, including people with disabilities.

The first of these issues focused on obtaining informed consent from all participants who engaged in this project. Information was provided within the consent process regarding the purpose, method, and reporting of results. Informed consent was obtained before participants attended or participated in any processes associated with the project, and verbal consent was tape recorded when the participant engaged in an interview by telephone or forgot to bring their form to the interview. Semi-structured interviews were conducted for periods of one to two hours. These interviews were conducted face-to-face as well as by telephone when face-to-face interviews were not possible. All paper copies of signed consent forms and interview notes were stored in a secure office and in a filing cabinet to ensure confidentiality of all data. Computer files were protected by a secure password.

The second concern focuses on maintaining confidentiality, privacy and anonymity within this project. While it was imperative that individuals not be named or identified in any way that could be traced, there were perceived risks of identification associated with the small number of people who met the criteria for this research (Cripps 2006). Therefore, considerable efforts were made to de-identify the content of acquired information. This necessitated attention to confidentiality and privacy to ensure that organizations assisting with the distribution of information about the project were unaware of the involvement of their clients within the consultative process for the project.

Participants were encouraged to voluntarily participate in this research study. In the event that individuals experienced problems with any part of the research process, they were encouraged to discuss their concerns with the consultant and advised that they had the ability to voluntarily withdraw from the project without any fear of penalty or retribution.

Moreover, explanations were provided to each person that their interview information would not be used in the project report if they chose to withdraw for whatever reason.

### **3.6 LIMITATIONS OF THE CURRENT STUDY**

This section discusses some of the limitations associated with this project. These limitations relate to the small sample size, non-representation of people from the Northern Territory and Tasmania and subsequent potential for missing data, issues regarding accuracy of responses, understanding the different definitions that are currently in use related to self-directed / self-managed support arrangements across Australia, and the implications arising from conducting insider research.

Considerable effort was placed on attempting to eliminate any concerns about trustworthiness that could result in invalid conclusions, due to factors such as reactivity, researcher bias, and respondent bias (Maxwell 2005; Padgett 2008). Within the semi-structured interview, the consultant focused on asking open-ended questions that were not leading, as far as possible, by following a general list of prompts. Prior to commencing a semi-structured interview, the consultant provided some general information about her own longstanding experience in the disability sector, as well as activities associated with managing a formalised service structure for her daughter's funds for the past thirteen years. This experience also assisted in addressing any concerns about the consultant's credibility (Patton 2002; Neuman 2003).

At the same time, it was acknowledged that the researcher's own values, expectations and subjectivity influenced the conduct of the project (Strauss & Corbin 1990; Loseke 1999; McGee cited in Germov & Poole 2007). This influence was addressed within the design of the project, by conducting a systematic approach to the analysis of the data. Moreover, the project enabled the acquisition of a number of participant perspectives, apart from that which 'stood out' to the consultant (Maxwell 2005). This meant that the consultant had to continually stand back and examine the fit of emerging understanding within the data, as well as leaving the data for a period of time, before reviewing the content from a fresh perspective. Similarly, participants in this project may have withheld key information as a way of avoiding the possibility of revealing unpleasant truths, provided inaccurate accounts to protect their privacy (Padgett 2008), or been in a position where key points had been forgotten.

Throughout the data collection process, the consultant ensured that there was no pressure placed on people to participate. This was supported with the content of the Participant Information Packs (see *Appendix 1: Participant Information Pack*). Furthermore, participants were advised that they did not have to answer questions, if they chose not to, and that there would be no adverse consequences associated with their decisions. This enabled participants to relax during the semi-structured interview, and to engage in the discussion process as fully as possible. This enabled a range of varied and rich data to be collected and the majority of participants expressed an appreciation for being able to contribute to the topic. While personal experience in this area showed a shared understanding of the issues as well as a capacity to interpret the many different possibilities as socially relevant (Neuman 2003), during the course of the project, the consultant moved continually between a number of dimensions, depending upon the stage of the project, topic being examined at the time, participant content, as well as external events occurring at the time (Mercer 2007). Additional factors related to transparency with insider researcher status included regular self-reflection and participation in external supervision processes, and an audit trail of documentation acquired and developed throughout the duration of the project itself.

In common with other qualitative studies, problems arise when generalizing the data to a wider society, as it contains only a random sample which may not be representative of the entire self-directed / self-managed community. This form of data can provide a comprehensive examination of issues or opinions that are held by a given group, but cannot tell us how widely these views or opinions are held. Therefore, due to the size of the sample, conclusions should be seen to be indicative only and therefore not definitive of the breadth of practices that are currently in use. Further research would be required to quantify the depth to which these views are present for people with disabilities, family members and significant other people living in other Australian states and territories, as well as for younger people with disabilities and family members aged less than 45 years.

The next section of this report presents an overview of the literature, before continuing on to acquaint readers with participant experiences of self-directed / self-managed arrangements. The experiences and voices of participants will progressively unfold the realities associated with undertaking self-directed / self-managed practices, and considers the impacts of these arrangements on the individual over time.

#### **4.0 LITERATURE REVIEW**

This chapter begins with what is known about self-directed / self-managed practices that incorporate flexible funding approaches before exploring the impacts of self-directed arrangements, concerns arising from this approach, and the implications related to monitoring and evaluative strategies over time. By exploring the environments that are conducive to successful self-directed / self-managed practices over time, this chapter seeks to identify the context in which these practices are promoted or inhibited, as well as assist in understanding what is involved in maintaining these arrangements over a long period of time.

Flexible funding programs, also referred to as direct payments, individual budgets, self-directed support, self-management, consumer-directed care, personal assistance, and individualized funding, have been promoted for a number of years throughout Australia, and reflect the continuation of international policy trends (Fawcett & Plath 2012; Ungerson 2007) that have been operating in one form or another for at least the past fifty years (Duffy (2013)). While these arrangements are not new, considerable interest has been placed over the years on specifying what self-direction and flexible funding means to government, service structures and individuals. For example, Bogenshutz and colleagues (2010 p345) state ‘self-directed support is a program or service option in which people with disabilities, their families, or their allies manage and direct their services and supports’, while Fawcett & Plath (2012) consider this to be a method for people to cash out their package to design their own support requirements and purchase these in a way that suits them best.

Traditionally, this has been achieved by specified budgets that people use to select, purchase and manage their own supports within an established framework of guidelines. This approach provides the opportunity for people to have greater control over the recruitment, hiring and management of support staff (Bogenshutz et al 2010; Moseley 2001), and to use the fund flexibly to address other essential requirements. According to researchers such as Ashcroft (2009) and Glasby (2011), these approaches recast the person with disabilities from being a passive recipient of pre-purchased services, towards active citizenship where the person has the right to assert and exercise control over their supports and their own life. This has seen a progressive shift away from a ‘professional gift model’ towards a citizen-based approach which is more in keeping with what is valued in most people’s lives (Duffy 2011; Glasby 2011).

As a process, self-direction appears to have a number of common elements. These include specific budgets being attached to the individual, with these funds addressing support coordination, use of fiscal intermediaries (Scala & Nerny 2000), updating information technology, and adequate training being offered to ensure optimal benefits are experienced by the individual (Walker et al 2009). The ability to use funds in flexible ways is critical in promoting true self-determination as well as achieving the impacts of effective implementation of self-directed services.

In conjunction with enabling social participation, flexible funding is seen to be the ‘glue’ that contributes to a viable and sustainable society and a means for citizens experiencing a good quality of life (Laragy 2010). Numerous studies examining self-directed / self-managed flexible funding arrangements have shown that the satisfaction levels for people with disabilities and family members or significant others refer to the benefits of greater autonomy, choice and control over who provides what personal assistance when, as well as flexibility over the supports they receive (see, for example, AGPC 2011; Arksey & Baxter 2012; Ashcroft 2009; Blyth & Gardiner 2007; Bodenschutz et al 2010; Clark et al 2004; Davidson & Luckhurst 2002; Ellis 2007; Ferguson & Plath 2012; Fisher et al 2010; Glasby & Littlechild 2009; Glendinning et al 2000; Hasler 2003; Laragy 2010; Maglajlic et al 2000; Netten et al 2012; Newbigging & Lowe 2005; Scourfield 2007; Spandler 2004). Moreover, flexible funding and self-directed / self-managed arrangements are viewed as the main presupposition for user control and for freeing people with disabilities from their reliance on welfare professionals and unpaid carers (Ashheim 2005). In the past and under mainstream service provision arrangements, many people experienced feelings of frustration and fatigue dealing with an apparently inflexible support system, the effects of time consuming, continuous battles for even the most basic support or provision (Read & Clements 2001), as well as misdirected resources, multiple funding streams, inflated needs, stifled innovation and over-management with existing service provision (Hatton et al 2008). As Harlock (2010) states:

*“The current system has long come under criticism for its top-down approach to service planning and provision with little say for service users over the services they receive and how they receive them. Personalization is proposed as a means to move*

*away from a one-size-fits-all approach towards provision which meets the individual needs and requirements of users.”*

In contrast to the ‘old system’ where professionals made all the decisions about the support people could have and who would provide it, resulting in situations where the person needing support had very little or no control, the introduction of self-direction, flexible funding strategies provides the opportunity for people to be in control of support they need to live their life as they choose (Tyson et al 2010). As noted by Spicker (2012), there is a common view that people with disabilities and family members or friends will manage their affairs better than public services do, with many arguments for personalized responses being based on a criticism of the alternatives. Instead, alternative forms of payments that are directed towards the individual are a major step towards a redistribution of power and resources in terms of enabling people with disabilities to ‘wrest control of services away from local authorities into their own hands’ (Spandler 2004 p192).

However, there is more to self-directed / self-managed flexible arrangements than simply talking about the benefits. As Australia faces the introduction of a National Disability Insurance Scheme (NDIS), there are important lessons to be gleaned from the ways individualised and flexible arrangements have been conducted, not only in other countries, but throughout Australia as well (Duffy 2013). There is evidence to suggest that people who undertake various aspects of managing these arrangements have a range of requirements that need to be in place to facilitate successful outcomes over time. The following section reviews the literature around the practical elements of managing and monitoring self-directed / self-managed arrangements.

### **Practical elements of managing & monitoring self-directed / self-managed arrangements**

Over the years, it has been recognized that people in receipt of flexible funding need support in understanding the long-term issues and risks that may arise, as well as ongoing monitoring and seeking advice from knowledgeable practitioners as their situations, needs and capabilities change through time (Arksey & Baxter 2012; Ashcroft 2009; Blyth & Gardiner 2007; Scourfield 2007). This involves building internal capacity to monitor and evaluate activities for the person with disabilities, or family members and significant other people

(Ellis 2008), and understanding the responsibilities related to the practical aspects of managing these arrangements over time. Kendrick (2002) confirms that the many models of self-direction currently in place throughout a number of countries rely quite extensively on the person acting as a direct administrator of their own support. This entails the person being (amongst other responsibilities) the employer of support staff and other people, an accounts record keeper, staff supervisor, scheduler, planner, payroll manager, and the intermediary for managing external supports from fiscal intermediaries. People undertaking this form of arrangement need to be more informed about perceived advantages & disadvantages associated with managing funding as well as staff, and have the opportunity to acquire other skills, such as developing a more robust understanding about the requirements of being an employer, the work involved in managing direct payments, and balancing friendships and relationships with personal assistants against the downside of meeting changing needs & circumstances (Arksey & Baxter 2012).

While a number of skills and abilities are required to manage self-directed / self-managed flexible arrangements, limited attention appears to be placed on the practicalities of the primary person themselves managing over time. Research indicates that the recipients of care and support increasingly depend on unpaid carers such as friends and family members (Askheim 2005), with most of the care and support being provided by their mother or other female relation (Qu, Edward & Gray 2102). However, there can be a financial ramification from undertaking this level of support for the primary person. Hughes (2007) and Edwards and colleagues (2007) provide stark evidence of the realities associated with caring responsibilities and the adverse effect this has on the carers' financial situation, ranging from the extra costs of care and a subsequent decrease in income being a reality for many people who assume the caring role, to situations where carers are limited in their ability to participate economically and socially in the community (Spicer 2007). This results in poverty, social isolation, loss of friendships, problems of mood and stress, serious health problems, marital and relationship issues (Schofield et al 1998; Saunders 2007).

Another problem is the inability to retire from the caring role at an appropriate time, while at the same time having confidence that the person with a disability will continue to receive the best care and support possible (Spicer 2007). Research suggests that there is an increased anxiety for older parents, who may experience a depth of guilt based on their inability to provide care and support. Qu and colleagues (2012) note that there is a substantial minority

of parent carers aged 65 and over, with a large proportion of people approaching old age (55 – 64 years). Similarly, there are many ageing parent carers who do not live with a partner, resulting in the need to shoulder the bulk of the caring responsibilities for a person with a disability while at the same time experiencing difficulties associated with a reduced income level and poor retirement prospects (Qu, Edwards & Gray 2012). This necessitates future planning activities to address events such as a crisis happening as well as the assumption that extended family and friends will take over at some future time (Bowey & McGlaughlin 2007).

However, while Rabiee and colleagues (2009) note the concerns of parent carers who assume responsibility for managing the person's funding in the event they [parent carer] were suddenly taken ill, limited attention appears to be placed within the literature on the implications for people with disabilities who assume the full responsibility for managing their arrangement, and who want to pass on the responsibility to another person or entity at some future time. Similarly, for people with disabilities managing their own arrangements, there are demands on their time, the costs of providing and meeting their own support and care needs, as well as the correlation with the limited ability to participate economically and financially in the community. This poses questions about appropriate alternative care and support arrangements in the event the person is no longer able to manage their own arrangements, or is temporarily unable to provide this level of support to themselves or for a family member with a disability.

