nous group

Evaluation of Individualised Support Programs: Final Report

Department of Family and Community Services: Ageing, Disability, and Home Care

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Contents

Executive Summary

Background

The NSW Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) engaged Nous Group (Nous) to conduct an evaluation into the experiences of service users within the four Individualised Support (demonstration) Projects (ISPs), which are funded through the *Stronger Together: a new direction for disability services in NSW: 2006-2016* plan for disability services:

- *my plan, my choice:* Early Start (ES)
- Extended Family Support (EFS)
- *my plan, my choice:* Older Carers (OC)
- The Self Managed Model (SMM) of the Community Participation (CP), Life Choices (LC), and Active Ageing (AA) programs.

The projects are designed to empower people with a disability to tailor the supports and services that they receive to their individual needs, and to develop their capacity to be at the centre of the decision-making process.

The aim of this evaluation was to better understand the diversity of experiences of service users, their families and carers in the ISPs and the decision support mechanisms associated with these projects. The evaluation results will be used to inform the development of the broader person centred approach (PCA) to disability services based on individualised funding arrangements. The evaluation focussed on two key evaluation questions:

1. What were the different experiences of service users, their families and carers in the Individualised Support (demonstration) Projects?
2. What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs?

Key findings

The key findings for each key evaluation question were:

What were the different experiences of service users, their families and carers in the Individualised Support (demonstration) Projects?

- Service users, their families and carers purchased a diverse range of supports and services with their funding. These supports and services fell into three broad categories: respite and care; therapies and activities; and equipment or capital purchases.
- Service users within the same ISP tended to access the same types of supports and services.
- Service users initially took a conservative approach to purchasing services (maintaining or extending existing supports) but managed their funding more creatively over time.
- Service users typically followed a similar path through their ISP, which can be described as a five phase journey from the start of the ISP through to the achievement of their goals.
- Service users generally reported that their capacity to self-manage increased over time.

- The interviews revealed a mix of positive and negative experiences in terms of the extent to which service users were able to achieve their goals. Positive experiences were illustrated by case studies to understand the diversity of experiences (summarised in Table 1), and contrasted with other experiences to identify critical success factors.
- Service users' long-term goals typically focussed on reaching a transition point such as starting school, entering the workforce, or moving to new residential arrangements.
- Service users generally had positive experiences with their ISPs if the duration of the funding coincided with their transition to the next life stage (the achievement of their goals). Conversely, service users with funding that ceased before they reached their next transition point generally had negative experiences.
- Alignment between the goals of the service user and the aims of the ISP seems to be the most critical factor for ensuring a positive experience. The ISP eligibility criteria assume that the goals of a person with a disability (e.g. living with a recently diagnosed disability) are linked to their age (e.g. 0-5 years). This works best for people who have a disability from birth (e.g. autism), but not as well for those who acquire a disability later in life (e.g. acquired brain injury). These people have goals similar to someone with a recently diagnosed disability but at an advanced age.
- Nous did not find a relationship between positive ISP experiences and service user age, cultural background, gender, nature of disability or previous disability service experience.

What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs?

- There were three broad types of decision support: financial management; informal support[1], advice, and case management; and research and coordination of supports and services.
- There was no clear consensus amongst the providers of these services about what is involved in providing decision support, including:
  - what supports are components of "decision supports";
  - what decision supports need to be provided to their service users; and
  - what is involved in providing specific decision supports such as support planning.
- The level of decision support provided depended to a large extent on the capabilities of service users, although 'tailoring' this support was not always easy to achieve.
- The administration cost for decision supports is effectively a fixed percentage for all service users in each ISP, regardless of their level of need. This has led to dissatisfaction on the part of some service users who would prefer to receive less decision support and have lower administration costs. The fixed cost also potentially creates an incentive for service intermediaries to select service users with low needs and hence require less decision support.
- The type of decision support required by service users depended on the stage of the service user's journey through the ISP.
- Decision support (including clear, concise information) is especially important in the first 6-12 months as service users become familiar with the concept of self-management.

[1] Emotional and conversational support provided by service intermediary/provider outside of other services, e.g. phone conversations

- Decision support mechanisms that encouraged idea generation in the early stages, e.g. circle of support sessions, typically led to more innovative uses of the ISPs over time.
- Flexibility in purchasing arrangements and the portability of funding between service intermediaries were important to service users in realising their support plans.
- Service users who required specialist carers or alternative or non-traditional services (e.g. to overcome 'supply' problems) were able to access these through their ISP when supported by their service intermediaries through additional capabilities such as payroll management. This gave service users the ability to make decisions to use specialist, alternative or non-traditional services over traditional supports and services.
- Service intermediaries had different views on whether Aboriginal and culturally and linguistically diverse (CALD) service users required a different level of decision support. The most significant difference was the extra effort required to build relationships with Aboriginal service users, their extended families and communities before and during their participation in the ISPs.

Implications and conclusions for the person centred approach

How might the success factors in implementing decision support mechanisms be implemented as part of the broader person centred approach?

The following success factors for decision support should be considered during the implementation of a person centred approach:

1. **The right fit**: Service users and service intermediaries noted that the best outcomes were achieved through the ISPs when the goals of the program matched the goals of the service user. Suggestions for the decision support mechanisms that may improve 'fit' include:
   - engaging the person with a disability, their family or carer prior to the start of the funding to find out their goals and discuss key elements of the program
   - techniques to assist service users to articulate their individual goals
   - selecting a service intermediary that can provide the capabilities needed by the service user
2. **Getting started:** Understanding the flexibility and responsibilities associated with the ISPs is a major challenge for many service users at the start of their funding. Some of the decision support mechanisms that service intermediaries have had success with include:
   - early education about ISPs prior to the start of the program
   - providing information progressively and innovatively to service users
   - standardisation of toolkits and training modules for service intermediaries
   - seminars and support groups that bring families on the same program or in similar circumstances together to share knowledge
   - processes enabling service users to change their plans as they familiarise with the system
3. **Settling in:** Service users who had high functional needs and/or wanted to engage informal or non-traditional supports relied on decision support capabilities that were offered by some, but not all, service intermediaries. These capabilities included:
   - sophisticated HR and OH&S capabilities, including the ability to hire casual staff
   - financial management and budgeting to coordinate multiple funding sources
   - knowledge of legal and insurance issues associated with non-traditional services or supports

- expertise in specific disabilities and/or early intervention
- capability to educate service users in tasks such as online research

4. **Flexibility:** Portable funding and flexible purchasing arrangements were cited by service users as reasons for their positive experiences in the ISPs. Suggestions from service intermediaries to provide these characteristics include:
   - processes that enable easy portability of funding between service intermediaries or providers by the service user
   - rapid invoicing, reimbursements, and/or pre-approval processes to effectively address crisis or emergency situations
5. **Reaching goals:** People plan their goals around reaching their next life stage rather than according to funding schedules. Service users expressed their desire for an option to vary the period of funding depending on their circumstances. Some decision support mechanisms that may also assist people in reaching their goals include:
   - budgeting advice to ensure that sufficient funds are available to support individuals through the entire funding period
   - option to pay in advance for recurrent services (such as therapy) that will be delivered after the funding period
   - expert advice and innovation in suggesting alternative supports, education, or equipment purchases that can provide long-term benefits to the individual with a disability
6. **Meeting decision support needs:** Service intermediaries found it difficult to provide the right level of decision support to service users, because the system lacked the flexibility for people to choose their decision supports and vary the administration fee to fund these. Some of the mechanisms that were suggested to resolve these issues include:
   - allowing service users to choose the level of decision support provided by the service intermediary depending on their own capabilities and skills
   - enabling the administration fee to be varied for different service users depending on the decision supports that they require