However, as Fawcett & Plath (2012) observe, there is more to personal control than having a budget allocation and the choice of providers. If personalization becomes aligned with individual responsibility, at the expense of social responsibility, advocacy, and community capacity building, then strong cause for concern emerges. The way forward for flexible funding in Australia could be based on having a system that combines individualization with flexibility and empowerment, while also integrating financial entitlements into networks of private and social resources to get improved outcomes (Duffy 2013). While Duffy (2013) states that no system should assume that everyone needs a facilitator, or that everyone needs a plan, distinct bank accounts, audit trails, or intrusive planning sessions, the literature suggests that government representatives and researchers experience concerns as well as criticisms about self-directed / self-managed approaches. For example, there appears to be a requirement for safeguards and reassurances that funds will be wisely spent and that people

involved in these approaches will be professional at all times, thereby eliminating the possibility of errors occurring. Similarly, because there are perceptions that the administration of these arrangements are onerous, people with disabilities and family members tend to opt for directly provided services. Moreover, barriers to take-up and risks associated with implementing this approach on a widespread basis have also been identified. It is to this area that we now turn.

### **Concerns about self-directed / self-managed arrangements**

Over the years, there has been a plethora of discussion and debate about the risks associated with implementing and undertaking self-directed / self-managed flexible arrangements. These have included a lack of confidence with managing these forms of payment options (Carmichael & Brown 2002; Glasby & Littlechild 2001; Hasler & Zarb 2000; Maglajlic et al 2000), as well as paternalistic approaches to risk and user control (Clark & Spafford 2002). The importance of empowerment for people with disabilities has to be balanced against the responsibility the welfare state has for all its inhabitants and for protecting them against misfortunes and risks, of which users might not realize the consequences due to, for example, cognitive limitations, lack of life experiences or mental imbalance (Askheim 2005; Bigby 2006; Brennan 2006; Gauthier 2006; Laragy 2010; Mansell 2006), where abuse is not reported or where families and circles [of support] do not deliver on expectations (Kendrick 2002).

Fawcett & Plath (2012) discuss the risks for the individual when they are responsible for choosing services and finding that the market will not deliver the required services. They observe that there is no guarantee that the scope and quality of services will be adequate to meet requirements. Similarly, while an improved quality of life may result from controlling an individual budget, positive outcomes cannot be assumed for marginalized groups who experience other structural disadvantages alongside disability, for example, indigenous Australians or people from different ethnic backgrounds.

Debate about other risks associated with self-directed / self-managed arrangements continue to be argued at different levels within government, academia and the wider community. For example, there is an increased risk of conflicting views and interests between carers and users, as well as the complications for natural relationships where legal rewards are offered to

family members (Ashcroft 2009 p14). These situations may include assisting relatives to be able to draw on public benefits, or situations where funding is used in ways that erode the traditional family responsibility for care, thereby increasing the amount of public dependency (Askheim 2005). Another area of risk relates to the direct employment of support workers. Studies in this area warn against workers being exploited as well as being sacked for no good reason (Leece 2010), amongst other workforce issues related to wage structures, staff retention ramifications, and staff training beyond a general skill set (Bodenschutz et al 2010). The reality, though, is that these forms of arrangements constitute purchasing power, which changes the dynamic between people with disabilities and their workers (Leece 2010). While the employer may have more power and their interests will be served more than workers in this instance, it would appear that researchers consider direct employment to somehow be more harmful to workers employed or contracted through self-directed / self-managed flexible arrangements than is the case for an employment arrangement with a service provider.

Scourfield (2007) discusses the assumption that the modern citizen needs to be autonomous, managerial, enterprising and entrepreneurial, with public responsibilities being transferred to the individual. Similarly, these individuals assume the role of managing themselves, while at the same time being the manager of public funds, presenting records for inspection and audit, and assuming responsibility to achieve outcomes. This means that they are more than managers – they become calculated risk takers and innovators who need to be trusted and acknowledged by government that they are competent to make their own decisions (Duffy 2013). The system needs to be controlled by ordinary people and their representatives, not critics and bureaucrats who may be policy experts (Simon-Rusinowitz et al 2002) who have no lived experience of what people with disabilities and family parent carers manage with these arrangements on a daily basis.

However, Laragy (2009) stresses that having inadequate safeguards could present unacceptable risks to vulnerable people with disabilities. On the other hand, Bigby & Fyfe (2009) believe that too many controls & monitoring of expenditure can have the consequence of interfering or constraining individual choice and undermine the opportunities for flexibility and responsiveness. To address this possibility, Kendrick (2002) believes that there needs to be more effort placed in ways to discern vulnerability, as well as ways to recognise the limits and fragilities of existing arrangements. He states that there is a requirement to redesign the

overall context of how self-direction is offered so as to strengthen, add on or reconfigure features that will ensure greater success on a prolonged basis. Moreover, support structures are necessary for many users to enable them to manage the financial responsibilities as well as other requirements that go hand in hand with managing their arrangement (Ashcroft 2009; Witcher et al 2000). Attention to support structures can assist with minimising mixed attitudes, limited attention to capacity building, poor information regarding the levels of paperwork, administrative and bureaucratic burdens that prohibit these self-managed arrangements (Adams & Godwin 2008; Fisher & Campbell-McLean 2008; Hatton & Walters 2011; Glenndining et al 2008).

There is a requirement for balancing the safeguards and mechanisms to protect vulnerable people with the entitlement to have individual control, choice and flexibility and ensuring monitoring processes to prove accountability in the use of government funds (Craig & Cocks 2009). Ferguson (2007) discusses the transfer of risk from the state to the individual service user, observing that people will be expected to shoulder more responsibility for assessing and managing the risks of their own behavior (Leadbetter & Lownsborough 2005). Relatives, family members and parent carers frequently feel responsible for making these arrangements work over time, with the result that they have a long-term sense of being the backstop in the system, to be there when things go wrong (Ashcroft 2009).

Another concern raised by researchers refers to the pressures associated with audit processes. Audits frequently involve determining the economy, efficiency, and effectiveness of organisations, programs, activities and functions in addition to their compliance with laws and regulations (Davis 1990), as well as standards. However, researchers have noted that the ability to be flexible in the use of funding can be reduced by cumbersome audit systems designed to manage the risk of misuse of public funds (Askheim 2005; Pearson 2000) and limit the ability to provide empowering choices (Ellis 2007). Clegg (2008) observes that audits often inhibit rather than open-up debate about improving supports to people with disabilities. Instead, people in receipt of flexible funding need support in understanding the long-term issues that may arise over the years, as well as practical advice and support from knowledgeable practitioners as their situations, needs and capabilities change through time (Arksey & Baxter 2012; Ashcroft 2009).

In Clegg's opinion, audit processes investigating adherence to government policy impose ideologies, squander resources, and demoralize carers and staff, whereas effective evaluations can inform new care systems which make effective use of all those engaged with people with disabilities (Clegg 2008). Evaluation is the planned and periodic assessment of a program or project and builds on the monitoring process by identifying the level of short to medium term outcomes and longer term impacts achieved, the intended and unintended effects of these achievements, and approaches that worked well or didn't work well. In this way, evaluation seeks to understand 'Why this is so' and 'What happened as a result?' (Kendrick 2006; Maughan 2012) by identifying the reasons for success or failure and provides the opportunity to learn from both (Markiewicz 2013).

While monitoring and evaluation processes are not the same, they are frequently combined and viewed as interdependent components (Maughan 2012; Markiewicz 2013). Monitoring and evaluation can point to the requirement for changes in service practices, but are not a substitute for effective practice (Kendrick 2006). As Markiewicz (2013) states, monitoring is the continuous collection and analysis of information that is able to provide management and key stakeholders with an indication of the progress a process, program or project makes against stated goals and objectives. Monitoring answers the question, 'Did we deliver?', and considers 'What is happening to people?' in the process (Kendrick 2006). This approach requires the involvement of people self-selecting evidence that shows how practices impact on quality and improvements in service delivery and responses. Strategies that strengthen monitoring activities include educating and building people's capacity about what is involved, being alert to issues that trigger the requirement for attention and action, considering ways in which more meaningful actions may be required, sharing information, and encouraging transparency.

Similarly, questions need to be asked about whether the processes related to monitoring and evaluating self-directed / self-managed arrangements are designed to serve the individual with disability or the general population as a whole (Jacobson et al 2013). Moreover, the validity of data collection methods should be studied further to ensure that recipient voices, particularly those expressed by people with a disability, are accurately represented, and that evaluations are designed strategically to achieve desired goals. As Kendrick (2006) notes, there are different evaluation methodologies that can be used but the essential question is whether it is possible to require evaluations to be done while at the same time having a range

of default optional evaluation methods. Evaluation in this sense would still need to be credible, independent, performed competently, and be responsive to the system and service user concerns about quality.

Research indicates that the inclusion of different stakeholders, including people with disabilities, has long been an important consideration for evaluation practices (Jacobson et al 2013; Orr 2010), and evaluations need to answer questions that are of interest to stakeholders (Kotvojos & Hurworth 2011). However, while the focus of much research conducted on self-directed / self-managed arrangements appears to be on satisfaction levels with the use of the funding (see, for example, Conroy et al 2002; Miltenberg et al 1996; Powers et al 2006), limited attention appears to have been placed on the ways in which family members and people with disabilities may be supported to successfully evaluate their arrangements and contribute to continual improvement processes, or even if there is a need for this to be considered, based on the paperwork involved in managing a self-directed / self-managed arrangement. For example, observations have already been made by parent carers who state that while they are happy to take on the extra work because of the benefits they expected to accrue, they would walk away from being involved or actively undertaking any such arrangements if an excessive burden of paper work and review processes outweighed the benefits (Rabiee et al 2009).

With this in mind, it is possible that any evaluation of self-directed / self-managed arrangements will need to be conducted on a micro (individual), meso (service organization) and macro (broader systems and policy) level (van Loon et al 2013) and unobtrusively capture ‘the way we do things around here’ while also providing robust data as a way of informing government of the ongoing success of these arrangements. Evaluation questions examine suitability in terms of achieving the desired effect, effectiveness of objectives, efficiency, positive and negative, intended or unintended long-term effects, as well as sustainability over time (Markiewicz 2013). In this way, evaluation provides an opportunity to reflect on situations that will need to be addressed at a future time, changes that have happened as a result of the support, how the changes occurred as well as what lessons were learnt. Moreover, as Jacobson and colleagues (2013) point out, addressing the myth of homogeneity whereby a ‘cultural outside assumes that all members of the cultural group are the same as one another’ also needs to be addressed. This incorporates questions about the specific considerations for linguistic, cognitive and cultural diversity as people enter into and

maintain self-directed / self-managed arrangements, and broader questions about how to engage people with disabilities, family members and significant other people in a process so that they will agree to provide input into a broader evaluative framework that could have benefits to many other Australians with disabilities.

How such strategies are implemented, including the practice principles that guide implementation and the level of resources, will determine whether the pitfalls associated with a free market model are adequately addressed (Fawcett & Plath 2012). This will be the challenge for the future and follows on from the Australian Government Productivity Commission Report (2011) which proposes that the quality of services would be monitored and addressed by a national data collection system and the publication of outcome results for consumers to appraise. This is similar to movements across a number of countries for governments to be accountable for results, transparent and to provide more efficient & effective services (Kusak & Rist 2001).

While the practicalities associated with managing and monitoring self-directed / self-managed from the perspective of people with disabilities and family members is not immediately apparent in the literature, details about the levels of responsibilities assumed by the primary person in these arrangements as well as how these people maintain themselves over time is also not well known. Therefore, the consultation process associated with this project provides an opportunity for more clearly understanding these realities from people who have been self-directing / self-managing flexible arrangements for a number of years, as well as people who have not commenced as yet. It is to the results of this process that we now turn.

## **5.0 RESULTS**

This section provides responses to the main questions:

1. What are the reasons for commencing self-directed / self-managed arrangements?
2. What supports facilitate the implementation and establishment of an effective self-directed / self-managed arrangement that can be maintained over time?
3. What level of monitoring are family members and people with disabilities prepared to accept with managing self-directed / self-managed arrangements?

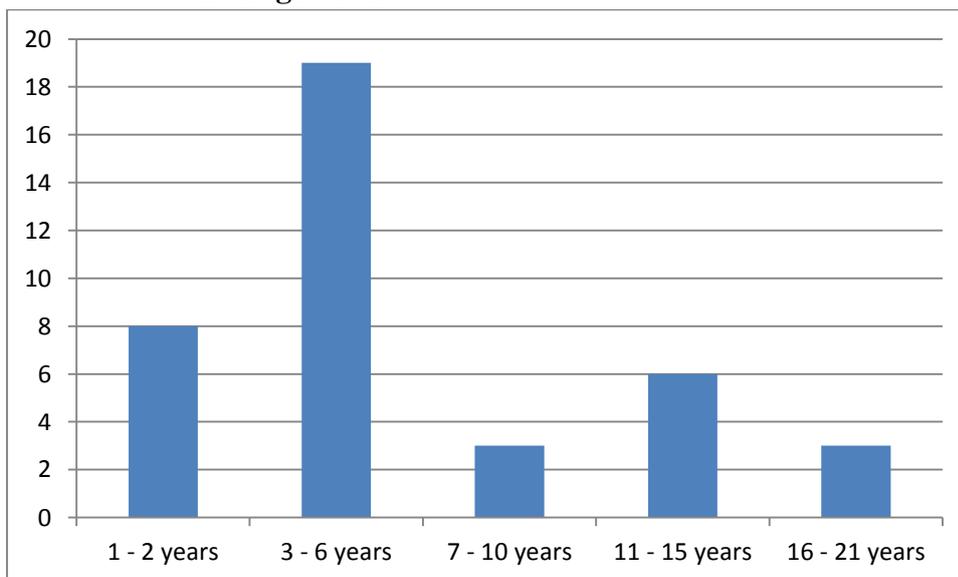
4. What are the critical success factors for monitoring and evaluating self-directed / self-managed arrangements?

Each of these questions is now discussed with illustrative quotes from participants themselves.

### 5.1 REASONS FOR COMMENCING SELF-DIRECTING / SELF-MANAGING ARRANGEMENTS

As a lead in to each semi-structured interview, participants were asked about the length of time each person had been self-directing / self-managing their arrangements, or the time frames for participants seeking to be able to do so at some future time. The following figure shows participant details, incorporating the number of people as well as the length of time in which they have engaged in self-directed / self-managed activities. Timeframes varied from one (1) month to twenty one (21) years, with the majority sitting in the mid-range.