Table 1 Summary of the five case studies chosen for each stage of the ISP cycle

	1. The right fit	2. Getting started	3. Settling in	4. Flexibility	5. Reaching goals
Background	Young man living with worsening muscular dystrophy, now in full-time care	A young woman living with Down syndrome raised by her foster mother	Older carer in regional NSW supporting husband and daughter who both live with a disability.	Young man living with a genetic disorder, paraplegia and an intellectual disability	Mother with two young boys living with Autism-Spectrum Disorders
Situation	Living with depression due to an event which left him in 24/7 care	Home-schooled, she has no existing social contacts	Under increasing stress as both she and her husband become more frail	Living with the loss of his social networks after graduation from high school	Both boys slated to start school within the next year
Goal	Re-engage with friends and go to TAFE	Pursue her athletic interests while participating in the community	Access a mix of supports and services to maintain care for her dependents	Create a social network of age-appropriate carers	Both boys to speak before they start primary school
Challenges	• Delay in replacing a carer when they left at short notice • Difficulty in finding a carer whose personality suited that of the service user	• Initially felt overwhelmed by the amount of information at start of funding and pressure to formulate a support plan quickly	• Lack of local support planner, closest planner resided in another town	• Lack of supply for specialist carers in regional NSW. • Insufficient ISP funding to provide all desired supports	• Lack of flexibility to purchase supports to keep the family together through the stress • Insufficient information during the early months of the project, lack of engagement prior to funding starting
Critical success factors	• Program goals matched that of the individual with disability • Uncle able to manage funding on behalf of CALD family	• Intermediary used a step-by-step process for family to complete application forms • Case manager was very knowledgeable about the disability • Novel techniques used to communicate with service user and work out her goals	• Flexible financial arrangements and management of budget and invoices by intermediary • Assistance with researching local supports and services	Intermediary provided: • Sophisticated HR processes to hire, fire, and manage casual carers • Expert knowledge of taxation, workplace law, OH&S regulations • Managed disparate funding sources, budget and carer hours • Coordinated multiple carers on flexible schedules	• Funding period covered the boys until they were ready to start school (transition point) • Service intermediary suggested non-traditional/alternative supports • Opportunity to meet with other families on the same ISP funding

1 Background

1.1 The person centred approach

The NSW Government's ten year plan for disability services, *Stronger Together: a new direction for disability services in NSW: 2006-2016*, aims to improve the lives of people with a disability by strengthening families, promoting community inclusion, and improving services. Through *Living Life My Way* the NSW Government has identified what people with a disability say that they need and want from disability services[2]:

- having a real say in planning supports and services;
- having their views respected;
- exercising greater choice and control over services and supports;
- controlling a personal budget; and
- the ability to access services and supports in flexible ways that suited their lifestyles.

The NSW Department of Family and Community Services: Ageing, Disability and Home Care (ADHC) is currently implementing these outcomes through a person centred approach, based on individualised funding arrangements for people with a disability, their families and carers. This approach recognises the diverse needs and situations of people with a disability. Part of this effort includes an extensive series of consultations around NSW on the best way to implement person centred supports and funding arrangements through *Living Life My Way*. The vision for the person centred approach is to create a system in which:

- individuals are supported to achieve their full potential and participate in their communities and the economy;
- families and carers are supported to sustain a care relationship and pursue their own goals; and
- a diverse and sustainable service sector that provides person centred supports and services in a cost-effective way.

1.2 The Individualised Support (demonstration) Projects

The four Individualised Support (demonstration) Projects (ISPs) that were the subject of this evaluation are funded through *Stronger Together* and designed to inform the wider implementation of a person centred approach. They are: *my plan, my choice: Early Start; Extended Family Support; my plan, my choice: Older Carers; and the Self-Managed Model*[3].

[2] Source: Living Life My Way, NSW Government, August 2011

[3] Note: the Self-Managed Model differs from the other projects in this evaluation as it is not a stand-alone program - it is one of three service types (the others being Centre-based with Community Access and Individual Community-based Options) that are available for three ADHC community participation programs aimed at people with a disability: Community Participation, Life Choices, and Active Ageing.

In each ISP, support plans are developed by the person with a disability, their family or carer with support from ADHC support planners and/or a service intermediary. These plans are then implemented by the service intermediary or service providers using the funding provided.

The key characteristics of these ISPs are outlined in Table 2.

Table 2: Summary of the ISPs.

	Summary[4]		Funding	No of Participants[5]	Average annual funding[6]
my plan, my choice: Early Start	Eligibility is for children up to (but not including) six years of age with a developmental delay or disability who are yet to start school. Priority access is for children currently not receiving any early childhood intervention services. 20 packages are available at any given time for up to two years, with a review after 12 months.		Up to $8000 per annum for up to two years. Up to 10% of this funding is allocated as administrative fees to the service intermediary.	31	Data not available
Extended Family Support	For families with a child with a disability who is between 0-18 years old, and which are at risk of relinquishing care and already accessing ADHC-provided or funded services. 100 packages of funding are offered per annum.		Up to $50,000 per annum. Up to 12% of this is for administrative fees.	104	$36,380
Self Managed Model	One of three models for the delivery of three ADHC community participation programs (CP, LC, and AA). SMM is designed to enable service users to plan the activities that they want to do. A goal of SMM is for the service user to self-manage their money, their budget, and the people that work with them.	Community Participation is for young school-leavers up to 25 years old who are not in paid employment for more than four hours per week or in full time vocational training. CP is designed promote participation by people with a disability as active and valued members of the community.	Available funding dependent on the individual program allocation and the assessed level of need. Up to 12% of this funding is for administrative fees to the service intermediary.	179	$31,372
		Life Choices is for people with a disability aged between 25-54 years and is designed to provide opportunities to participate in the community and to enjoy a range of purposeful leisure activities.		119	$16,727
		Active Ageing is for people with a disability aged between 55-64 years (45-64 with early onset ageing; from age 40 for Aboriginal people).		8	$15,678
my plan, my choice: Older Carers	For people aged over 60 (over 45 for Aboriginal people) who are the primary carers of a person with a disability. Total funding for the pilot program is $1.5m for service delivery and $500,000 for support planners and program administration.		Up to $40,000 per annum depending on assessed level of need, with up to 12% for administrative fees	43	$40,413

[4] Summaries and funding information obtained from ISP pilot process maps [13] [14] [15] [16] [17].

[5] Obtained from ADHC Central Information Service (CIS) for EFS, SMM and OC [2] [3] [4]. Data for ES was obtained from ADHC/Nous data request [5].

[6] Sources: Average annual funding per participant in the ISP, calculated from CIS data (not available for ES) [2] [3] [4].

Figure 1 illustrates the program logic for the ISPs from the programs through to the longer term aspirations of *Stronger Together*.

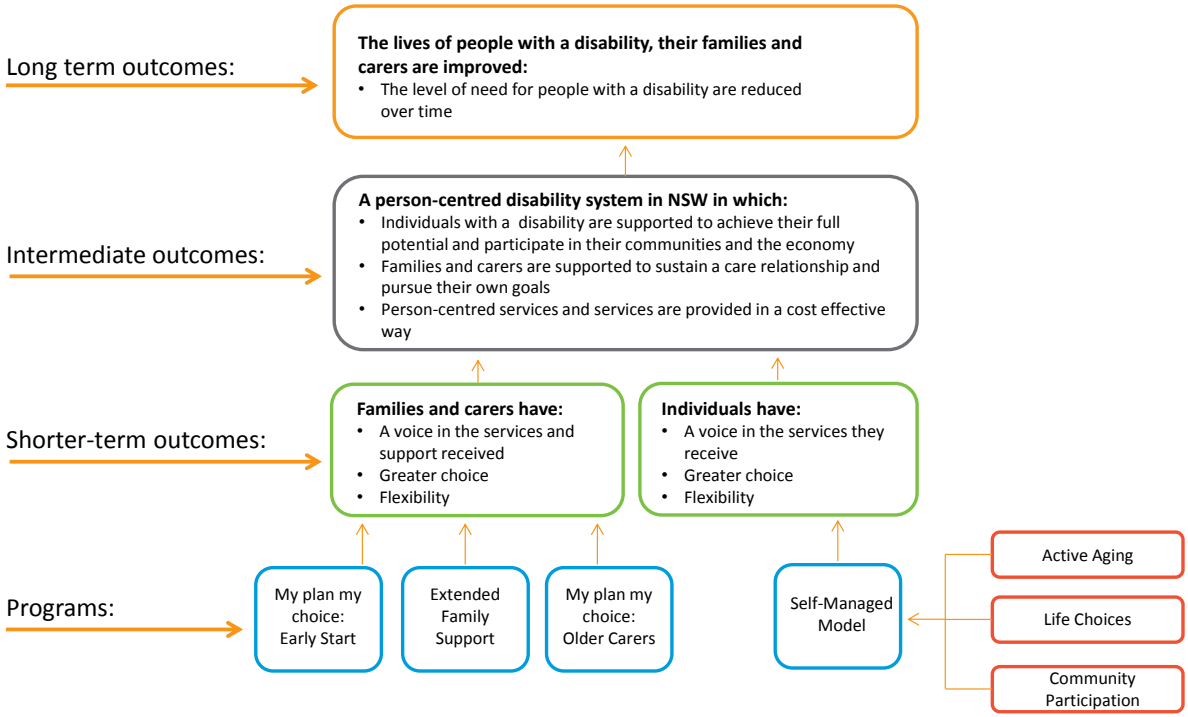


Figure 1: Overall program logic for the ISPs and person centred approach

1.3 This evaluation

1.3.1 Purpose

ADHC engaged Nous to conduct an evaluation into the experiences of service users and decision support mechanisms across the four ISPs. The conclusions from this evaluation will be primarily used to inform the development of a person centred system for people with a disability, their families and carers based on individualised funding arrangements.