**Figure 1: Duration of time since commencing self-directed / self-managed arrangements**



Nine (9) participants had not commenced self-directing / self-managing their arrangement at the time of the interview process. These people stated that they had been seeking this style of service management for periods up to five (5) years with no success to date. Moreover, five (5) people expressed confusion about transferring to a self-directed model, primarily because the service provider was actively involved in providing a number of services that they (the participant) considered important in their life. For these people, it was unclear what benefits self-directed arrangements would offer in contrast to their existing arrangements.

Participants were offered the opportunity of explaining the reason for considering self-directed / self-managed supports instead of continuing with mainstream service delivery. Western Australian participants explained that they were “not really given an option”, and this reflects the current stance in that state for people to have a shared role in the management of their services. Eight (8) participants stated that the reason for commencing self-directed / self-managed practices was based solely on the ability to save money.

However, for participants in the eastern states, namely, Queensland, New South Wales, Victoria and South Australia, a different perspective was evident. This centred largely on previous experiences with service providers, and the actions that subsequently resulted in the person deciding to self-direct or self-manage the arrangements themselves. For thirty-three (33) participants, experiences focused on continual problems with the provider that were not resolved. These problems were in the following areas: disagreements with the service provider, funding issues, and problems with the service provider’s staff. Examples include the service provider:

- Being perceived as being completely disorganized, with poor or no responses to queries about support or practices, with the result that the person with disabilities and family members were *“treated as a second class citizen.”* (FM17)
- Not handing over funds which meant that family members and/or the person with disabilities were always out of pocket. Also, *“I have a confused situation with the accountant because it looks like income when you have to pay out of your own pocket before getting reimbursed. What I mean by that is that I send an invoice to the not-for-profit agency and they pay 6 weeks later, so I am really out of pocket for 2.5 months.”* (FM20)
- Providing inflexible support, which included multiplied bureaucracy; stricter reporting environments; lots of policies and procedures that were not tailored to include specific living or support requirements of individuals; extreme restrictions working with staff on short timeframes; and having to seek approval for *“petty things”*. (P14)
- Engaging Coordinators and other staff without the values, beliefs and practical experience of providing timely and relevant support to people with disabilities.
- Enforcing mandatory WHS through a ‘1 size fits all approach’, and conducting irrelevant training.

- Not providing information to people with disabilities or family members about funding details, resulting in people feeling like they were in the dark about what could or couldn't be done.
- Charging high fees but not being transparent in how the funds were being spent. For example, situations where CEOs and senior management were provided with high-end vehicles with accessories, such as roof racks and customised items, and having these people express pride in being in receipt of such items. At the same time, people with disabilities and family members required access to support hours for deteriorating health needs or other specific support requirements but were unable to obtain what was required.
- Not responding to missed sessions or being unsure where the funds for these missed sessions went. For example, questions about using the funds at another time when the person with disabilities was well again, only to find that there was no way to reclaim the lost hours.
- Not being able to manage situations where family members and people with disabilities 'fall out' with CEOs over changes to the organization and its focus, for example, moving from an inclusion focus to a focus that emphasized safety before the individual's needs.
- Charging very high fees but not being transparent with how the funds were being spent, or situations where the service provider would not pay for supports for up to 2.5 months.
- Not following up on complaints, including a situation where *"a letter to the Board sent 6 years ago still has not been responded to."* (FM 3, 4 & 5)
- Not addressing the specific requirements of the person with disabilities, or being able to provide specific support staff to meet the detailed requirements of the person with disabilities.
- Not being 'up front' about what supports cost, what the service provider will and won't supply. For example, *"When we first started, I had come from a traditional service provider where my rights were taken away. The staff came to the house and made judgements about what that looked like. The service provider didn't give us all the information we needed either. For example, for years I had been buying gloves to supply to staff and then I found out that I could have getting funding to help with this, quite apart from the responsibility of the service provider to provide this to staff. There*

*were other things that I found out I could have been doing with the support funding, but at the time, I wasn't told any of this. (P15)*

- Telling the parent carer that the situation for her family member was not sustainable, with the result that when she got sick the service provider told her that she couldn't get respite because she was self-directing her family member's arrangement (FM25). This also occurred for a person with disabilities (P14) who said that she had been looking at being her own provider but was subsequently told that she could not receive respite, even though she cares for her family members as well.

Other situations relate to problems with support staff and other people employed by the service provider. Examples referring to support staff and coordinators include situations where:

- Support staff did not turn up for shifts, were unsuitable or lacked in experience, appeared to not care whether they were there for the person or not, and the organization not responding to these situations.
- People with disabilities became *"sick of service providers dictating my life or using 14 different support workers each fortnight"*, or situations where the person with disability had *"24 different agency staff in a 5 month period as well as staff who did not have a safe level of the English language"*. For example, the person would ask the support worker to wash their groin and instead the worker would wash the person's feet.
- Misinterpretation and an inability to listen to the person with disabilities occurred, and where the person with disabilities experienced the real fear of dying based on workers not understanding the differences with medication, for example, between 6 and 60 units of insulin.

The person with disabilities and family parent carers became sick of support workers and service providers dictating how they should live in their own home. For example, *"I was sick of the service provider saying 'no' to me, for example, when I wanted to stay at my son's wedding until midnight. I had to make phone call after phone call about this, and I found it completely humiliating and very stressful. After I did end up staying at my son's wedding as I had wanted, I was then told that because this had happened once, that I couldn't do this again, like, stay out until 11pm for example. I*

*really don't think there is a place for service providers who do this sort of thing, and to be honest, I never want to see another service provider ever again." (P18)*

Dissatisfaction and even conflict may be an inevitable part of the process as service users and professionals have different priorities than those expressed or required by family members and people with disabilities. The literature refers to organisations not responding but the question is more about why are they not responding? It would appear that some organisations are ignoring wider outcomes and some have chosen to be non-responsive. At the same time, people with disabilities and family members bring personal and emotional insights and express ideas and experience in language that professionals can feel threatened by, with the result that the direct experience of users can sometimes be dismissed as too distressing or disturbing (Carr 2004). Similarly, there can be differences placed on professional assumptions regarding decision-making competence (as in the case of people with mental health service users & survivors), can make it difficult for them to be heard. This can also result in a mismatch where their views are not being taken seriously (Carr 2004).

For a number of participants, there was the experience of the parent carer's life being taken away, and a subsequent belief that the system falls away too. For one participant who had been seeking an increase to more appropriate levels of support for her husband for a number of years without any success, stated:

*"I used to think that people who need support could get it, but I don't believe that anymore. It is so difficult to get even basic support for people with ABI in the city, and I don't even want to imagine what this is like in country areas. Especially for men with ABI, there is no help, no information, no links, no peer support" (FM14).*

Similarly, there are issues with service providers being able to assist second generation support, for example, the move from mother / parent carer to the person's siblings.

For thirty-one (31) participants, there was a need to withstand negative attitudes from funding bodies, government staff members as well as from their local service providers about taking on the responsibilities associated with the self-directed/self-managed arrangement. Moreover, there can be a toll when external criticism continues unabated for a long period of time, and there are limited external support options available to give the person a break. One

participant who had been seeking some external support but without success, explains this in the following way:

*“This is the biggest human rights infringement. I have suffered huge hurt and betrayal by the Australian Government. I live in a situation where I have to have support workers in my space. I have to be diplomatic and professional all the time, and I can’t let off steam in my own home in my own time.” (FM25)*

This means that parent carers and/or the person with disabilities managing the arrangement had to “put on strong armour” to prevent them being “dragged down by the naysayers”. For several parent carers, there was an awareness of the really good job they were doing with the support arrangements and managing staff, while at the same time, they were aware of not getting paid anywhere near the same as a Coordinator who they perceive as receiving lots more respect than what they [family member or person with disabilities self-directing / self-managing arrangements] would do:

*“Coordinators can burn out in their job, go on stress leave but I can’t even get basic respite. They get a far better deal than I do.” (FM25)*

Participants provided a level of criticism about the ways funding is provided to organisations and the lack of accountability about how these funds are spent internally. This was based on perceptions about the use of funds to purchase high-end vehicles and accompanying accessories for the CEO and senior management personnel. Similarly, family members had found that service providers could not comprehend or had difficulty rationalizing when the person with disabilities was experiencing problems arising from support workers did not turn up for shifts, or where there was a requirement for additional support when changes to the person’s health had become apparent.

Similarly, participants expressed concerns about the apparent disinterest in funding bodies towards the helping them develop more creative ways of using the funds so that the funds provide the support they require. Other participants stated that people with disabilities and family members need to understand how the system works:

*“There is a real need for people to understand how not-for-profits work, who pays the salary of the CEO, what the unit costs are, what the agency costs are, how staff get paid? People need to know what the gap is.” (FM20)*

However, participants stated there were problems when they approached the service provider about being more flexible with the use of funding, particularly with employing support staff. As one participant observed:

*“I would like to employ carers directly but I can’t do this under the current arrangement. I know that the service charges \$50 per hour for carers, but the carers only get \$21 per hour. The way I see it is that there is a waste of \$25 per hour there. I get that they are running a business, but I would be able to save money and get more care. Like I could get a carer who could help me get into bed later in the evening. I think I could employ carers directly, have more hours of support, more value for money. But doing this would be disadvantageous to [name of service].” (P11)*

When one participant expressed an interest in self-directing his arrangement with his service provider, he was asked, “What would happen if everyone wants to go elsewhere? Where does that leave us [as an organization]?”(P3). However, when these sorts of situations had arisen for other participants, they stated that they had taken matters into their own hands:

*“It costs \$70 for 2 hours for the support worker to take me shopping. I have worked out that it is cheaper for me to do online shopping instead. I have also looked at other ways to be really smart with the money. For example, I bought one of those robot vacuum cleaners. Yes it was expensive, but if this cuts down the cost of a support worker by one hour a week, I will have it paid off in about 8 months. You have to be smart with the money so that it works better.” (P12)*

As stated by most of the participants, there are benefits associated with implementing self-directed/self-managed flexible responses, and there is a strong requirement to be resilient against the opinion of people who may express fear about these sorts of arrangements. However, for many participants, making these arrangements work is not just a matter of luck, rather, there is a lot of work that occurs ‘behind the scenes’, with the assistance of other supporters around to help over time. What these look like and how these are implemented is the subject to which we now turn.

## **5.2 SUPPORTS THAT FACILITATE THE IMPLEMENTATION & ESTABLISHMENT OF A SELF-DIRECTED / SELF-MANAGED ARRANGEMENT**

Fifteen participants (15) referred to the assistance of key people in the lead-in to implementing & establishing their arrangements. These key people assisted with:

- Proactive thinking about what would be needed to self-direct / self-manage, content in conversations and ideas which focus on what a good life looks like, and the practicalities associated with what is involved in self-managing before building a long-term vision that was subsequently written down & formalized.
- Being involved in strategic thinking about the future and help to set up the team before this person withdrew. *“She also took the emotional heat away from me at this time.” (P15) and “She was the spark behind me and off I went [with self-directing]. If it had not been for her, I wouldn’t have ever done this.” (P17)*
- Planning, including developing a person-centred plan and thinking about the vision and focus of the arrangement, as well as helping to establish a circle of support, particularly in the early stages.
- Helping people to connect with other people who are self-directing / self-managing arrangements. For example, *“Some people working in the Department were incredibly helpful, and I kept notes, emails about discussions about who would do what by when and tracking what was done. This was particularly helpful when the person’s condition was deteriorating.” (P16)*

In similar vein, Marlett (2006) explains that the assistance of key people who believe in the person and help with the thinking before commencing the arrangement ultimately serve the person living with the disability in many ways, These include providing advice and assistance to the person with disabilities and family or friends to identify supports needed, securing funding resources, and negotiating the establishment of customized services to meet the person’s specifications. This is in contrast to the standard idea of a case manager who is there to serve the service system (Williams 2007).

Of note were discussions where it was observed that nothing was written down in a formal sense, like a plan. Eight (8) participants expressed skepticism about the usefulness of plans, when, in their view, the focus needed to be on the person’s aspirations and addressed in a spontaneous manner. For example, one participant stated:

*“Goals are more about ticking boxes ... just a hoop to jump through for the funding. Goals are more about the vision for [name] but I don’t feel the need to justify this to the service provider or to disability services funding providers. This sort of paperwork is boring to do and generally meaningless.” (FM1)*

And:

*“They expect us to do goals and plans for three years here. We do a lot of nonsense goals that are ridiculous to do. It is like training pigeons to turn around four times to get food, but if you don’t do it [plans] then you won’t get the funding.” (P18)*

And:

*“Plans that are pages and pages long are pointless. You really need to get back to reality. For example, big visual plans are irrelevant to us. It really comes back to being truly person-centred and recognizing that progress can be really minute yet mean so much to the person”. (FM4)*

Another participant noted that:

*“ISPs are only there for support information, nothing else. It is really important to maintain the division between support and goals.” (P1)*

For a participant with disabilities, this was expressed as:

*“I have to do a plan every 12 months. I think this is bullshit. I get that a personal support & expenditure plan needs to be done, because this includes information that is critical to the support arrangement. But I think it is completely up to me what my goals are, and I think it is completely up to me to choose solely and alone how to work out what to do with the money.” (P12)*

She went on to explain:

*“I do resent having to put in a plan every year. There is that underlying assumption that we will fritter it all away and fuck it up. I know that people with disabilities have failed before and been given a lot of chances, but how is that different to the guy who misspends his credit card or government misspending funds? The problem here is that they penalize me if I am late putting in my acquittal. We have to be allowed to fail, have an allowance for the oppression we have suffered and the allowance for no training on any of this.” (P12)*

As Williams (2008 p13) notes, agencies can undertake too much planning with people, with the result that there is a sense of orchestration in a person’s life that exceeds what someone would typically do when thinking about the future. Instead, there is a need to consider naturally occurring and informal planning opportunities in people’s lives. This was the experience of a number of participants who considered that the work they do in the circle of support encompasses the necessary monitoring. When asked about this, one participant explained:

*“Every year, we revisit the vision, we go through ‘Who is [name]?', all the things that are under this to make it happen, pick out the bits that have to do with funding and*

*service delivery. We have people on the circle who have no involvement with disability. For example, people who work in other completely different industries and service sectors. Is this challenging? Bloody oath it is (laughs). The biggest battle we address is 'Where to next?'" (FM10)*

For several participants, the development of a strategic plan had been recommended. However, this was not necessarily a useful exercise:

*"We did a strategic plan but it was a complete waste of time. I was advised that this needed to be done for the next five years but really it could only be done for the next one year ahead, certainly not ten years ahead like we hear about. The focus is on the person's life, so planning ahead like that is really like pie in the sky." (FM4)*

Several participants questioned the true usefulness of plans with achieving robust outcomes, particularly when these arrangements work best with a flexible approach to addressing changes that can happen so quickly. Moreover, participants stated that other safeguards need to be in place to facilitate long-standing stability in managing these arrangements. These supports include the development of emergency back-up plans (also explained as being a 'succession plan', 'contingency plan', 'Plan B', 'Plan C', or a 'will'). All but two (2) participants spoke about the need for these arrangements, with one person saying:

*"It is a difficult thing to do as you are trying to foresee what could happen, plus these place impositions on other people. I think it is a work in progress that just goes on forever. I see that it will always be that way but I plan to haunt people from beyond the grave [to make sure expressed wishes are acted upon]; that is how seriously I take all of this." (FM3)*

And another person reflected:

*"The difficulty is how to replace me? I think that I should be immortal to do this. I don't have all the answers, but the immortal bit sounds like the best one so far (laughs). I think that I need to employ someone else to do my job & then step back.... I know that I can't really afford to disappear for 6 months." (FM5)*

Other participants considered that the need for a succession plan was addressed within their circle of support that would support the person's brother in the event this was needed, or that existing community resources, including the use of Red Cross alarm systems, having a list of neighbours, technology backup and staff who can back up each other, being the main backup system in use (P20). However, several people candidly admitted that they had not done anything tangibly to address their succession plan:

*"I haven't done anything so far about this, as it would be about 20 years before I would consider handing the responsibility for this over to anyone else. I know that I could have an accident, this could easily happen, and then I would need to hand it over but I have not done anything about this so far." (P2)*

And another person cheerfully stated:

*"I am too busy enjoying Plan A of my life to consider Plan B!" (P19)*

However, participants discussed situations where changes occurred and people had become ill or required hospitalization for a period of time. This resulted in situations where the practical aspects of the arrangement fell behind. For two participants, this highlighted the need for a form of backup plan:

*"You know, the changes sort of crept up on us, so that was why I needed to bring in a key worker role. I had been sick, in hospital and therefore not able to do anything [about the arrangement] and no-one else [family, parents] knew what to do either. They didn't know the roster, they had no idea about how to manage the staff. My family really had no idea at all. Another reason for bringing in the key worker was the need to cut the umbilical cord from my family. This role has provided functional support all round, apart from my family. I know that Mum gets quite upset by this, I know that there is a lot to being a Mum but it has been pretty hard over the past [number] years to make it all work. It is a hard conversation to have with the family. So the key worker has been an important way to make this all sustainable and to have very necessary safeguards in place for me" (P15)*

And for the other person:

*"I got sick and the spreadsheets fell behind by about 3 months. I was then asked for an acquittal, and when I said I had been sick, I was told to go to an accountant. But this approach was hopeless, as it would have cost a fortune for an accountant to look at this. It was really frightening, very overwhelming when this happened. I was also really worried about the cost of a device I really needed so that I can continue to live independently here and I didn't know if I would have to repay this. I just thought that there would be many multiples of the pension to repay this amount if I had to and I think I would have been repaying this for the rest of my life. I really didn't know then and I still don't know now what are allowable expenses, and this contributes to my stress levels about all of this. You would think that is predictable that people will get sick but I don't think that is completely reasonable to assume people won't manage at times like this. I ended up having friends help me out." (P17)*

Five people commented on the fact that they don't see themselves managing the arrangement over the long-term. When asked about that, one person said they would be developing a team leader in the short-term so that if something unforeseen happened, there would already be a strategy in place. Several participants stated their accountant would provide the back-up needed. Another person who has been self-managing for over a decade commented on the role of their key support staff in a backup contingency plan. This person said that, in his case, he would rely on this person because *'he [support person] is familiar with my management methods'*, and *'he [support person] has access to a range of resources that I would not immediately be aware of'* (P7). A similar observation was made by one parent who noted that:

*"There will be more situations where key support people will assume the role as an informal decision maker who can take over when the primary carer cannot, when that person has passed away."* (FM15)

Yet other family members stated that the brother or sister of the person with disabilities would assume responsibility for managing the arrangement in the event the parents were no longer able to do so, or in the event of death or other forms of permanent impairment of the parents. However, while there is discussion about the level work undertaken by parent carers and people with disabilities to manage these arrangements, it is not clear how equipped other family members will be to manage and monitor these arrangements when the time comes for them to assume this level responsibility.

### **5.3 LEVELS OF MONITORING WITHIN SELF-DIRECTED / SELF-MANAGED ARRANGEMENTS**

During the interviews with participants, it became apparent that a significant amount of work is being undertaken by people who have become experts at managing the monitoring and maintenance of their self-directed/self-managed arrangements. These people spoke primarily about the financial accountabilities they do on a daily, weekly, monthly and annual basis. This work includes general activities such as:

- Organizing insurances, such as domestic and formal workcover, as well as public liability, and reviewing all insurances at least annually.

- Organising all staff matters, such as payroll for staff, whether for people engaged as contracted staff or as casual or permanent part-time or full-time staff; keeping a track of hours worked by staff, including tracking hours on mobile phones, on rosters, spreadsheets, and other documented methods; doing tax and superannuation payments for staff; and ensuring staff have relevant cards, first aid certificates and keeping training course details up-to-date. For situations where staff are on a contract, staff members have their own ABN plus an invoice book that they sign. When this happens, *“staff are paid in cash, and they are responsible for their own superannuation and PAYG. This is set out in their agreement”* (P19; FM20). These participants state they conduct regular staff functions and meetings, as well as observing how people are going informally. Several people had instigated the role of a team leader in assisting with monitoring practices.
- Managing daily, weekly, monthly monitoring of funding through the use of spreadsheets and other methods, and cross-checking expenditure and time sheets with bank statements on a regular basis. This included having an account that is separate to the accounts used for personal funds. A separate bank account facilitates easier monitoring by the person as well as easier auditing processes by the funding body. Other financial activities include keeping copies of receipts and sending one copy with the acquittal documents to the service provider along with the bank statement.
- Considering ways to pull back costs, for example, having family members provide care and support on public holidays, as well as family involvement and support, instead of paid support, at functions.
- Considering who else is in the person’s networks, as well as what the community’s assets are that can be tapped into. This can address the situations where funding doesn’t cover everything which means that people have to look at what the community can offer as well.
- Conducting regular reviews of progress with funding and activities at the beginning of the year, and then developing goals for the year, areas to grow in, before having smaller review each quarter and at the six month point as an audit tracking device with funding. Participants also spoke about the annual financial audit process to meet Departmental service agreement obligations.

All participants who currently self-direct / self-manage their arrangements stated they undertake regular work related to maintaining their staff. This includes activities related to staff management commenced at the point of advertising for staff, and progressed through the recruitment, selection, induction, and performance review processes. This process also encompasses developing tailored position descriptions, organizing criminal history checks, employment activities, conducting reference checks, organizing ‘buddy’ or ‘shadow’ shifts for new staff, and conducting subtle observations of staff over time. Interviews frequently include reference to the ‘blurry line’ between friendships and employment responsibilities, as well as the importance of trust.

Eleven (11) participants spoke about the requirements for making sure training content suits the specific requirements of the person with disabilities, while also addressing the obligations associated with meeting specific work health & safety legislations throughout Australia. For several participants, there was no expressed requirement to do performance reviews because *‘they [support staff] are here all the time’* (P19). Five (5) people spoke about the need to be able to seek advice in the event they needed to terminate a staff member who did not work out.

Seven (7) participants specifically spoke about the positive impacts of staff matching, with one person stating:

*“Staff matching is such a big, big component to making all of this work for [name of person with disabilities]. This approach really helps with matching the staff member with [name of person with disabilities] aspirations and to help him to move more into broader aspects associated with his interests. For example, [name of person with disabilities] likes to go surfing and now with the help of a closely matched staff member, we can see the possibilities of [name of person with disabilities] eventually being included in the local board riders group. This would make such a difference to [name of person with disabilities]. But it wouldn’t be possible without the staff matching process. This helps so much not only with learning but also links into life.”*  
(FM16)

Participants who recruit their own workers stated that they use word-of-mouth, newspaper advertisements, and notices at local venues, which then enable them to control both the type of care worker to assist them as well as the timing and type of care they received. Similarly, workers can often feel like they are more valued by the person with disability and their

family, instead of being treated like they ‘work on a conveyor belt’ with a service provider. Throughout the interview process, participants who are currently self-directing / self-managing stated they had not been ‘left in the lurch’ because a support staff member had not turned up for a shift. On the contrary, all but two people talked about the difference between self-directed / self-managed and standard service delivery in relation to support staff commitment and integrity. This was viewed in a positive light, for example, with explanations about the closer ‘relationship’ and more comprehensive appreciation of what would be likely to happen to the person if the support worker didn’t turn up or simply rang the service provider and said they were not coming in for the shift.

The experience for a number of participants was that they had longstanding staff, with a stable working environment that suited both the person with disabilities as well as the staff. For a number of participants, their support staff perceived their work as a “*dream job*” where “*It is such a pleasure to work here that I would crawl to get here to work*”. These observations were explained with points such as staff commitment, staff working out the rosters for themselves, help with daily planning, factors which all hinge on a strong basis of trust, common values, family ties, relationship, and friendship between the worker and the person with disabilities, their family members or other supporters.

As a result of having regular, general conversations with staff about the personal care and other essential requirements, several participants stressed the importance of “*not letting things fester*”, and other participants observed that there is the reality of dealing with staff issues within the framework of a shift. This was explained by one person as:

*“Having to deal with support workers who have personal crisis, marriage breakdowns, depression and teenager issues – these all come into the home. It sometimes feels like the home is a welfare agency, but support workers need to know work is not the place to unload. I have contributed to this to some degree, so now I have an external consultant who can deal with support workers going through their own personal issues.” (FM25)*

A number of participants contrasted the staff situation in their arrangement with staff employed by the service provider. According to these participants, staff members directly employed by service providers do not appear to have the same understanding or awareness of the consequences of non-attendance or poorly matched situations. For one of the two people

who did not want to speak to the positive experiences of support staff in self-directed / self-managed arrangements, the opinion was that these people [support staff] can prey on weak clients, with the result that clients are placed in untenable positions as a result of being bullied or threatened by more powerful support workers.

For participants who undertake part of the self-directed arrangement in conjunction with a service provider, a number of different approaches were taken. These included having the service provider doing all of the recruitment and selection processes, including the administrative requirements associated with criminal history checks, payroll details, and organizing the roster. Other options included situations where people selected their staff and the service provider paid wages, tax, and superannuation costs on their behalf. In yet other scenarios, family members assume responsible for monitoring the content of communication journals, while the organization maintains the responsibility for all other aspects of service provision. For some people, having the service provider take on some of the responsibilities and ensuring everything about the arrangement was legal was like *'the diamond cherry on the cake'* (P7).

### **5.3.1 Time to manage the arrangement**

Questions about the time it takes to perform tasks to maintain and monitor the self-directed / self-managed arrangement varies from person to person, and arrangement to arrangement, with the result that no two situations were exactly the same. For example, while some people stated they spend an hour or two each month monitoring the arrangement, other participants stated they are doing something on the arrangement every day. When asked what was being done on a regular basis each day, examples included:

- staff observations;
- discussions with staff (formal / informal);
- negotiating with funding providers;
- giving instruction to staff and/or other people providing a range of other services;
- paperwork and paying bills;
- looking for better support services in the community;
- organizing and/or participating in training;

- meeting with people in the support network;
- occasionally having to deal with emotional content (such as keeping the peace, personal relationship issues, marital / relationship breakdowns, death of significant people, financial difficulties, life dilemmas, or celebrations, such as births, marriages, new relationships, moving house, etc.) within conversations with staff. For example, as one participant put it, *“You have to be prepared to live through World War III when there are staff issues. These times can happen in a snap”*. (P17)

The majority of participants indicated that while these practices add time to the day, they considered this to be *‘just something you have to do’*. This necessitates a level of people management skills that assist in making the arrangement work over time. However, this can sometimes place a burden on the primary person managing the arrangement. In amongst discussions about what is done on a regular basis, six (6) participants spoke about the stresses of having inadequate funding amounts to provide the necessary care and support for the person with disabilities, as well as dealing with personal health and emotional wellbeing at the same time to keep the arrangement going. This was a particular concern for single parents, as well as the spouses of people with significant acquired disabilities. This led into discussion about the ways in which the key person holding the arrangement together maintains themselves over time.

### **5.3.2 Longer-term impacts on the primary person responsible for the arrangement**

Thirty-eight participants, inclusive of people with disabilities and family members, who currently self-direct / self-manage spoke at length about what they do to personally manage the practical aspects of their arrangement. While four (4) participants expressed some initial confusion about the activities they undertake to care for themselves, this progressed to discussion about what they do, while at the same time emphasizing that they don’t see that there is anything remarkable about these activities. Similarly, people with disabilities were explicit in their frustration about the focus of managing these arrangements always being on the family members. For example, three (3) participants with disabilities commented on the need for equal recognition of the responsibilities and work that people with disabilities undertake in maintaining these arrangements.