1.3.2 Scope

Two of the four ISPs (ES and OC) are still in the formative stages of development and all four are currently "demonstration" projects. It is therefore not appropriate to focus an evaluation of the ISPs on the outcomes achieved for the participants in the programs, i.e. this is not an impact evaluation.

Rather, ADHC wanted to use this evaluation to understand how the pilots were working and explore what could be learnt to inform the development of a person centred system.

Specifically, the key high-level evaluation questions were:

1. *What were the different experiences of service users, their families and carers in the Individualised Support (demonstration) Projects?*

2. *What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs*?

This required a different type of evaluation than the more common impact evaluation that seeks to understand and establish the causal relationships between program activities and outcomes. This evaluation focused on understanding the diversity of experiences of those involved in the ISPs, and the processes at work that influence these experiences. The limitations of this evaluation are detailed in Appendix C.

In their typology of evaluation approaches (see Figure 2), Owen and Rogers describe Nous' approach as a *process* evaluation (i.e. looking inside the 'black box' into what's happening) and the general approach as *illuminative/responsive*, i.e. understanding the voice of the participants in the programs.

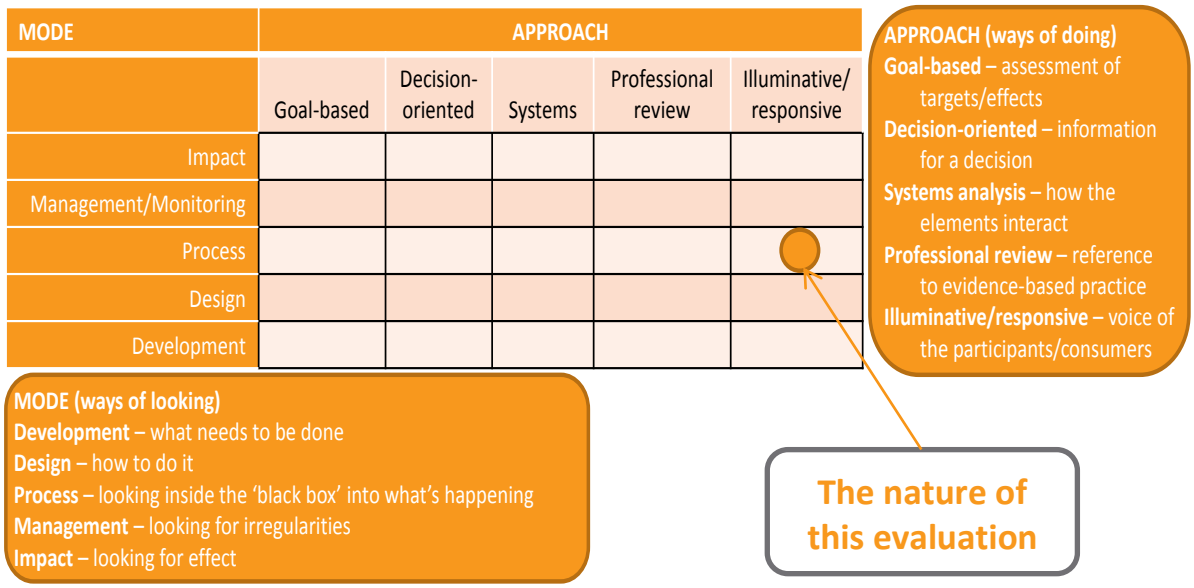


Figure 2: Evaluation typology (Source: Owen, J and P Rogers. 1999. *Program Evaluation: Forms and Approaches*)

The scope of this evaluation has informed the key evaluation questions (outlined in more detail in Appendix C) and the data collection and analysis design (see section 1.3.3 methodology below).

1.3.3 Methodology

The evaluation used three data collection and analysis activities (described in more detail in Appendix C):

1. ***Desktop review to understand service user characteristics:***

   A desktop review was conducted on both quantitative and qualitative data obtained through previous evaluations.

   Quantitative data sources included reports from the ADHC Client Information System [1] [2] [3] [4], data requests [5] [6] [7] [8] [9] and quantitative data collected through previous evaluations by Nous Group [10] [11]. Details about these sources are listed in Appendix C.

   Qualitative data sources included existing literature and documentation from previous reviews, including surveys [12], pilot process reports [13] [14] [15] [16] [17], Participatory Action Research (PAR) reports [10], and previous evaluations of the ISPs [11] [18].

The results from the desktop review were used to select interviewees based on their demographics and services/supports history in order to obtain a wide diversity of experiences across the four ISPs. The strategy used to select interviewees is outlined in Appendix E.

2. ***A. Structured interviews to illustrate experiences:*** 25 structured interviews were conducted with service users, their families and carers to glean insights into their experiences in the ISPs and the impact of decision support mechanisms. Six interviews with representatives from service intermediaries were also conducted in order to obtain their perspectives on the success factors and challenges involved with the processes in the ISPs. The number of completed interviews for each program is listed in Table 3 below.

Table 3 Number of completed interviews

PROGRAM:	Completed interviews
Early Start	5
Extended Family Support	4
Older Carers	4
Self Managed Model - Community Participation	7
Self Managed Model - Life Choices	5
Service Intermediaries	6
TOTAL:	31

B. Identifying key findings and case studies: Two Nous consultants reviewed the data from the structured interviews and independently identified findings from each transcript. These findings were then consolidated into a common set of key findings across all the interviews, and used to select five case studies that illustrated the experiences of people within the ISPs. Information from other interviews was used to highlight critical success factors, challenges, and key decision support mechanisms in each case study.

Similarly, a system case study was also produced from interviews with service intermediaries, focusing on the success factors and challenges they experienced in providing decision support to service users in the ISPs.

3. ***Testing key findings through focus groups:*** Nous conducted two focus workshops with key stakeholders.
    - The first workshop was conducted with key stakeholders in ADHC, including the participatory action research champions for three of the four ISP (ES, EFS, and OC). This workshop focused on testing our findings.
    - The second workshop was designed specifically to close any gaps in our understanding and was conducted with nine support planners from ADHC and service intermediaries.

2 KEQ1: What were the different experiences of service users, their families and carers in the ISPs?

This section outlines the key findings in response to Key Evaluation Question 1: *What were the different experiences of service users, their families and carers in the ISPs?* Specific findings for the sub-questions relevant to this Key Evaluation Question are provided in Table 5 at the end of this section.

2.1 Service users purchased a diverse range of services

Key findings

- Service users, their families and carers purchased a diverse range of supports and services with their funding.
- These supports and services fell into three broad categories: respite and care; therapies and activities; and equipment or capital purchases.
- Service users within the same ISP tended to access the same types of supports and services.
- Service users initially took a conservative approach to purchasing services (maintaining or extending existing supports) but managed their funding more creatively over time.

As a cohort, service users, their families and carers purchased a wide range of supports and services with their funding. Examples of specific supports and services identified in this evaluation are listed in Table 4 below.

These supports and services broadly fell into three categories:

- ***Respite and care*** **-** services intended to relieve family members or primary carers for a brief period of time
- ***Therapies and activities*** **-** supports and services for the person with a disability used to treat specific needs, improve their independence, or participate more effectively in the community
- ***Equipment and capital purchases*** **-** devices, aids, or modifications to existing equipment or infrastructure designed to assist in the care and safety of the person with a disability

Table 4: Examples of supports and services accessed in the ISPs. This list is not comprehensive for all supports and services accessed through the ISPs as this evaluation did not include interviews with every service user in these programs. Sources: Structured interviews and data requests from ES, EFS, and OC.

Respite and Care	Therapies and Activities	Equipment and Capital
• accommodation at respite facilities • hiring private or agency carers • playgroups • holidays • home maintenance (and domestic assistance): cleaners, painters, tilers, gardeners etc. • airfares • petrol costs • meals • shopping assistance • podiatry • personal care • transport e.g. taxi vouchers	• speech therapy • massages • occupational therapy • physiotherapy • swimming lessons • dance classes • day centres • training sessions for the carers to provide these services • English lessons • gym classes and membership • music lessons • horse riding • festivals • TAFE fees • continence clinic • pre-school • family advocacy	• iPad • home renovations: fencing, disabled bathrooms, reinforced doors, alarm systems, driveway • furniture • weighted blankets and vests for autism treatments • play mats • exercise equipment • orthopaedic shoes • carpeting • car repairs • customised bike • customised pram • toys • school clothes • bedding

Service users within the same ISP tended to access the same types of supports and services. Different supports and services were accessed in different ISPs. These differences were primarily due to the life stage of the participants and the guidelines of the particular ISP, e.g.:

- *Early Start* families predominantly accessed therapies (physiotherapy, speech therapy, occupational therapy) and educational aids.
- Carers in the *Older Carers* project purchased respite, home renovations and furniture.
- Individuals in the *Self-Managed Model* accessed a mix of respite and carers. Funds were also used for a range of community and recreational activities.
- Families in the *Extended Family Support* program purchased a diverse range of supports for family members (following the program guidelines) including holidays and home renovations.

The types of supports and services accessed by services users in different ISPs is illustrated in Figure 3.

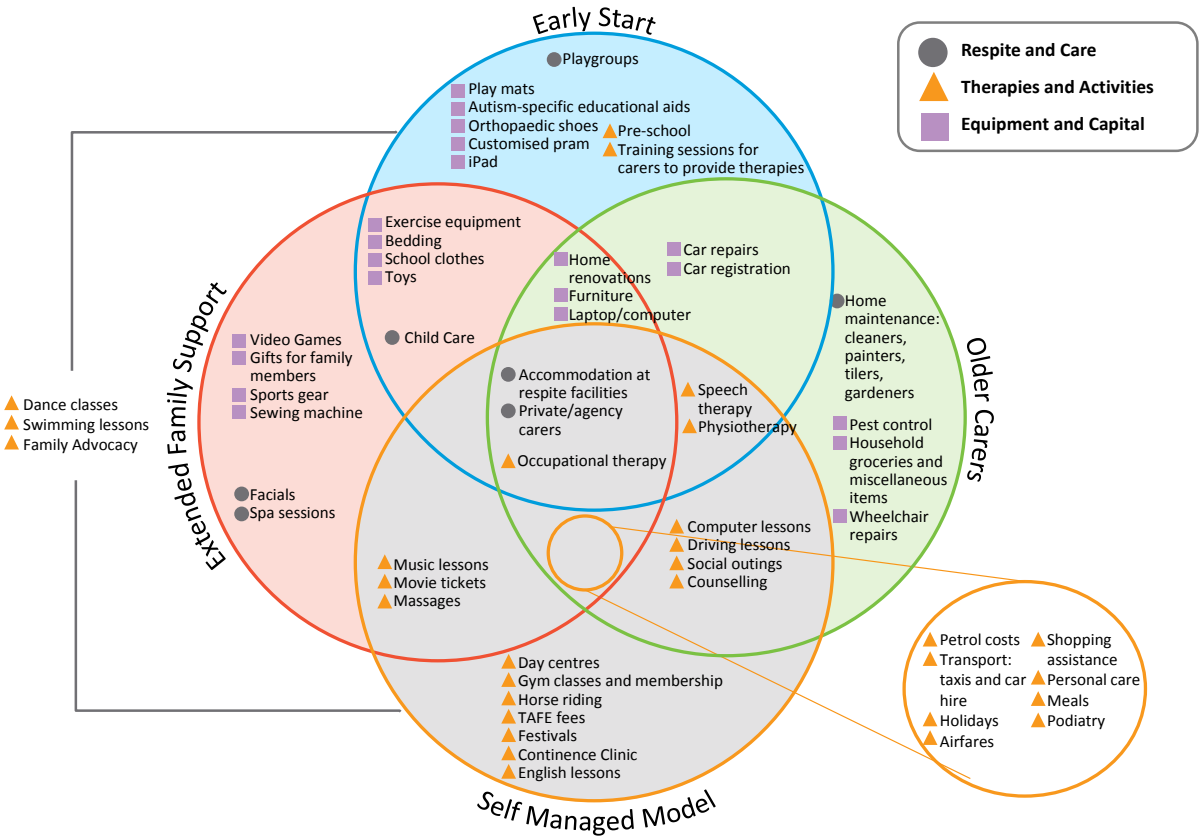


Figure 3: Types of supports and services accessed by service users in different ISPs. Source: Structured interviews and data requests from ES, EFS, and OC.

Most of the interviewed service users initially took a conservative approach to purchasing supports and services in the first twelve months of the program, i.e. they maintained and extended supports that they were already using through other disability programs or private funds.

However, after 6-12 months, service users began to gain confidence in managing their funding and started using it more creatively. Some of the more innovative supports accessed by service users included training classes for parents to provide speech therapy and the purchase of educational aids.

2.2 Service users moved through a number of phases

Key findings

- Service users typically followed a similar path through their ISP, which can be described as a five phase journey from the start of the ISP through to the achievement of their goals.
- Service users generally reported that their capacity to make decisions increased over time as they moved through these phases.
- The interviews revealed a mix of positive and negative experiences in terms of the extent to which service users were able to achieve their goals.

Service users, their families and carers typically followed a similar path through their ISP from the start of the program through to achieving their goals. This journey consists of five phases:

1. ***The Right Fit*** **-** At the start of the funding, the person with the disability and their family are unfamiliar with the goals and processes of the ISP that they are entering. It is important that the program's goals match those of the service user at this stage, so that the supports and services allowed under the program guidelines are capable of meeting their needs and circumstances.
2. ***Getting Started*** **-** The early months of the funding are an opportunity for people to learn about the ISP and its person centred approach. Mechanisms to educate, guide, and familiarise the service user and their families and carers in this phase are key to helping them get started.
3. ***Settling In*** **-** The first support plan developed by the service user is typically conservative and requires support from the intermediary to be successfully implemented. Supports that are useful in this phase include financial management, budgeting advice, and assistance in researching supports and services.
4. ***Flexibility*** **-** Subsequent support plans by the participant tend to use a more innovative mix of supports and services than the first plan, especially after the first 6-12 months. Additional decision support mechanisms may be needed from the service intermediary to enable these more creative but complex plans.
5. ***Reaching Goals*** **-** People living with a disability typically have goals based on reaching the next life stage or transition point, such as starting school, graduating, or entering the workforce. A key factor in supporting their efforts to reach these goals is to ensure that the funding period for the funding covers the individual up to their transition point[7].

Service users generally reported that their capacity to make decisions increased over time as they moved through these phases.

The situation of each of the service users interviewed for this evaluation can be located somewhere along this journey as indicated in Figure 4 below. Some people achieved all of their goals in the ISPs. Others had a mix of positive and negative experiences which affected whether they were able to achieve all their goals. In both cases, people encountered opportunities and constraints that influenced their experiences as they progressed through the ISP. The things that worked and didn't work are analysed more comprehensively through the five case studies and critical success factors described in section 4.

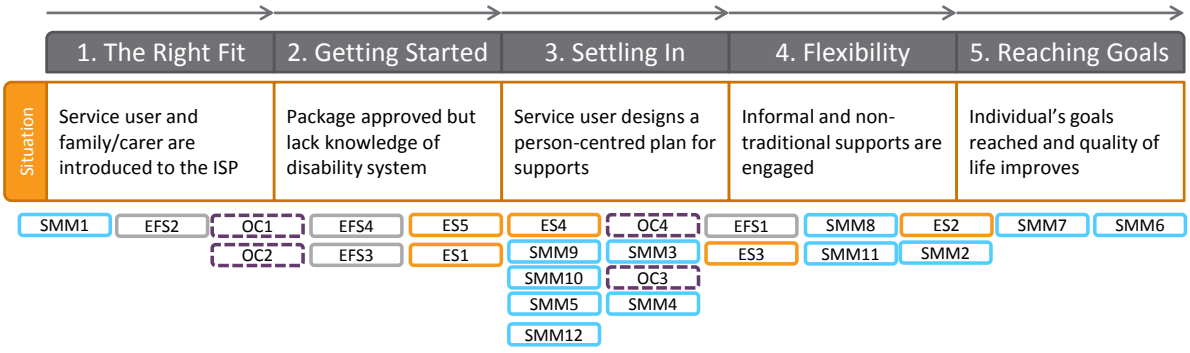


Figure 4: The five phases experienced by people with a disability in their passage through the ISP (and the relationship with specific interviewees).

[7] This is a particular challenge for programs that run for only one year. E.g. children in Early Start (a one-year program) are either enrolled for the year leading up to school, which supports them through to the start of school but comes too late for early intervention strategies; or they are enrolled at a younger age in which the converse situation occurs.

2.3 Success was getting to the next transition point

Key findings

- Service users' long-term goals typically focussed on reaching a transition point such as starting school, entering the workforce, or transitioning to new residential arrangements.
- Service users generally had positive experiences with their ISPs if the duration of the funding coincided with their transition to the next life stage (the achievement of their goals).
- Conversely, service users with funding that ceased before they reached their next transition point generally had negative or neutral experiences.

Service users, their families and carers have long-term goals that focus on reaching a transition point such as starting or finishing school, entering the workforce, or transitioning to new residential arrangements. These do not always correspond to the funded period of their ISPs.