In the process of acknowledging the role each person has with maintaining the arrangement over time, participants who contributed to this project noted that they currently do a number of things to care for themselves. This was seen to be important, particularly as there were distinct concerns about who would perform their duties if they could not (for whatever reason). Examples of what people do to maintain themselves include:

- Sharing things & talking a lot with other key people you can trust to share the dreams with, going through the difficult & joyous times, and providing mutual support e.g. *“If I didn’t have that, then I wouldn’t survive.”*
- Investing in other people to make sure the success of the arrangement doesn’t just rest with the primary carer or primary person responsible for the arrangement. For example, having external friends, external networks or a microboard of people around you, and working as a team in partnership with the support staff. In addition, having different levels of options in place helps people to be healthy in mind. (FM11)
- Remembering that caring is part of life & shouldn’t be thought of as a chore.
- Doing activities the person enjoys e.g. *“lots of computer stuff to help other people” (P20)*, painting, singing, craft, and creative work, and remain as socially active as possible.
- Having supportive family members (if possible) & pets.
- Learning to say ‘no’ to other things that take away your time & energy.
- Having some time out, for example, holidays to look forward to.
- Considering practical responses such as employing a key worker who can start to take on the responsibilities of the primary carer. This role provides support to the staff, and provides a go-between role between staff and the primary carer, and can assist with the paperwork such as timesheets, rosters, and crisis management if the primary person is unwell. This role can be very flexible, for example, with no calls for a week or 2, sometimes 3-4 times a week – all depends on issues at the time. Costs could vary \$840 per month or up to a \$1000 month depending on the work that the key worker does during the month.
- Be aware of the implications of project managing all aspects of life!

Several participants consider their role to be the ‘lynch pin’ in the arrangement. When asked to explain this further, these people described the role as having all of the responsibilities ‘all

on you' and that the role encompasses protecting the person who may be vulnerable to the actions and intent of other people.

Some of the difficulties associated with maintaining themselves over time were also raised. For example, situations were discussed where the person was on their own without any substantial supports around them, or where they state they live 'on the poverty line'. For one participant, while there was a strong commitment to self-directed responses for her family member, there was also an expressed resentment for being expected to professionally and rigorously manage the arrangement on a reimbursement model while also having to manage on the carer pension (around \$400 per fortnight). Combined with financial pressures and the reality of not having any key supporters around her, she said that she experiences a high level of exhaustion because she is doing this [managing the self-directed arrangement] basically on her own. At the same time, this person stated:

*"I am on the receiving end of dealing with a stupid ex-husband, intractable & ignorant government, and ignorance by the community, which means I am always dealing with high levels of difficulty with making this [self-direction] work. I am constantly fighting." (FM 7)*

While the situations were different from one semi-structured interview to another, one woman reflected that due to a lack of practical support from service providers and from other significant people:

*"I feel like I live in an emotionally impoverished place. I don't have the energy to go out. I can only sleep because I am so exhausted all the time. This tends to spiral downwards. I can only say that is happening because I don't get any support and my family member does not get the amount of hours that are needed for the level of support that he requires. (FM25)*

Attempting to explain this level of exhaustion while at the same time trying to get departmental staff to understand the need for particular support arrangements resulted in other forms of frustration for the primary carer:

*"There is no respect for carers [who self-direct / self-manage] who sacrifice to make these arrangements work. There is no room for vulnerability, no funding for other aspects of care, for example, incontinence pads. This places so much extra pressure on you." (FM 12)*

Another participant with disabilities who has been self-directing for some time said:

*“Financially, I need more funding to cover my needs. I am getting tired trying to get better value for money. It would be so good to get some acknowledgement from the Department, to have other choices of service providers who could do what I am doing now, instead of just one option.” (P14)*

During public holidays, a number of family members and people with disabilities who self-direct / self-manage attempt to save funds by not employing staff during these traditionally more expensive times. However, this presents other challenges that people require resilience and a good deal of internal fortitude to get through:

*“Over the Christmas period, it [support arrangement] is quite fragile, terrifying really, how fragile the whole edifice really is. It is like if there is one more thing that happened then I don’t know what I would have done. But most of the time I don’t think about it as it works pretty well most of the time.” (P18)*

And

*“The truth is that I am worn out by all of this, but I am determined not to go back to the Department. I don’t know of any service providers that would do what I do here, and that is another worry for me. I don’t want to be completely ignored, like what has happened to me in the past, because the reality is who would know my [family member] better than me?” (FM2)*

For spouses of people with disabilities, there are other challenges that must be faced. One woman spoke about the effort it takes to get \$132 ahead in a quarter, when there are fundamental costs such as \$1000 for specialized shoes that are required for her husband. At the same time, a number of people expressed awareness that in some states, host agencies receive funding for each client, whereas family members doing self-directed supports don’t receive this sort of funding. For these participants, this did not seem to be equitable or supportive for them. As one person said,

*“Where does that money [\$1000] come from? Why does it not come to me? Why is it provided to an agency but not to me?” (FM14)*

This person went onto say:

*“The person who gets caught in between is the carer and the mother, who is the lynch pin. It is all on you. You have the responsibility for protecting people who are completely vulnerable. There should be a red alert about caring all the time.” (FM 14)*

As a way of managing their arrangement, several participants decided to do some personal development work to practically assist them with the behind-the-scenes management practices that they felt they needed. This encompassed recognizing that self-directed / self-managed arrangements are a form of a business, which necessitates ‘stepping up’ in both mind and body to manage professionally and well over time. For one person, the hiring of a business coach proved an invaluable investment, particularly with helping the person to understand the importance of staff management practices, removing people who are not interested in working this way, professional hiring and firing practices, and ways to keep the team happy. For another person, this involved building capacities and personal beliefs which were enhanced as a result of attending self-confidence and assertiveness skills courses. This helps with dealing with support workers who *‘will walk all over people with disabilities’* (P12.)

Several participants who have not commenced self-directed / self-managed arrangements at the time of the interview process said they could not comment on this point, as it was not relevant to them at the time. They did say, however, that they were aware of the need to maintain themselves over a long period of time. The remaining six (6) participants did not express any particular observation about what they would need to do to maintain themselves, primarily because they thought they would remain with the service provider they currently have and therefore would not need to undertake any personal management activities.

#### **5.4 CRITICAL SUCCESS FACTORS FOR MONITORING & EVALUATING SELF-DIRECTED / SELF-MANAGED ARRANGEMENTS**

This question provided participants with the opportunity to state what they believe to be the critical factors that may encourage the long-term success of self-directed / self-managed arrangements. This included addressing potential barriers to people taking up this form of arrangement at some future time. Participants provided an abundance of information about this topic. The following factors are provided, in no specific order of importance:

## 1. Have good information before starting self-directed / self-managed arrangements.

Participants who have been self-directing / self-managing for some time, as well as those people who had not commenced these arrangements as yet, were quite clear about the need to have widely available and easily understood information about what is involved in self-directed / self-managed arrangements for people with disabilities, family members and other interested stakeholders. This information needs to be able to build upon a *'big picture of the collective needs of the person'* and *'tools that focus on a full life, not just a medical life'* (P16). According to these participants, people who are interested in self-direct/self-managed arrangements should:

- Gain as much information as possible from workshops, reading books;
- Have conversations with people who are already doing this so that you have good insights into what is expected before you commit to start;
- Ask around for the right questions to ask, and consider questions that have a logical order to find a solution;
- Understand and have the knowledge about employment practices and financial accountability practices as well as WHS and industrial laws; and have clear job descriptions that include the rate of pay, details of the job and broad aspects of the job
- Understand the costs of insurances and the importance of having insurances;
- Have good templates for rosters, payroll, timesheets.
- Be competent with the use of the computer for communicating with people , including funding bodies and have access to technology for people with visual impairment (such as Dragon software)
- Be able to seek advice about what to do and who can assist when there are pitfalls, for example, when dealing with *'horrible support workers, those people who are parasites and prey on people who have this sort of funding'* (FM11) or ask the funding organization to do some tasks if things 'get messy' or if you are unwell or other challenging life situations occur.
- Be flexible and give a little as an employer when working with staff, which includes working on developing a strong team spirit amongst the staff members and not treating staff like slaves. *'It is important that the arrangement is flexible both ways'* (P18). This also includes being aware of the interpersonal relationship issues or personal

problems that can arise for workers, and for the primary person to understand what to do and how to manage when these occur. At the same time, remember that this is a business that is about people. It won't work if it is not about the people.

- Make sure that support staff are paid at a fair rate, and to have enough staff so that there is not one person constantly feeling under pressure to fill in shifts and making sure there are enough staff so the arrangement does not fall over. This includes having back-up staff and having enough hours to make the work worthwhile.
- Undertake some mandatory thinking about the employment of support staff. For example, thinking about the tasks and roles they will be undertaking, as well as being aware of the myth that support staff can easily obtain friends for the person with disabilities.
- Become really *au fait* with the tools that need to be used for self-directed / self-managed arrangements
- Have the authority to do self-direction / self-managed arrangements, and to manage this at a local level (meaning with local people, local council, etc. not be managed from a remote / distant location). Similarly, get pre-approval for things so that the funds are not unnecessarily jeopardized or have the funds put at risk. Find out about the capacity to carry over funding from one year to the next.
- If people want help with planning, they should be able to employ whoever they require to do this. This can include having the flexibility of using generic businesses within the community to assist, not just service providers
- An awareness of the commitment and time required to manage a self-directed / self-managed arrangement
- An understanding that this is really like running a small business but "*don't chuck it in when issues crop up*" (FM12)

Participants considered that if an interested person was not 'mentally competent', they could get the service provider to pay bills, while also having a family member around to assist with the process (P11). Similarly, partners of people with disabilities need to understand the funds are there for the disability or the illness, and three (3) participants stressed the need for awareness about the implications of divorce and relationship breakdown on funding.

## 2. Be aware of the personal implications.

The majority of participants, whether a person with a disability or a family member or significant other person, indicated that a critical factor had to be about the awareness of the personal implications associated with undertaking and managing a self-directed / self-managed arrangement over time, while several people regarded this as an emotional question. The following points were offered by participants about the awareness of personal implications:

- Be prepared to be supported as the key person holding the arrangement together. This is critical, as *“you can face unfair opposition, based on other people’s ignorance and prejudices to doing this work”*. (FM5)
- Have a good amount of pig-headed determination – you really need this - be aware of the need to wear different hats but be mindful of not abusing power or being arrogant.
- Accepting that not all things are going to be done perfectly – particularly an issue for mothers! Be aware that *“the wheels will ‘fall off’ the arrangement from time to time – but this can get fixed up”*, and that if something doesn’t work, it is not a failure. It is a learning experience.
- You need to be very even tempered most of the time, and have a good supply of stress pills!
- Learn to ask for help, as this helps not only the transition phase into successful self-direction / self-management practices but also helps with maintaining arrangements over a long period of time.
- Be committed to the belief that support staff need to understand the focus is on the person with disabilities, and that they need to put the person forward in all instances.
- Link in with other people who are doing self-directed / self-managed arrangements as it can be isolating not knowing who else is around. This enables people to learn from the experiences of others. One participant stated that service providers could facilitate this process, but from her experience, this has not occurred. This was frustrating, particularly when she discovered through other networks that there were other people within the service who could have helped her at an earlier stage, and similarly, she could have assisted and supported these other people as well.
- Be aware that you take on a leadership role that encompasses a lot of relationship

building, not just with your staff, but with external people including funders and community members who are critical of self-direction / self-managed arrangements.

- Consider having a critical group aligned to the person with disabilities. Participants of this group need to be supporting and also have a questioning nature. It is recognized that this could take time to build.
- Be organized! If this is not the person's preferred style, consider who else can assist with this.
- Consider developing learning leadership and management skills or having the option to explore this as a way of enhancing the person's own capacities to manage the arrangement. One participant spoke about the positive experience of contracting a business coach for several months to help in the early stages of the arrangement, while another person recommended doing assertiveness, self-confidence building, and effective communication courses.

### **3. Careful monitoring of routine practices.**

While participants had previously noted the range of activities they undertake to monitor and manage self-directed / self-managed arrangements, the need for careful monitoring was also raised in response to the critical factors. This was based on:

- Staying faithful to what you want out of this, and don't forget who and what you are doing that for.
- Really understanding the financial implications, whether self-directing or self-managing. This includes accounting principles, wages, superannuation, legislations for staff, as well as places to access information, for example, for equipment, and funding to pay for equipment.
- Really being committed, for example, to attend to the paperwork on a regular basis.
- Being aware of other places to obtain funding, for example, from Lotteries West, Gaming Machine Fund.
- Understanding the importance of managing staff and developing good communication skills to undertake routine activities with and for staff. This includes being aware of the wellbeing of staff as well as of the person with disabilities.

- Being aware that the relationship with support staff is closer and more focused on trust and commitment than with a standard service delivery model.
- Work on ways to encourage the community to be supportive of the person with disabilities, for example, *“so that they are not going to clobber you when things go wrong, like broken windows.”* (FM7)

#### **4. Broader implications.**

Participants considered that there were broader implications associated with the critical factors. These included:

- Consideration of people’s computer skills, as so much of these self-directed / self-managed flexible arrangements depend on the use of a computer. There is a need to consider the age group and competency of people and help them to acquire the necessary skills.
- Providing the option for people with disabilities and family members to share an arrangement with other people in similar situations. In these events, all parties need to be aware of what will occur in the event the relationship disintegrates. This may also mean that parties will require legal intervention in these situations.
- Being aware that if so many people and family members have to set up companies to do this, there will be broader implications with auditing, keeping abreast of WHS and QA which means *“They will have to keep building the central processes to address compliance. But this is one way of ensuring people get the services they are paying for.”* (P16).
- People who are against the government saying that people with disabilities can go into one house, and questioning what happens if they don’t get along. There is a concern about discriminating against people with disabilities because *“The options to self-direct / self-manage arrangements are not widely known, with the result that people with disabilities who may want to live on their own may not be able to do so because there are inadequate funds and security in place.”* (FM22).
- The need for funding providers and government officials to have trust and the belief that family members and people with disabilities can manage the responsibilities associated with self-directed / self-managed approaches and are quite prepared to be

accountable for their actions. This means stopping the prevailing thoughts and statements about self-directing / self-managing being *'too hard'* and something to be feared. As one participant noted: *"I think that once you are eligible and deemed capable of self-directing, I don't understand why they [Government officers] talk to you like they do when you have already passed the criteria."* (P14)

- The need for 'really good and receptive self-managed Departmental managers who *"actually get back to you / respond to your email"* (FM14) and who *"don't talk down to you."*(P13)
- The need for broader professional development for the increasing number of small providers. *"If this is not provided, there will be a lot of people doing this without the checks and balances about what needs to be done. Perhaps this could be done online as well to help people to understand what the responsibilities are. Training could also be needed on legal entities, the pros and cons, also have less formal structures. There are huge decisions that need to be made."* (P16)
- The need to consider the implications of changing data management practices as well as 'the cloud' for data storage which may enable easy access by the Department for financial acquittal procedures.
- Capacity building for people who want to self-direct / self-manage, as well as capacity regeneration for the future when the person requires additional assistance, as well as to address personal responsibilities associated with maintaining these arrangements. The risk here is about sabotage mainly because people don't have the skills to maintain arrangements over time.
- Consider 'Self-Managed 101' training for people who are interested in doing self-directed / self-managed practices & have this training facilitated by people who have been self-directing / self-managing their arrangements for some time so that the content is practical & credible. Alternatively, consider including a stepped approach to commencing self-directed / self-managed arrangements. For example, Step 1, do this; Step 2, build on skills; Step 3 (etc.)
- Recognize that there are cultural aspects that need to be considered, for example, people from different ethnic backgrounds, indigenous Australians, as well as for people who need assistance to make adjustments to the roles of women in managing funding.
- These arrangements are simple but made more complex by occupational health & safety.

- Issues where support workers take advantage of people who are self-directing / self-managing. One participant claimed that *“Seven out of ten support workers do this [take advantage of people]. This is the reality for us now” (FM11)*. Another participant spoke about the implications of support workers changing hours and times, and the links with power imbalances between support workers and the person with disabilities (FM20). Questions about how to share power need to be answered.
- Assessment of equipment will continue to be needed on an annual basis for some people with disabilities. For example, some people require updated shower chairs, modifications to wheelchairs, mobility devices for amputees as well as orthotic shoes, but problems arise when some government disability departments don’t approve of these expenditures or don’t explain to people what can / can’t be purchased when people commence self-directed / self-managed arrangements.
- Cautions about the adequacy of funding and the review process, for example, *“People fight the Department to get more funding because they [family members, people with disabilities] need this additional funding, even though they are going well, the funds get reduced because there are informal supports in place for the person with disabilities.” (FM5)*
- Broader questions about the NDIS, for example:
  - “With a change of government, will this be ripped out?”
  - “When did NFPs become corporations?”
  - “What are the intentions of the powerbrokers behind the NDIS?”
  - “Who is accountable for all of this?”
  - “Who is going to assess the funding for people?”
  - “Will people’s lives be even more intruded upon?”
  - “Will the states inject funding into this?”
  - “How do services come up with a fee structure in a business model?”
  - “What safeguards will there be for people who choose a small service over a larger NGO e.g. if the small service falls over?”
  - “How flexible is the service delivery?”
  - “How are Government and NGO funds being used?”
  - “How will these arrangements be monitored and evaluated?”
  - “How do we minimize the approaches from the past and work alongside

organisations to get better outcomes?”

## 5.5 CONSIDERATION OF EVALUATION PRACTICES WITHIN SELF-DIRECTED / SELF-MANAGED ARRANGEMENTS

During the semi-structured interviews, it became apparent that evaluation is not a generally defined consideration or expectation within self-managed or self-directed arrangements. This meant that when participants were asked about evaluative processes, five (5) out of forty (40) people who are currently self-directing / self-managing stated they believe evaluation is a component of formal audit processes that they undertake. This showed a level of confusion about what the differences are between audits, evaluations, and to some degree, monitoring practices. The following table provides a comparison of the features associated with audits, monitoring / reviews, as well as evaluations.

**Table 1: Comparing key features of audits, monitoring / review, and evaluation**

	<b>Monitoring / reviews</b>	<b>Evaluation</b>	<b>Audit</b>
Why?	<ul style="list-style-type: none"> <li>• Checks progress</li> <li>• Informs decisions &amp; remedial actions</li> <li>• Update plans</li> <li>• Supports accountability</li> </ul>	<ul style="list-style-type: none"> <li>• Assesses progress &amp; worth</li> <li>• Identifies lessons learned &amp; make recommendation for longer-term planning &amp; organizational learning</li> <li>• Provides accountability</li> </ul>	<ul style="list-style-type: none"> <li>• Ensures compliance</li> <li>• Provides assurance</li> <li>• Provides accountability</li> </ul>
When?	<ul style="list-style-type: none"> <li>• Ongoing during the life of the program</li> </ul>	<ul style="list-style-type: none"> <li>• Periodic</li> <li>• Can occur after a program has been completed</li> </ul>	<ul style="list-style-type: none"> <li>• According to (donor / funder) requirement</li> </ul>
Who?	<ul style="list-style-type: none"> <li>• Internal</li> <li>• Involves key stakeholders involved in the program</li> </ul>	<ul style="list-style-type: none"> <li>• Can be internal or external to the organization or service</li> </ul>	<ul style="list-style-type: none"> <li>• Typically external to program</li> <li>• Can be internal or external to the organization / service</li> </ul>
Link to logical hierarchy	<ul style="list-style-type: none"> <li>• Focuses on inputs, activities, outputs &amp; short-term outcomes</li> </ul>	<ul style="list-style-type: none"> <li>• Focuses on outcomes &amp; overall goal/s</li> </ul>	<ul style="list-style-type: none"> <li>• Focuses on inputs, activities, and outputs</li> </ul>

(Adapted from White & Wiles 2008)

Similarly, there were questions raised about why family members have to do an audit for the company they had established solely for their son / daughter / sibling, whereas people with disabilities who self-manage are not required to undertake audit processes at all. For several family members who have developed support processes based on a company model, there were questions about what they really expected to benefit from an audit (Trotman & Trotman 2010). At the same time, people with disabilities who are responsible for their company and its approaches to self-directed / self-managed support stated that they do not participate in such processes, even though they would appreciate some formal level of monitoring on a relatively regular basis.

In relation to auditing processes, a number of participants commented on their lack of preparation about having an external agency involved in assessing or auditing their service. Similarly, participants stressed the need to ask for straight answers from the government about the audit requirements:

*"I found that when I asked, they couldn't answer questions like 'How strict are the auditors? How far back can they go?' I hated not knowing information like this"*  
(P18)

In situations where family members and people with disabilities undertake self-managed practices, initial forays into the world of auditing appeared quite daunting. As one participant explained:

*"I thought we were all done [after the time it took to get the company set up & then to get the funding through], then we were hit with accreditation. I was thinking, 'Oh my God! This doesn't relate to us'. And then we were blinded by the organization that was supposed to help us, they confused us even more. It took hours and hours to get through what was needed for accreditation, mainly because I didn't think this was what we do.... The problem was that most of the CBs [Certifying Bodies] had no idea of where we were coming from. They were more service oriented, which is not us."* (FM3)

This person went on to say that she didn't see the point of any other form of external evaluation, stating that one audit a year was more than enough. Moreover, for other participants, experiences of audit processes appeared to be inequitable when contrasted with audits conducted with mainstream service providers. As one person noted:

*“I believe that service providers need to be held accountable but they can get by when they don’t have evidence of doing things for people with disabilities. On the other hand, when I was audited, I was threatened with, ‘Have you got this? Have you got that?’ I don’t see any outcomes for service providers who are not doing the right thing, but for people who are self-directing, they are expected to have an extraordinary amount of accountability in place. This doesn’t seem right to me.” (FM 11)*

This person went on to state that she is constantly re-evaluating and self-monitoring what is being done on a daily basis, through the use of feedback, texting, emails, and attending meetings. As noted by a number of participants, audits *“should be the potential for completing a checklist of things [of value] instead of ‘pages and pages of “stuff” that anyone can put on paper’* (FM4). Indeed, there is a requirement to reflect on the fact that the tasks and people involved in the audit process are different between family and nonfamily business, such as non-government service providers, which in turn affects audit judgements and decisions (Nelson & Tan 2005; Sharma 2004; Trotman & Trotman 2010).

While several participants with disabilities stated that they would appreciate having some form of ‘audit’ process, even if only for a couple of hours, as they usually do not have anyone monitoring what they are doing, these observations were a distinct minority amongst the participants of this project. Similarly, observations about consideration of outcomes apart from simply acquiring data on the efficiencies of self-directing / self-managing were not explicitly obtained during the semi-structured interviews. This was because the focus of the work undertaken to self-direct / self-manage arrangements is on monitoring what is being done on a daily, weekly, fortnightly or monthly basis, with the result that limited attention is placed on longer term reviews or evaluation processes. This was explained in the following way:

*“On a quarterly basis, I develop a new set of goals with the staff. I look at the weekly notes, debrief staff where needed, ask them how it went, what issues arose, what were the positives, how could we make more improvements and inroads into [name of person with disabilities] goals. It doesn’t take all that long to do, but those chats with the staff are such a necessary component to make it all run properly. This makes such a big difference.” (FM16)*

This person continued to explain what she does on annual basis:

*“We monitor this arrangement on an annual basis, on [name of person with disabilities] birthday. It is a conversational approach with notes taken down, and we reflect on all of the good things and the challenges that have occurred during the past year since [name of person with disabilities] birthday. We look at what we can do for the next year, and [name of person with disabilities] is really invested in this.” (FM16)*

For the remaining forty-five people, there was no sense that they undertook any form of evaluative or external review activities directly related to their arrangement, and for the majority of these people, their service providers did not place any specific attention within evaluation activities about self-directed arrangements either. When asked about this, the consultant was informed that the usual process was for the service provider to send out a survey that only addresses more general service delivery, not specific to self-directed / self-managed situations. Moreover, there are no supports provided to people to consider evaluating what is being achieved in the arrangement, or to acknowledge that:

*“Sometimes there are no fantastic goals, so there are no ‘leaps and bounds’ changes. It can be so frustrating having to show this, when there may only be small, fleeting improvements or changes.” (FM1)*

Three (3) participants stated that some easy-to-do monitoring and evaluative practices should be used to gather evidence for positive outcomes. In situations where people with disabilities and family members are involved in evaluations, these tend to be conducted on an ad hoc basis, and tend to emphasise the feedback from support workers instead of a defined interest in their [family members or people with disabilities] direct opinion or lived experience. One participant with disabilities said he sees evaluation as *“a positive experience that is based on developmental content where mistakes are made and from which lessons are learned”* (P20), and another person with disabilities stated that it was *“easy to gather evidence related to positive experiences for an evaluation process”*. (P1) According to these participants, evaluation questions might refer to:

- How many people turned up for shifts?
- How frequently are you doing the activities you want to be doing?
- What is the turnover rate?

- How satisfied are you with your arrangement?
- Are you happy with your support workers?
- Are you happy with the amount of training these people have?
- Are you getting what you need?
- What is being achieved as a result of receiving the funding?

As a result of regular monitoring activities, the majority of participants who have been self-directing / self-managing for some time stated they could identify tangible differences that have occurred in the life of the person with disabilities since starting this form of support. For example, a person with disabilities who had not had any confidence while he had been at school now coaching football teams as a young adult, another person now assisting behind the scenes at local theatre productions, and situations where the person with disabilities had assumed other valued roles in their community. However, there are currently no formal processes within existing self-directed / self-managed flexible funding arrangements to capture this sort of learning.

This means that the agency (in this context, DisabilityCare Australia, the national disability insurance scheme) needs to be collecting performance information that is useful to the provider, the funder, for reporting performance to government and to the evaluators who at a later date will want to assess the effectiveness and appropriateness of implementation and service delivery (Ryan 2003). Similarly, this process needs to be understood, welcomed and appreciated by people with disabilities and family members or significant other people who are involved in managing self-directed / self-managed arrangements. However, at the point of conducting the semi-structured interviews as well as the literature review for this project, details about the federal government's interest in embedding comprehensive evaluation frameworks that are inclusive of the voice and lived experience of people with disabilities, family members or significant other people involved in self-directed / self-managed flexible funding arrangements within DisabilityCare Australia was not clear or evident.

## 5.6 RECOMMENDATIONS TO PEOPLE WHO MAY BE INTERESTED IN THIS MODEL

The majority of participants (n =37) who currently self-direct / self-manage arrangements resoundingly responded in the affirmative when asked if they would recommend self-direction / self-management to other people. For example, participants responded in the following way:

- Absolutely! I recommend self-direction all the time. It is far better & easier than traditional services. You can't make any of this worse than what a NGO [service provider] does. (P4).
- This approach can also really help address the life requirements of people with challenging behaviours as well, particularly for people who want to be included. Similarly, when this is set up well, the behavior can markedly reduce. (FM11)
- Definitely would if you want your own life & be in charge of the supports around you. As one participant explained, '*Otherwise my needs don't come first*'. (P17).
- You'd be crazy if you don't do this. It is really about building up relationships. If you do that well, people won't let you down. (P19)
- Self-managed arrangements solve the problems, it is easier and it is about having control and giving control of life to the person [with disabilities]. It enables the person [with disabilities] to live life the way they want. It is not like jumping off a cliff. It is more about getting into life. (FM1)
- Absolutely! Everyone should have the choice to do this. We know that some people won't manage what we have here but they should still have the right to choose (FM13)

A number of participants expressed concern that a large number of people had not heard of self-direction / self-management as an option for providing supports. This was encapsulated in statements such as '*Self-directed approaches are not promoted very well*' (FM1). Similarly, these participants expressed sorrow about the propensity of people with disabilities to be doing demeaning activities or not being engaged in life to their [the person with disabilities] fullest capacity.