Many service users were concerned that their funding would not see them through to the next transition point or past their current crisis. This is a problem for funding that has a fixed duration e.g. *Early Start* and *Extended Family Support*, and is compounded by the uncertainty of obtaining future funding.

Service users generally had positive experiences and achieved their goals in cases where the duration of the funding coincided with their transition to the next life stage. Examples include *Self- Managed Model (Community Participation)* service users that sought to gain independence following departure from school, or *Early Start* families that received funding in the year prior to commencing primary school.

Conversely, service users with funding that ceased before they reached their next transition point generally had negative experiences. Service users expressed a reluctance to engage services through an ISP that they would be unable to maintain without funding. This hampered their ability to use their current funding to its full potential or to achieve their goals.

The capacity of participants to make decisions and/or self-manage was strengthened by the extent to which ISPs helps them to achieve their goals. Getting people to their next transition point or through their current crises was therefore an important requirement for an ISP to be successful.

2.4 Alignment between individual goals and ISP aims was critical

Key findings

- Alignment between the goals of the service user and the aims of the ISP seems to be the most critical factor for ensuring a positive experience.
- The ISP eligibility criteria assume that the likely goals of person with a disability (e.g. living with a recently diagnosed disability) are linked to their age (e.g. 0-5 years). The guidelines for supports and services in the ISPs are designed to help people reach these goals. This works best for people who have a disability from birth, but not as well for not those who acquire a disability later in life who may have different goals than most people their age.
- Nous was unable to find a relationship between positive ISP experiences and service user age, cultural background, gender, nature of disability or previous disability service experience.

There was a clear relationship between the positive experiences of service users and how closely their goals and circumstances aligned with the aims and guidelines of their allocated ISP. For example, a

person seeking to rebuild social links has individual goals that are aligned to the *Self-Managed Model (Community Participation)* program, and is likely to have a positive experience if allocated to this ISP. In fact, alignment between the individual goals of the service user and the aims of the ISP seems to be the most critical factor for ensuring a positive experience.

In their current form, the ISPs are most suited to supporting people with a disability from birth. This is due to the age-based eligibility guidelines of the ISPs. These guidelines implicitly align the aims of the program with the likely goals of a person with a disability on the basis of age. For example, *Early Start* aims to provide service users and their family with early intervention supports and educate them about the disability system. These aims are typically similar to the goals of people eligible for *Early Start* – families of a child with a disability aged between 0-5 years of age.

However, these guidelines work less well for those who acquire a disability after birth or those whose needs or circumstances do not fit the current model for eligibility into the ISPs. For example, a person who acquired a brain injury in adulthood may be placed, on the basis of their age, into a program that aims to improve social interaction when their individual goals may reflect the fact they are still in the early stages of living with a disability.

Service users expressed a desire for program guidelines to be revised so that eligibility is not dependent on age but on the stage of the person in dealing with their disability. Following from the above example, this would enable a person who acquires a brain injury later in life to access a program that provides access to early intervention/therapies and education about disability services.

The demographics and history of service users did not appear to affect their chances of having a positive experience in the ISPs. No relationship was found between a positive ISP experience and characteristics such as age, cultural background, gender, nature of disability or previous disability service experience. An exception is that living arrangements appeared to have an impact. Carers for service users in group homes reported that the service users faced different challenges to people living in private residences. These service users did not have the ability to make decisions and/or self manage and also lacked family who could assist them. However, positive experiences from these service users were still reported as a result of the tailored supports that they were able to purchase through the ISPs.

Table 5: Specific findings for each sub-question of KEQ1

KEY EVALUATION SUB-QUESTIONS:	SPECIFIC FINDINGS:
1.1 What were the types of services / supports accessed by service users, their families and carers before entry into the ISPs?	◦ The types of services and supports accessed by service users, their families and carers before entry into the ISPs were predominantly respite, therapies and carers. ◦ Participants within the same ISP tended to access the same types of supports and services
1.2 How did types of services / supports change during their time in the ISPs?	◦ The supports and services accessed by service users, their families and carers fell into three broad categories: respite and care; therapies and activities; equipment or capital purchases ◦ Activities and equipment were more heavily accessed in the ISPs compared with before entry into the ISPs by service users, their families and carers. ◦ See Table 4 for a list of the types of supports and services accessed through the ISPs ◦ Participants started conservatively in the ISPs i.e. the early purchases of supports were similar to those accessed before entry. ◦ After 6-12 months, participants tended to use their funding more creatively e.g. diversifying into training classes for parents to provide speech therapy, purchasing educational equipment.
1.3 What happened in the ISPs, what worked and what didn't work?	◦ This question is dealt with comprehensively in the descriptions of the five case studies and the associated discussion of critical success factors in section 4 below
1.4 To what extent were the experiences of services users, their families and carers influenced by characteristics such as: age; cultural background; location; gender; living arrangements; disability; or previous service experience?	◦ The key factor influencing the experience of service users was the extent to which their goals matched those of the ISP. E.g. a person seeking to rebuild social links with goals that are aligned with those of the *Self Managed Model (Community Participation)* ISP was more likely to have a positive experience with this ISP ◦ Other characteristics did not appear to affect a person's chances of having a positive experience in the ISPs ◦ The one exception was people who acquired a brain injury in adulthood - due to their age they can be placed in an ISP that aims to improve social interactions when their individual goals can be significantly different i.e. associated with the early stages of living with a disability
1.5 To what extent do service users, their families and carers feel their skills and	◦ Service users, their families and carers improved their capacity to make decisions over time ◦ Improvement depended on the ability of participants to achieve their goals through the ISP:

KEY EVALUATION SUB-QUESTIONS:	SPECIFIC FINDINGS:
capabilities have been improved by the ISPs?	◦ Multi-year ISPs (SMM and OC) had the greatest effect on decision-making abilities ◦ Single-year ISPs (ES) also improved skills and capabilities, but were more effective if the funding was renewed for a second year ◦ EFS participants (single year) reported little change in their ability to manage their own supports

3 KEQ2: What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs?

This section outlines the key findings in response to Key Evaluation Question 2: *What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs?* Specific findings for the sub-questions relevant to this Key Evaluation Question are provided in Table 8 at the end of this section.

3.1 There were a wide range of decision supports provided

Key findings

- There were three broad types of decision support: financial management; informal supports, advice, and case management; and research and coordination of services and supports.
- There was no clear consensus amongst the providers of these services about what's involved in providing decision support.
- The level of decision support provided depended to a large extent on the skills and capabilities of service users, although 'tailoring' this support was not always easy to achieve.

While there were a wide range of decision support mechanisms accessed by service users, their families and carers, these mechanisms essentially fell into one of three broad categories: financial management; information and advice; and coordination of supports and services. Specific examples of decision support services accessed through the ISPs are provided in Table 6 below.

Table 6: Examples of decision support services accessed through ISPs

Financial Management	Information and Advice	Support Coordination
• budgeting • invoicing • financial reports • progress reviews • managing multiple funding and purchase types by a single family	• direct support • information on program guidelines • suggestions for supports/services • seminars • support groups • advocacy and mentoring services • face-to-face meetings • developing service user profiles • regular phone/email contact • emergency or crisis advice • legal advice	• finding supports and services • researching therapies and disabilities • purchasing supports • coordinating services / supports e.g. tradesmen • employing carers and specialists • HR and OH&S support • translation services • connecting service users to support groups, e.g. Marumali • applying for other disability funding

There was no clear consensus about what is involved in providing decision support to service users. The key providers of these services – the various service intermediaries, service providers and support

planners – had different perspectives on the role of decision support. These ranged from service intermediaries who encouraged service users, their families or carers to take on the bulk of the logistical and coordination activities associated with self-management to those, at the other extreme, who provided a wide range of additional support mechanisms and only required the service user to nominate the desired types of support and preferred supplier.

Contributing to this wide range of perspectives is the fact that service users can receive support from a wide range of sources to help them make decisions. To illustrate this, Figure 5 identifies the primary sources of planning support for three of the ISPs.