From the original number of participants who said they would recommend this approach to others, thirty one (31) people said that while they would recommend this approach, there needed to be a proviso. Examples of these include:

- Have a good reason to do this, and make sure you have enough funding to cover the actual costs of what the person with disabilities actually requires.
- Only do this if you are committed to doing this over time, and be aware that you have to have a good skill set, or the willingness to acquire the necessary skills and the tools, the backup if you don't understand what you are doing. This means that you will need a good support system, and a good backup plan to keep people safe. You need to develop your own capacity to do this well, otherwise it will end up being a mess.
- Going directly to self-managing would be 'a big ask' as you have to 'hit the ground running' and have your systems in place, policies & procedures in place. Instead, start slowly, and know that when things don't work out or something goes wrong, that you can ask for help and have the right to change things if this is needed. In this case, consider choosing a service provider who can show you the ropes and help you to learn before considering what you can do on your own.
- Be aware that it may be useful to engage consultants to assist on the practicalities about how to do self-directed / self-managed processes well, and to assist in determining if this process is for you. Otherwise there will be a marked increase in emergency responses which will equate to markedly increased expenses and impacts not only on people but support agencies as well.
- You need to be aware that this process involves sacrifice – how much are you willing to do? You have got to be realistic as there are also consequences on your career by doing this.
- You need to know what resources and services are available, and what you can outsource, for example, payroll, and then make use of them. You must be transparent and accountable with what you are doing, and not rot the system.
- Be mindful that self-direction is not for everyone. Some people just don't want to take responsibility for their own life, but I certainly would recommend this to someone who could achieve this or want to do this. (P15)

- Be mindful of the fact that frequently staff are living week to week so if you are not prepared to pay the staff on time, they [staff] won't be happy. If you don't think you can stick to timeframes like that then stay with an agency. (P7)

## **5.7 TOOLS TO FACILITATE EVALUATION PRACTICES**

While the primary focus of this project incorporated a literature review and exploring the lived experience of people who are currently self-directing / self-managing their arrangements, or anticipate doing so at some future time, the original proposal also included a focus on developing and trialing tools that would be used beyond the lifespan of this project:

“Developing, trialing and refining simple English tools that may assist people to manage the evaluation process in self-directed / self-managed arrangements beyond the lifespan of the project”.

In reality, developing useful evaluation tools was not formally undertaken during the project, as it became apparent that while participants have numerous tools they can use to help them commence and subsequently monitor their self-directed / self-managed arrangements, little attention is currently placed on evaluating these arrangements. In fact, standard audit processes linked to the various disability standards currently operating throughout Australia appear to be the prevalent method of ensuring these arrangements are compliant, with limited attention being placed on what has been learned from implementing these arrangements over the years and, in some cases, decades.

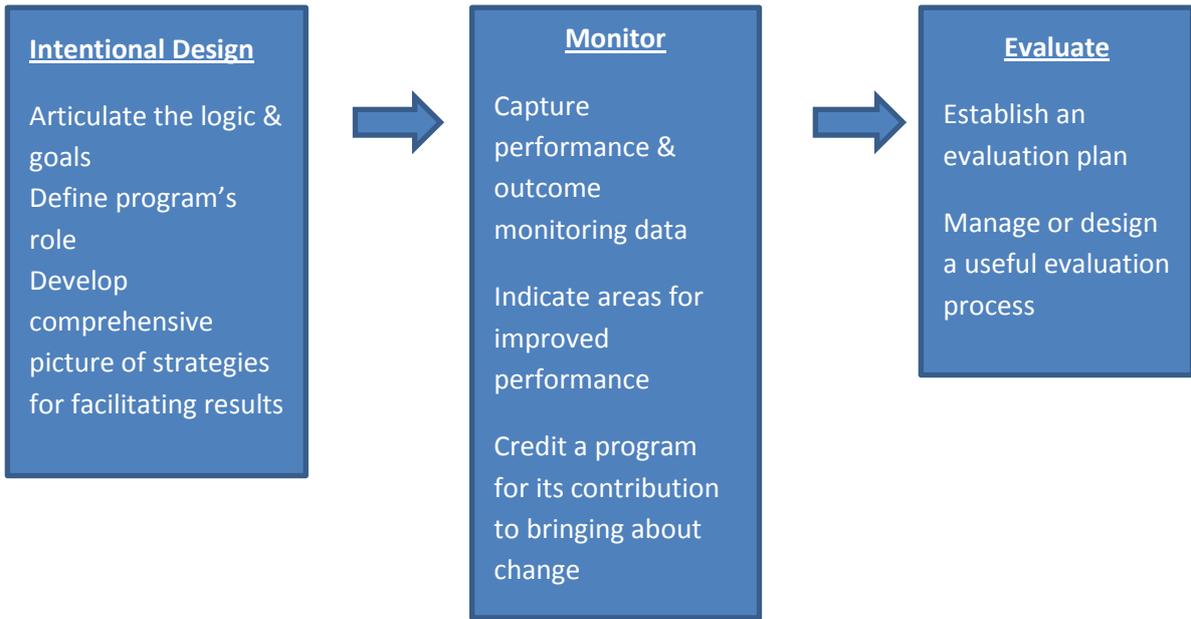
During the interviews, questions about evaluation practices in these self-directed / self-managed arrangements provoked, in some instances, a strong negative reaction towards the role of government wanting to obtain more information about what participants are doing, and why. On the other hand, several participants with disabilities expressed an interest in having their arrangement monitored, as a way of these people feeling assured that they are meeting the necessary requirements associated with their funding.

As stated in Section 5.5, it was not immediately apparent what role evaluation that is inclusive of the voice and lived experience of people who are directly involved in self-directed / self-managed flexible funding arrangements would have at the broader

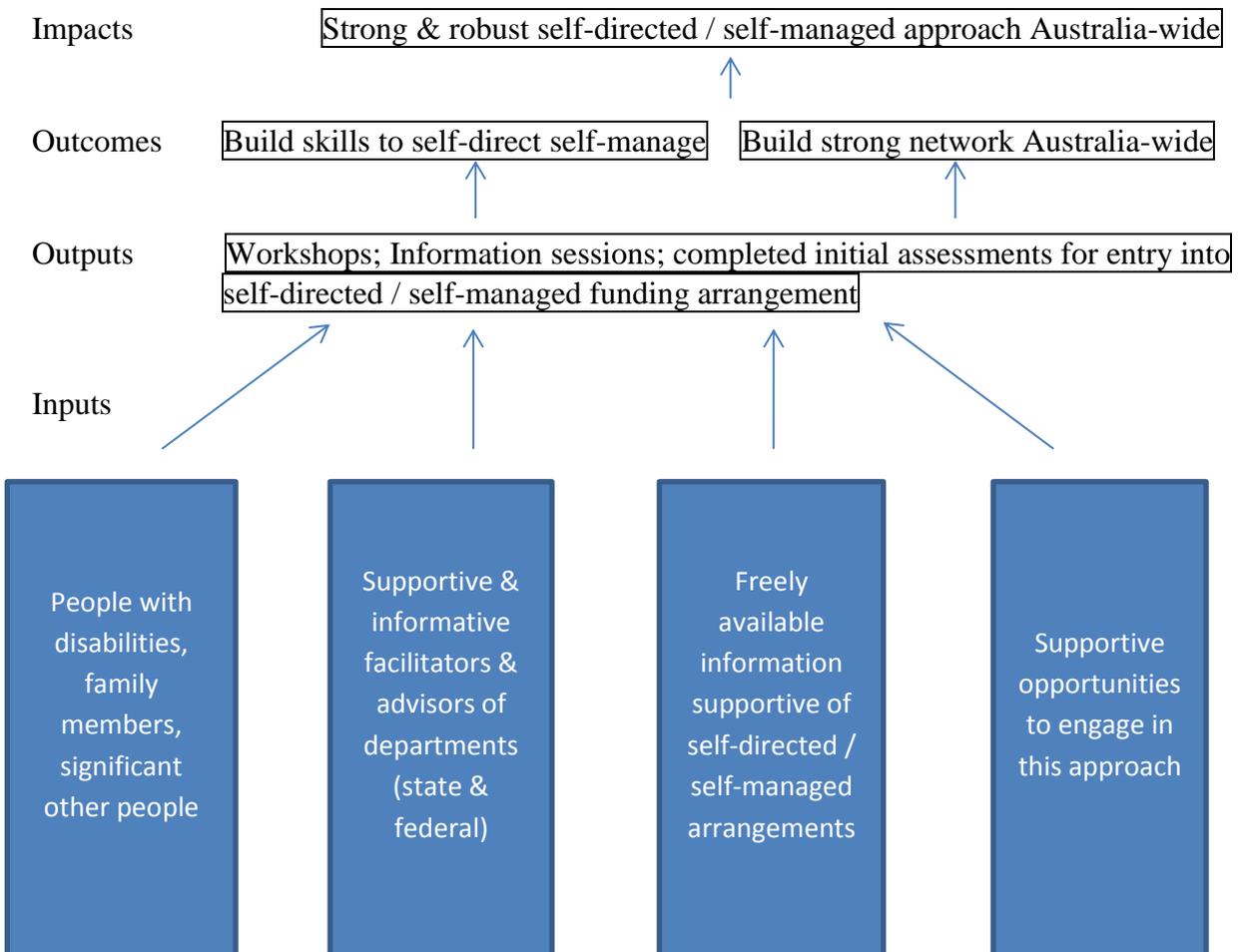
DisabilityCare Australia national disability insurance scheme systems level. With that in mind, as well as from the feedback from participants, developing formalized tools appeared to be somewhat premature at this point in time. This was based on the importance of knowing which evaluation framework will be utilized by the NDIS / DisabilityCare Australia, the focus of the evaluation approach, as well as what longer term aims and objectives should be aspired to within the overall framework. Similarly, having a structure around integrating the program learning, reflection and improvements arising from evaluation strategies would be strengthened by having a broader educative role in assisting people with disabilities and family members understand and appreciate the importance of evaluation within their particular arrangement. This also means that evaluation questions need to be useful to the participant, as well as to government and non-government organisations, and that all stakeholders understand the importance of having a long-term focus on outcomes and impacts.

Research indicates that a monitoring and evaluation plan ideally needs to be developed during the planning stage of the overall process, before commencing implementation. This process includes (amongst other components) the design of the methodology, identification and management of actual and potential risks, as well as data collection. A plan of this nature would help guide what should be evaluated within the self-directed / self-managed flexible funding strategy, as well as provide a guide to what information will be needed, as well as who will benefit from this strategy.

Moreover, incorporating a participatory methodology, increasingly viewed as ‘best practice’ in evaluation research (Fisher & Robinson 2007), would be useful to ensure that meaningful participation of a range of stakeholders occurs throughout the evaluation process. This form of methodology encourages the lived experience of people with disabilities, family members as well as other stakeholders to be incorporated into the qualitative data collection process. As a result of these activities, the program can be more effective in terms of the results that it achieves, and add value for monitoring and evaluating development programs where results and achievements are not easily understood with the use of quantitative indicators alone, but require the deeper insights of a qualitative, conceptualized story of the development process (Earl, Carden & Smutylo 2001). The following diagram shows the stages that outcome mapping uses:



As part of the intentional design process, the following diagram provides an example of what a program logic could look like for the self-directed / self-managed program:



To achieve positive outcomes, it is important to consider the role of enablers and constraints that influence the level of achievement of the evaluation process linked to self-directed / self-managed arrangements. This means considering the following factors:

- The roles of individuals who assume self-directed / self-management arrangements;
- The roles of internal stakeholders within services & departments;
- The roles of external stakeholders, including community organisations and services;
- The profile of people who assume self-directed / self-management arrangements;
- Availability of easy-to-understand information about self-directed / self-managed arrangements, as well as the availability of training & funding to assist people throughout this process;
- The availability of peer support & mentoring from other people who have been self-directing / self-managing for a period of time;
- The current skill sets within the individual, organisations and services to support self-directed / self-managed arrangements over time;
- Logistical and other forms of practical advice and support;
- Infrastructure to successfully self-direct / self-manage over time;
- Broader political and economic factors;
- Referral networks; and
- The disability system in general.

Therefore, based on the data obtained from the semi-structured interviews conducted for this project, the following questions might be useful in such a process:

- What are the immediate outcomes of service delivery within self-directed / self-managed flexible funding arrangements?
- What are the changes created in individual's status and condition of existence as a possible direct or indirect result of this arrangement?
- To what extent are the needs of the person with disabilities understood within the self-directed / self-managed arrangement, and how does the arrangement continue to provide appropriate and effective levels of service?
- To what extent do person with disabilities or family members or significant other people understand what they have to do to undertake self-directed / self-managed

arrangements over time and are motivated to do so?

- To what extent do the personal skills of clients and/or family members who are self-directing / self-managing increase over time to effectively and efficiently manage their arrangement?
- To what extent does the person's skills built upon and developed so that they increasingly feel confident to take on new tasks within their particular arrangement?
- To what extent do changed circumstances impact on their ability to manage their arrangement over time?
- To what extent does assuming increased skills and confidence increase the proportion of people in that category who successfully manage their arrangement, while at the same time see a corresponding decrease in the levels of inappropriate and unnecessary paperwork?
- To what extent do correct financial management practices increase the likelihood of people being creative within the realms of financial management practices and a corresponding decrease in the levels of financial mismanagement?

However, questions of this nature can really only be considered once the correct evaluation framework has been developed, along with a comprehensive program logic. At the same time, acknowledgement of the strong negative reaction towards the role of government wanting to obtain more information about what participants are doing, and why needs to be countered within a longer term strategy that is outside the timeframes and realm of this project. Broader evaluation initiatives undertaken for the DisabilityCare Australia strategy need to be robust, inclusive, and have a process to actively hear the voice and opinion of a number of stakeholders, including people with disabilities, family members and significant other people involved in self-directed / self-managed arrangements, representatives of service provider organisations, peak bodies, and government representatives. Such an approach would go a long way towards healing the difficulties of the past, such as negative experiences with service providers and funding agencies, and assist with the way forward, as proposed by the DisabilityCare Australia national disability insurance scheme.

## **6.0 DISCUSSION**

Self-directed / self-managed arrangements are at the forefront of recommendations arising from the Productivity Commission Report (2011) and provide an important addition to the long-term care and support landscape. These arrangements tend to have similar philosophies and service elements, and provide a basis whereby many people with disabilities can assume control of their supports (Powers & Sowers 2006). However, while this option has been utilised by a number of people who desire to control their supports, there are a number of challenges facing DisabilityCare Australia in supporting not only those people who have been undertaking and managing the responsibilities associated with managing these arrangements for some time, but also supporting people who have not commenced at this time.