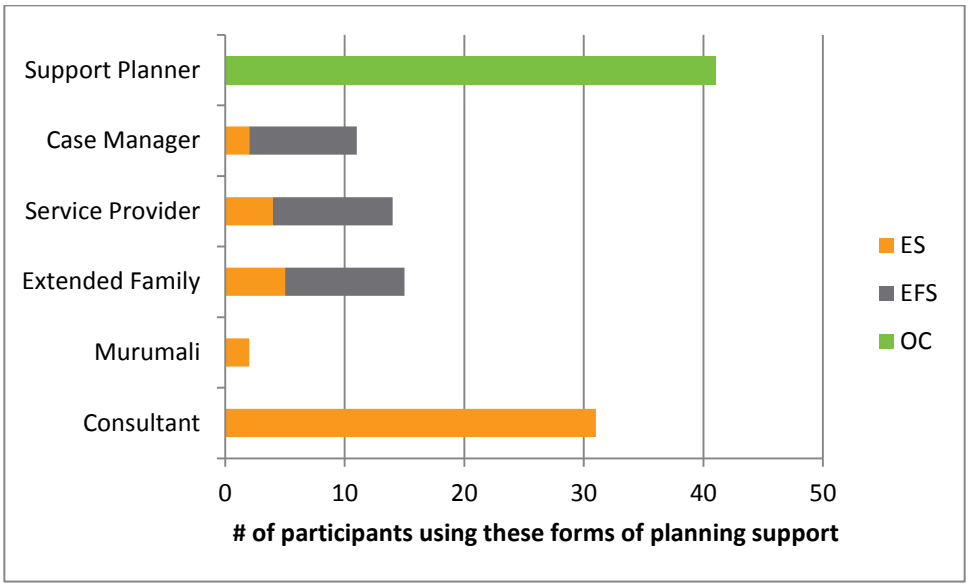


Figure 5: Breakdown on informal and formal supports in developing support plans by program. Information available for Early Start (ES), Extended Family Support (EFS) and Older Carers (OC) only. Similar data was not obtainable for the Self Managed Model service users. Source: Nous ADHC data request

The level of decision support provided to service users, their families and carers depended to a large extent on their individual capabilities. Service intermediaries reported that there was a wide variation in the capacity to make decisions and/or self-manage amongst service users. This in turn determined what decision supports the service intermediaries chose to provide. Table 7 outlines how the level of decision support varied as with the capacity of ISP service users.

In practice, service intermediaries often varied the level of decision support provided to service users. People with high needs were given more support, while those with low needs were given less. Service users were not given a choice as to how much decision support they would receive, especially if they wanted less support than they were currently receiving. No standardised methods existed for determining the capabilities of a service user, nor did service intermediaries always tailor decision supports to the service user's needs. In cases where the capability of the service user matched the level of decision support provided, their experiences with the funding were typically positive. In cases where capabilities and needs did not match, experiences were often negative.

Funding guidelines for the ISPs stipulate that service users in the same ISP are all charged the same capped rate for administration (e.g. up to 10% of the total funding in the case of ES). In practice, the administration fee is a fixed rate as virtually all service intermediaries charge the maximum amount administration in order to cover support costs. Service users with a low need for decision support therefore effectively cross-subsidised these supports for people with high needs, a situation that both service users and service intermediaries suggested was unfair.

The fixed administration fee also creates a disincentive for service intermediaries to take on service users with high needs as they cannot raise the administration fee to cover costs. Shortfalls in administration funding were cited as a contributing factor to staff turnover at service intermediaries due to the high workload for individual planners as a result of funding shortfalls. The loss of knowledge, experience, and relationships between service users and their service intermediary caused by staff turnover contributed to negative service user experiences in the ISPs.

Table 7: Different capacities to self-manage impact the types of decision support. The service user 'level of need' refers to their functional need for decision support mechanisms and is determined *ad hoc* by their service intermediary.

Level of Need	Description	Type of decision support mechanisms
Low	• Highly capable of making decisions • All decisions are implementation based: who, what, and when • Prefer to control funds and contact service providers directly • Typically pays directly then gets reimbursed, or obtains quotes directly	• Financial management: budgeting and invoicing • Information on guidelines
Medium	• Somewhat capable of making decisions • Happy to contact service providers if they have previous experience, or if associated with intermediary or funding • Desires tight financial management by the intermediary	• Mechanisms for "low" needs • Regular contact through face-to-face meetings and phone calls • Research and coordination of supports and services • Seminars and support groups
High	• Needs regular reassurance and advice about their plan • Requires facilitation, progress is incremental • Keen to have intermediary manage the funding apart from preferred types of support	• Mechanisms for "medium" needs • Advocacy and mentoring • Emergency, crisis, and legal advice • Extensive research and coordination support for purchases

3.2 Decision support requirements changed over time

Key finding

- The type of decision support required depended on the stage of the service user's journey through the ISP.

In section 2.2 above, we described how the ISP experience of service users, their families and carers can be explained by the stage of their journey through the ISP as service users move from the articulation of their aims through to the achievement of their goals. Similarly, the stage of their journey shapes the types of decision supports that they required and this is outlined in Figure 5 below.

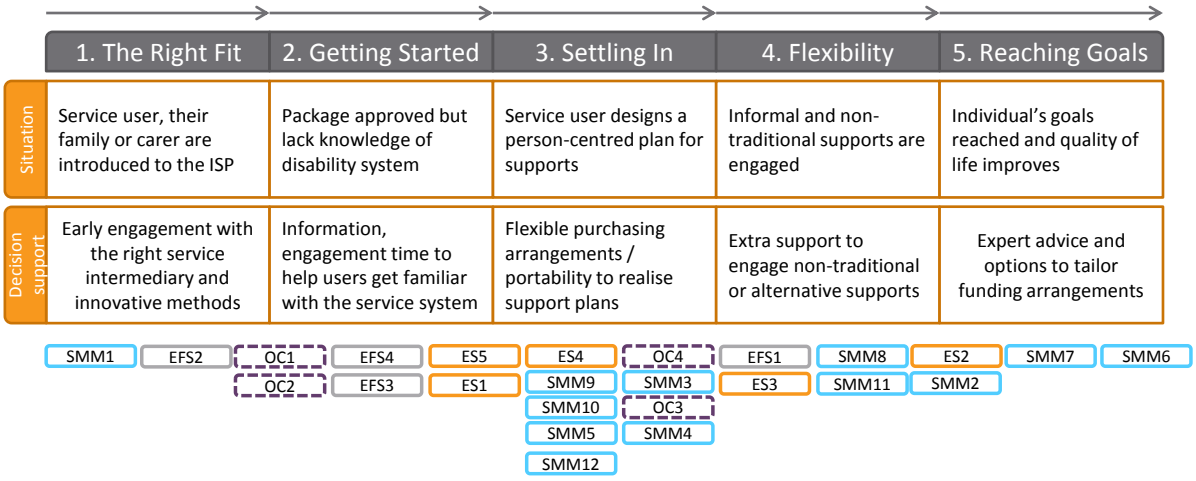


Figure 6: Decision support requirements change through the ISP process

This suggests that some regular monitoring of funding and goals is useful as these can frequently change from month-to-month. One service intermediary recommended formal reviews every 12 months, plus frequent informal reviews.

The types of decision support required at key phases of a service user's journey through the ISP are outlined in the sections below.

3.2.1 The Right Fit

Key findings

- Service users whose goals do not match the aims of their ISP typically have negative experiences. It is therefore important to engage with the service user as early as possible before the program starts in order to find out their goals and ensure that they fit with the ISP.
- Service intermediaries should be matched to service users to ensure they can provide the appropriate level of support and desired capabilities (e.g. complex financial management, translation services, expert knowledge, etc.).

As discussed previously in section 2.4, alignment between the goals of a person with a disability and their ISP is an important factor in ensuring a positive experience for the service user. There are two components to this alignment:

1. The aims of the ISP should be aligned with the goals of the service user. For example, *Early Start* is designed to provide early intervention supports and education with the aim of introducing people to formal and informal disability support services. These aims usually align with the goals of families caring for a child with a disability who have no previous experience of the disability system. By contrast, these aims would not align with the goals of a person with a disability who has had extensive experience of the disability system or had been dealing with a disability for a long time.
2. The service intermediary should be capable of fulfilling the needs and requirements of the service user. For example, a service user who plans to hire informal carers should be matched to a service intermediary with the appropriate HR and OH&S processes that would enable this support plan to be implemented.

Some of the decision support mechanisms suggested by service intermediaries that can help ensure alignment include:

- early engagement with the person with a disability, their family or carer to find out their goals and educate them about the aims and guidelines of their ISP
- providing a choice of service intermediaries or directly matching service users to service intermediaries that can provide the additional capabilities that are needed and wanted by the service user
- making communication supports available for service users so that their goals can be articulated, such as translation/interpreter services, visual facilitation techniques, seminars and workshops, or other methods

3.2.2 Getting started

Key findings

- Decision support (including the provision of clear and concise information) is especially important in the first 6-12 months, as service users become familiar with the flexibility and responsibility associated with the person centred approach in the ISPs.
- To improve the chance of a positive ISP experience, a period of engagement prior to the start of the ISP was proposed to educate people about the key elements of the program.
- Decision supports mechanisms that encouraged idea generation in the early stages e.g. circle of support sessions, typically led to more innovative uses of the ISP over time.

Decision support mechanisms are especially important in the early stages of the funding to help ensure that the ISP is a positive experience for service users, their families and carers. In these early stages, service users, their families and carers desired more information, more engagement and more time to familiarise themselves with their ISP.

Many service intermediaries and service users reported that it takes between six and twelve months for a service user to become familiar with the flexibility and responsibility associated with the person centred approach adopted by the ISPs. The two distinct elements involved in the learning process are:

1. Flexibility: Service users need to become familiar with being at the centre of the decision making process, researching supports and services that best suit their individual needs and goals.
2. Responsibility: Understanding their responsibilities in the ISPs, including budgeting, support planning, and coordinating their supports and services.

Service users described their difficulties in understanding the ISPs during the early months after their entry into the ISP. There was a desire for clearer and more concise written information on:

- the aims of the program
- guidelines for what supports and services are allowed
- their budget and the duration of the funding
- how the ISP funding relates to their particular circumstances including other funding that they might be receiving

Both service users and service intermediaries suggested that a period of engagement prior to the start of the ISP to better educate people about the key elements of the program would improve the chance of a positive ISP experience.

Service users reported that their early ideas were very limited. Those who explored a wider range of supports in later years described how they became more innovative because of decision support mechanisms that helped them with generating new ideas. These mechanisms included:

- circle-of-support sessions with service intermediaries and close friends and family
- support groups for parents in the same ISP
- information seminars
- suggestions from ADHC support planners or service intermediaries
- ideas from contacts in local community and disability groups

3.2.3 Settling in

Key finding

- Flexibility in purchasing arrangements and the portability of funding between service intermediaries were important to service users in realising their support plans.

Flexibility in purchasing arrangements and the portable funding between service intermediaries were central to a positive experience for service users, their families and carers. Service users were pleased with some elements of the funding arrangements for their ISP, including:

- management of timesheets and salaries by the service intermediary
- a long-term relationship with a support planner to ensure flexibility and support in purchasing arrangements
- the ability to pay for services or supports in advance
- control and flexibility over the payment of invoices, including:
  - ability to delay payment for services pending quality inspection of work done
  - flexibility to enter into joint purchases with others, such as neighbours
  - option to add funds to from private sources to supplement the ISP
- the option to pay for some purchases using the service intermediary's credit card to avoid being out-of-pocket

However, there were concerns (particularly within *Early Start*) about the reimbursement model of funding used, which can leave service users unable to take advantage of short-term offers, or to respond rapidly to crises.

Service users also indicated that the uncertainty of whether they would be reimbursed for supports and services purchased through personal funds caused them stress. They also expressed frustration at the

lack of portability of their funding from one service intermediary to another[8]. Some service users would prefer to use a direct funding model where funds are transferred into the control of the funding recipient.

3.2.4 Flexibility

Key findings

- Service users who required specialist carers, or alternative or non-traditional services (e.g. to overcome 'supply' problems) were able to access these through their ISP. However, this depended on the capabilities of the service intermediary to succeed i.e. flexible purchasing arrangements, sophisticated HR and OH&S processes, and expert knowledge.

The capabilities of effective service intermediaries included:

Flexible purchasing arrangements:

- Guidelines that allowed service users to engage supports in innovative ways (e.g. training students in TAFE/university in client-specific skills as carers)
- Ability to quickly change support plans to respond to changes in circumstance or crises

Sophisticated HR and OH&S processes

- Capability to support service users in hiring and firing carers sourced from family, close friends, or from unusual places (e.g. school networks) without contractor status
- Understanding of relevant taxation, employment, and OH&S legislation
- Management of timesheets and rosters for large numbers of casual carers
- Regular and customisable budget and financial reporting processes that can support multiple funding sources and purchasing pools

Expert knowledge

- Expertise in specialised disability areas (e.g. autism or early intervention) to assist in exercising informed choice
- Educational procedures to build capabilities in service users, their families and carers to research supports and services independently

[8] In general, service users within the ISPs are able to easily change the specific supports and services that they purchase with their funds, but face difficulties when attempting to transfer funding away from the service intermediary that coordinates their supports and services.

3.2.5 Reaching Goals

Key findings

- Service users do not typically plan their lives according to the funding cycle of the ISPs. It is important for them that funding arrangements can be tailored to their timelines for reaching goals. These include negotiable funding periods and options to pay for supports in advance.
- Advice on budgeting and disability-specific supports was also important for service users in order to help them reach their goals within the ISPs.

As described in section 2.3, service users typically planned their goals around reaching the next transition point in their lives. These plans do not necessarily match the funding periods for the ISPs, particularly in the case of *Early Start* and *Extended Family Support* which are limited to one or two years. It was important for service users to feel that they would be supported through to the next stage of their lives. Some of their suggestions for how decision supports in the ISPs could help them do this include:

- negotiable funding periods for the ISPs. For example, instead of receiving a set amount of funding for one year a service user may have the option to receive half the funding for two years
- option to pay in advance for some recurrent services such as regular speech therapy that will be delivered after the funding ends
- advice on budgets to help ensure that there are sufficient funds available to support the service user through the entire funding period, rather than expending all the funds in the first few months
- suggestions and innovation from the service intermediary on which supports and services to purchase, particularly alternative supports, education, or equipment that can provide long-term benefits for the person with a disability in a cost-effective way

3.3 More decision support is required for Aboriginal and CALD service users

Key finding

- Service intermediaries had different views on whether Aboriginal and culturally and linguistically diverse (CALD) service users required a different level of decision support.
- The most significant difference was the extra effort required to build relationships with Aboriginal service users and their extended families and communities.

There were different views from service intermediaries on whether Aboriginal and culturally and linguistically diverse (CALD) service users required a different level of decision support. Some service intermediaries reported no difference between Aboriginal and CALD service users and other service users in terms of the decision support mechanisms required to engage them. Others reported that Aboriginal and CALD service users required additional or different supports in order to use their funding effectively.

Key characteristics of working with Aboriginal service users reported by some service intermediaries included:

- involving the extended family or community in making decisions as part of the ISP
- engaging families through contacts in the Aboriginal community
- allocating extra time to build relationships, e.g. longer initial meetings, with a period of engagement prior to starting the funding
- aboriginal families often preferred to have funds available for purchasing supports on short notice. They emphasised the need for emergency funding to manage possible crises rather than planning their supports over the long-term.

Key characteristics of working with CALD service users reported by some service intermediaries included:

- highly variable requirements for decision supports, with some who are very capable making decisions and others who have higher functional needs in this area
- a link between a family's capacity to make decisions and their fluency in English. Those who were less confident with English were more likely to require additional supports such as assistance with researching service providers and language interpreters
- CALD families sometimes had fewer barriers to the concept of deciding how to use their disability supports than the average ISP service user, e.g. some CALD families were heavily involved in the recruitment process for carers
- cultural differences in the supports used by CALD service users in some cases, e.g. many CALD families are opposed to the idea of accessing respite, preferring to purchase supports that assist them with caring for the person with a disability.

The proportion of Aboriginal and CALD service users in the ISPs is indicated in Figure 7 below.

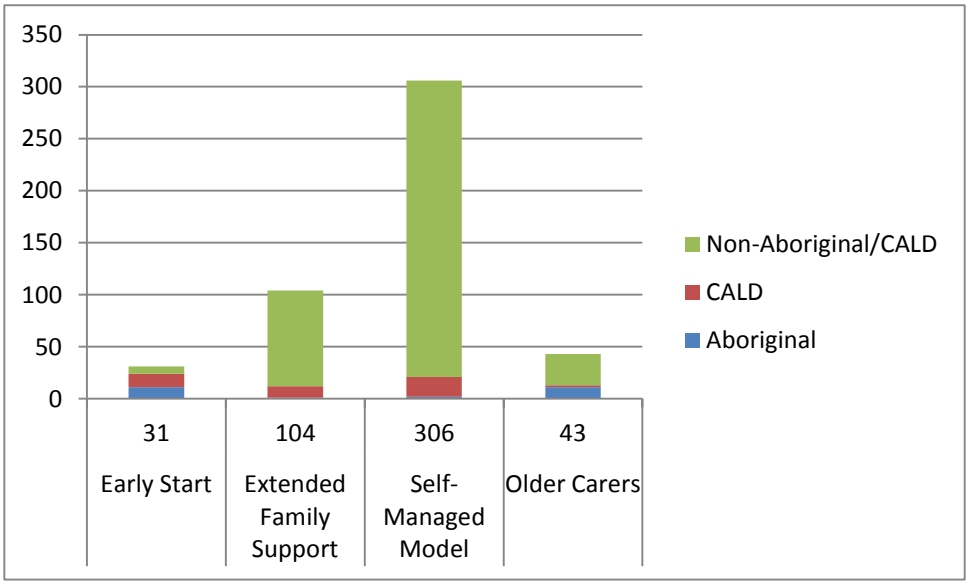


Figure 7: Breakdown of programs by number of Aboriginal and CALD participants. Source: SMM, EFS, and OC data from ADHC Minimum Data Set and ES data from ADHC/Nous data collection request. The numerical breakdown of service users within each program is provided in the table below.