### **Building the strategies for the way forward**

After reviewing the literature and the results of the semi-structured interviews, a number of considerations are apparent for progressing self-directed / self-managed arrangements across Australia. Amongst the challenges are subtle but far-reaching issues related to the attitude of funding bodies and organisations that provide support to people with disabilities in facilitating respectful and professional support and advice to people interested in this approach. While the participants in this project provided considerable evidence of the detailed monitoring practices they undertake on a regular basis, it was apparent that for the majority of these people there were still considerable hurdles to overcome with fear and limiting beliefs, points also identified in the research literature, amongst funding bodies and service providers. These continue unabated, even though there were numerous examples amongst the participants of successful practices within self-directed / self-managed arrangements being undertaken for many years, and in some cases, decades.

Addressing these concerns will be necessary for DisabilityCare Australia to successfully progress self-directed / self-managed supports as a viable and attractive alternative for people who want to assume more control in their lives, and to achieve the levels of satisfaction that are referred to in the literature. While attitudinal barriers are frequently the most challenging factors to address (Powers & Sowers 2006), there is an opportunity to work collaboratively amongst all stakeholders, thereby reducing the likelihood that people with disabilities, family members or significant other people will continue to be demonized for considering this form

of support. As other researchers have also noted, ‘more of the same approaches will not work’, necessitating a shift from service provision to a greater involvement and co-production of support to people who are involved in self-directed / self-managed arrangements (Ridley et al 2011). From the discussions with participants about the reasons for commencing self-directed / self-managed arrangements, there are lessons to be learned for service providers and funding bodies about the ways in which communication and fractured relationships propel people into this form of support arrangement. Moreover, the way forward for self-directed / self-managed arrangements throughout Australia will require organisations that provide support to people with disabilities to undertake an internal realignment of culture to successfully transition to a new landscape of support, broader initiatives that support individuals to also acquire and refine the necessary skills and knowledge required to manage all or part of their self-directed / self-managed arrangement. At the same time, significant efforts will be required to ensure that people have adequate funding levels to be able to succeed with these arrangements (Spandler 2004; Fawcett & Plath 2012), so that they do not experience some of the additional, difficult and significant financial, emotional and physical burdens placed on the primary person, whether a person with a disability, family member or significant other person, who assumes responsibility for the arrangement. Without these inputs, people with disabilities, family members or significant other people who are currently involved in these arrangements or may be at some future time will be set up to fail.

Participants provided many candid opinions about the ways in which they take personal responsibility for their self-directed / self-managed arrangement. Monitoring practices appear to address short to medium term outcomes in key areas that directly relate to the life of the person with disability. The general belief shared by participants was any person, regardless of age, ability or disability, cultural or ethnic heritage, who expresses an interest in undertaking self-directed / self-managed practices should be aware of the responsibilities and commitment needed to maintain these arrangements over time. This incorporates obtaining good quality information about the requirements to not only establish these arrangements but to consider what will be required to maintain them over time. Moreover, participants considered a sound contingency or back-up plan was necessary, with considerable thought being placed on what would happen in the event the person was not able to continue with the management responsibilities for whatever reason or for whatever period of time.

Similarly, there was an acknowledgement of the significant personal impacts on the person who is responsible for maintaining the arrangement, with a small number of participants indicating that these arrangements can become vulnerable in the event of their own ill-health, or implications associated with their own emotional and psychological wellbeing. While many participants initially struggled to explain what they do to maintain themselves, they were subsequently able to explain that they had moved to a point of not even seeing what they do anymore, therefore finding it initially difficult to explain in detail how these arrangements are maintained and sustained over time.

However, while monitoring practices appear to be firmly embedded within these existing arrangements, there did not appear to be any particular emphasis on evaluating these arrangements in a planned, periodic way, apart from participating in audit processes. The current use of audit or assessment processes throughout Australia is built on the requirement for services to comply with a number of standards, which do not always focus on outcomes or impacts for people with disabilities and/or their service structures, or whether interventions work well or not. Moreover, unlike evaluation processes, there is no formally stated requirement to learn from the reasons for success or failure within an audit process.

At this point in time, there does not appear to be any specific strategy or requirement to use evaluative frameworks and methods to understand, from the point of view of the person with disabilities, family member or significant other person, whether and how an arrangement, contained within a broader funding program, is meeting stated objectives as well as its outcomes and impacts. Without this level of information, it is difficult to see how the Australian Government can learn from the monitoring activities that are currently undertaken, as well as the practicalities associated with what people with disabilities, family members and significant other people do to make their arrangement work, how issues, concerns or potential crises are addressed, or what innovative practices are already in place. Over time, information such as this could be widely disseminated and build upon Australia's knowledge base about what helps to make these arrangements work and what can be done to minimize the likelihood of failure occurring. Moreover, this information can be used to enhance the likelihood of continual development of support responses to people with disabilities, family members or significant other people who may require additional assistance due to factors including (amongst others) age, cultural background, ethnicity, limited literacy and/or numeracy comprehension, or limited family supports to undertake these arrangements.

## **7.0 RECOMMENDATIONS & IMPLICATIONS FOR POLICY**

The information acquired from this consultation and literature review should be used to inform the next stage of implementing the DisabilityCare Australia national disability insurance scheme, particularly within the monitoring and evaluation arenas. It is recommended that DisabilityCare Australia:

- 7.1 Consider the use of consistent terminology pertaining to self-directed / self-managed / share-managed arrangements throughout Australia, thereby eliminating confusion about what these terms mean from state to state, and from one funding program to another, for people with disabilities, family members, significant other people, as well as service providers.
- 7.2 Consider developing a robust monitoring and evaluation framework that is designed for the self-direct / self-managed program under the DisabilityCare Australia, and include:
  - 7.2.1 A comprehensive and robust developmental phase that includes people with disabilities, family members, and significant other people alongside service providers and funding representatives to establish the monitoring and evaluation framework for self-directed / self-managed arrangements across Australia.
  - 7.2.2 An acknowledgement that monitoring and evaluation strategies should not be onerous. Instead, the focus of this work should be relevant, meaningful, and easily understood by all people involved in this framework.
  - 7.2.3 Strategies for incorporating this framework into everyday activities within each newly established self-directed / self-managed arrangement.
  - 7.2.4 Strategies to assist pre-existing arrangements transition into evaluation methodologies and practices.
  - 7.2.5 An investigation of methods for sharing relevant, easy-to-understand information about monitoring and evaluation practices to support people with disabilities, family members and significant other people to understand what is required.

- 7.2.6 The possibility of developing simple yet rigorous questions within the existing NMDS quarterly data collection procedure to capture important information pertaining to self-directed / self-managed arrangements.
- 7.3 Consider the ways in which the capacity of people with disabilities and / or family members to assume stronger control in evaluating self-directed / self-managed arrangements could be strengthened.
- 7.4 Ensure that there is an equitable process undertaken with any funding provided to assist with the establishment of self-directed / self-managed practices for service providers as well as people with disabilities or their family members / significant other people who undertake self-directed / self-managed arrangements.
- 7.5 Consider the establishment of a peer support network, comprising people who have been self-directing / self-managing for some time, as a method of assisting people living throughout Australia to be able to access practical information on the ground. Further, consider paying these peer supporters for their valued time and contribution.
- 7.6 Consider a range of successful communication and information sharing methods, including the use of modern technology, which can be used for people who are already self-directing / self-managing arrangements, as well as for people who are interested in undertaking this approach at some future time.

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## **APPENDIX 1:**

### **PARTICIPANT INFORMATION SHEET**

**Project title:** *It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements*

**Researcher:** Kathy Rees  
Gitana Consulting & Training Services

This project has been funded by FAHCSIA for the Practical Design Fund associated with the National Disability Insurance Scheme. The research conducted for this project complies with the requirements of the National Health and Medical Research Council.

#### **Invitation to participate**

You are invited to participate in individual semi-structured interviews as part of a project being conducted by Kathy Rees. This study is designed to explore the requirements for family members and/or people with disabilities to successfully evaluate their self-directed / self-managed support arrangements.

For this project, Kathy is responsible for convening and conducting semi-structured interviews with family members and/or people with disabilities who are involved in managing a self-directed / self-managed support arrangement, or who are interested in doing so at some future time.

You have been invited to participate and contribute your expertise on monitoring & evaluating self-directed / self-managed arrangements and associated practices related to the project topic.

In order for you to give informed consent, you will need to understand what is involved as well as the potential risks and benefits of the project. This form gives detailed information about the project. Before you make a decision to participate in the project, please read the following information.

#### **Purpose of the project**

This project explores the requirements for family members and/or people with disabilities to successfully evaluate their self-directed / self-managed support arrangements, with a particular emphasis on what is required to maintain these arrangements over time. In order to understand these requirements, the project includes interviewing a number of participants who have current experience with self-direction / self-management practices, as well as with people who have not currently had this level of experience.

The semi-structured interviews, convened by Kathy Rees, provide family members and/or people with disabilities with the opportunity to advise and provide information on issues relating to implementing and managing an effective self-directed / self-managed arrangement over time. This involves examining the levels of monitoring & evaluation that may be required for these arrangements, as well as considering the critical factors for ensuring self-directed / self-managed arrangements are successful over time. These sessions will be audio-taped, and transcribed at a later time.

## **Benefits of the project**

The findings arising from this project will be used to understand and document the requirements for monitoring and evaluating self-directed / self-managed arrangements. Ultimately, these findings will be used to advise government, as well as to inform current policies and practices designed to meet the requirements of family members and/or people with disabilities who want to self-direct or self-manage their arrangement. It is hoped that this research will initiate further discussion and awareness of the issues confronting stakeholders who either directly direct or manage their arrangement, or who are providing some form of practical or policy support.

## **Voluntary nature of participation in the project**

Your participation in this project is on a completely voluntary basis. If you wish to participate, you may still withdraw at any time. If you withdraw, all information obtained from you will be removed from the data base associated with this research project.

## **Requirements for participating in the project**

You have been nominated and authorized to speak about the ways in which people can successfully monitor & evaluate their self-directed / self-managed support arrangement. If you choose to participate, you will be involved in a semi-structured interview at a time and place of your convenience. The semi-structured interview will take approximately one (1) hour and will enable you to provide your own knowledge and opinions about the project topic.

## **Risks associated with participating in the project**

All information obtained during this research project will be maintained according to strict confidentiality requirements to minimize the risk of participant identification or breaches of privacy. Your name and address will not be attached to any information, and every effort will be made to ensure organizations will not be identifiable within the final write-up of the report. Storage of the information obtained from the interview will occur at the secure storage facility at Gitana Consulting & Training Services, and no other parties will have access to any information apart from the final report.

## **Findings arising from this project**

Upon completion of the research process, a report detailing results and recommendations arising from the project will be forwarded to all participants.

## **For more information**

This project has been funded by FAHCSIA and abides by the requirements of the National Health and Medical Research Council's guidelines for conducting research projects of this nature.

If you are not happy with the way this research has been conducted, or if you would like any further information about this study, please do not hesitate to contact Kathy on 0417608261.

If you wish to take part in the study, please scan and return the Participant Consent Form as soon as possible to [kathy@gitana.com.au](mailto:kathy@gitana.com.au).

**Thank you for taking the time to read this Participant Information Sheet.**

**You are welcome to keep this Participant Information Sheet for your future reference.**

**PARTICIPANT CONSENT FORM**

**Project title:** *It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements*

**Researcher:** Kathy Rees  
Gitana Consulting & Training Services

Yes, I would like to be involved in this project in my role as \_\_\_\_\_ (role) within \_\_\_\_\_ (name of organization, if applicable). I confirm that I am authorized to speak on behalf of my organization about monitoring and evaluative arrangements related to the provision of a self-directed / self-managed arrangement. By signing below, I acknowledge that I have read and understood the Participant Information Sheet. I have decided to voluntarily take part in this project, and understand that in the event that I do not want to continue participation in this project my information will be excluded from the analysis. I understand that all information is confidentially maintained, and that the information used in the project is de-identified, with no personal details being disclosed.

I also understand that all materials related to this research, for example, audio tapes, transcripts and notes taken within the interview, will be securely stored for the duration of the project, and subsequently destroyed when the requirements of the Practical Design Fund are completed.

Participant: \_\_\_\_\_ (Print name in full)

\_\_\_\_\_ (Signature)

\_\_\_\_\_ (contact details) \_\_\_\_\_ (Date)

Witness: \_\_\_\_\_ (Print name in full)

\_\_\_\_\_ (Signature)

\_\_\_\_\_ (contact details) \_\_\_\_\_ (Date)

## **APPENDIX 2**

### **KEY THEMES:**

#### **Introductory questions:**

- How long have you been self-directing / self- managing?
- What attracted you to self-direct / self-manage?

#### **1 Requirements for implementing and managing an effective self-directed / self-management arrangement over time**

- What activities are you currently undertaking to self-direct / self-manage the arrangement?
- How do these activities impact upon your role of managing an effective self-directed / self-managed arrangement?
- What actions and/or supports are required to maintain an effective arrangement over time?

#### **2 Levels of monitoring and evaluating self-directed / self-managed arrangements**

- What forms of monitoring assist with informing self-directed / self-managed arrangements?
- What level of monitoring are you prepared to accept with self-directed / self-managed arrangements?
- Are these monitoring arrangements challenging for you to do? If so, in what way? If not, what explanations may be used to describe this?
- In what ways does monitoring support other responsibilities & requirements?

#### **3 Critical success factors for monitoring and evaluating self-directed / self-managed arrangements**

- What are the critical factors to facilitate successful self-directed activities over a long period of time?
- Is evaluation routinely considered for self-directed / self-managed arrangements? If so, what supports are required to evaluate these arrangements?

#### **Completion questions:**

- Would you recommend self-directed / self-managed arrangements to other people?
- Reflecting on what you have learned about self-direction / self-management, what would you like other people to know?