	Total	Aboriginal	CALD	Non-Aboriginal/CALD
Early Start	31	11	13	7
Extended Family Support	104	1	11	92
Self-Managed Model	306	2	19	285
Older Carers	43	11	2	30

Table 8: Specific findings for each sub-question in Key Evaluation Question 2: What role did decision support mechanisms play in the experiences of service users, their families and carers within the ISPs?

KEY EVALUATION SUB-QUESTIONS:	SPECIFIC FINDINGS:
2.1 What were the types of decision support mechanisms accessed by service users, their families and carers?	◦ The types of decision support mechanisms accessed by service users, their families and carers fell into three broad categories: (1) financial management; (2) information and advice; and (3) support coordination ◦ See Table 6 for a list of the decisions support mechanisms
2.2 How important were decision support mechanisms in shaping the experiences of service users, their families and carers?	◦ Decision support mechanisms were important - especially in the early stages of the funding when participants desired clear and concise information on ISP aims and guidelines ◦ Both service users and service intermediaries suggested a period of engagement prior to the start of the program to educate people about the ISPs ◦ Suggestions on supports and services from case managers and other families were reported as successful aspects of the funding
2.3 To what extent did service users feel that they had a greater say in designing their support plans, and how did this gave them more flexibility and choice in the services / supports received?	◦ Many participants reported that the ISPs gave them a greater say in their support plans than they had received previously ◦ Specifically, participants were positive about the freedom to choose the mix of services or supports, and their suppliers ◦ However, purchasing options (such as advance payment, delayed payment, or changes to carer schedules) were also important factors in creating more flexibility and choice. There remain challenges here (*see section 3.2.4*)
2.4 To what extent do service users, their families and carers feel that their decision making capacity has been improved?	◦ Service users were empowered to make decisions on non-traditional or alternative supports ◦ In particular, decision-making on overcoming supply problems was improved through access to intermediary capabilities e.g. flexible purchasing and sophisticated HR/OH&S processes
2.5 What did service providers feel were some of the success factors involved in implementing decision support mechanisms?	◦ Service providers and service intermediaries reported that intensive case management and regular contact with service users were key success factors in delivering decision support mechanisms ◦ This was particularly significant for Aboriginal services users where extra effort in building relationships with them and their extended families/communities increased engagement ◦ Mechanisms designed to link participants with other families, close family members or friends, and their local community were also regarded as successful, e.g. seminars, 'circle of support', links to local support groups

4 Case studies: illustrating the diversity of experience

To illustrate the diversity of experience of service users, their families and carers, case studies were selected that best represented a positive experience at each of the five stages in the ISP process. To understand what worked and didn't work, these cases were compared with the experiences of other participants relevant to that stage. These comparisons enabled the critical success factors to be identified, i.e. the factors associated with positive experiences. The five case studies, and the associated analysis of critical success factors, are produced below. A summary of the key elements of the cases is provided in Figure 8.

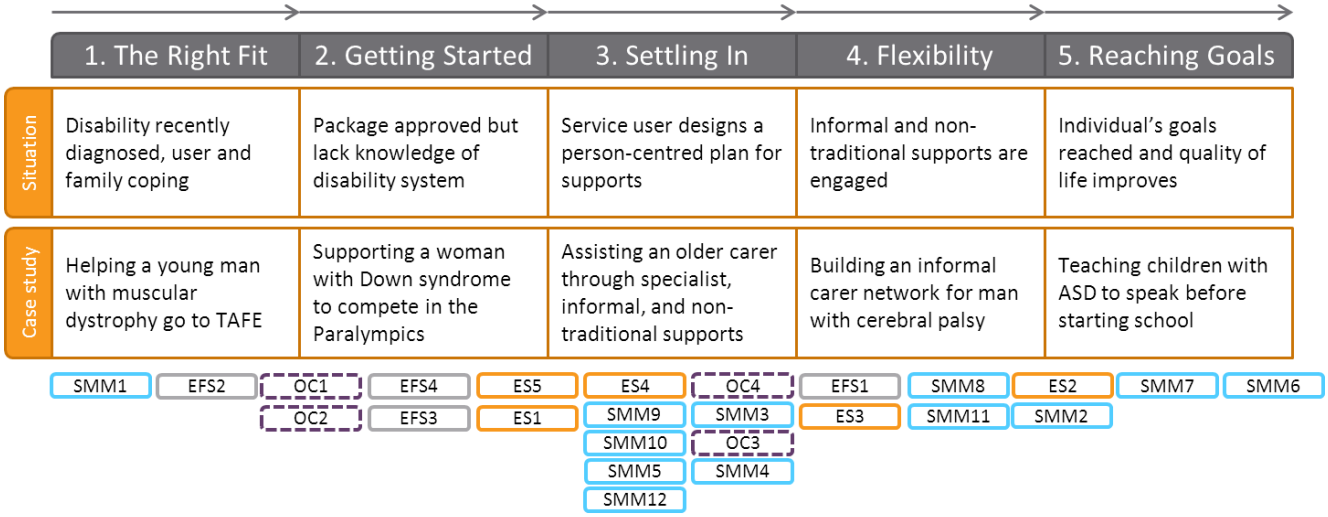


Figure 8: The relationship between case studies and the five phases of the ISP cycle

The names of individuals in the ISPs, their families and carers have been changed to protect their privacy

4.1 Case study 1: The right fit

4.1.1 Key elements

Overview	A young man from a CALD background recovering from health complications wanted to re-establish contacts with his friends and transition to tertiary education through the *Community Participation - Self-Managed Model* program.
Situation	He lives with muscular dystrophy and had lost all contact with his friends due to a catastrophic respiratory attack. This attack left him on a ventilator 24/7 and living with severe depression. He is reliant on full-time carers and with limited capacity to leave the home.
Capabilities	∘ A knowledgeable uncle with the capacity to manage supports ∘ Previous experience with disability services ∘ Immediate physical needs were met – e.g. rehabilitation aids
Decision supports	∘ Provided financial management for budgeting carer hours
Outcome	∘ Use of age-appropriate carers to build confidence with participating in the community and attend TAFE
Critical success factors	∘ Alignment of program aims to the goals of the service user

4.1.2 Narrative

"I need to live"

"When the idea came out for him to get out and about we thought that would be great"
Richard[9] has lived with the effects of muscular dystrophy his entire life. Despite the challenges posed by a disability which causes his muscles to gradually waste away, Richard managed to go through the public school system and looked forward to attending university or TAFE. These plans were derailed almost three years ago when Richard experienced a catastrophic complication with his respiratory system. Unable to breathe, Richard spent two years in intensive care at hospital. He was discharged home into the care of his extended family – two siblings, his parents, grandmother and an uncle, Marco – and moved into his refurbished bedroom with all the necessary life support equipment. This was critical, as he was unable to breathe without a respirator and required 24/7 care.

These events left Richard with severe depression. Unable to leave the house, he slowly sank into lethargy and developed a despondent view of life. When the family heard of the *Community Participation* program through social workers at the hospital, they saw it as a chance to improve his morale through rebuilding social links with school friends and to get him into the community again. The goal was to give Richard a purpose in life again, and this seemed to fit perfectly with the stated aims of the *Community Participation* program.

[9] Names have been changed to protect the identity of participants

"We [the family] had to make that decision...we gave it to him [initially] – you choose – but he couldn't make a decision"

Richard was initially uninterested in *Community Participation* and unable to participate in centre-based programs due to his physical needs. His immediate family was also unable to effectively engage with the funding as they are not entirely comfortable with English, having migrated recently from overseas. What enabled the funding to work was the arrival of an uncle, Marco, who was familiar with human services. Marco was able to act as an interpreter and manager for the family, translating their goals and concerns in meetings with their service intermediary. With this assistance, the family chose the *Self Managed Model* option for *Community Participation* in order to tailor the funding to the needs of Richard.

"The program has the freedom of letting him do what he wants to do...it works for people who can't have or don't want a routine"

The early consultations focused on analysing the needs of Richard and the activities that he enjoyed before his recent complications. These activities were then compared against the *Community Participation* program's goals and guidelines and adapted to Richard's schedule. The family settled on carers as the best option for Richard: age-appropriate people who could both care for him and share the same interests.

Advertising for carers was done entirely by the service intermediary. Each carer was interviewed by the family in order to ensure a good fit. The service intermediary then handled all the financial management and budgeting for carer hours. Although there were some early challenges with most carers being substantially older than Richard, the family was eventually able to bring in two young carers – Matthew and Sukesh – who fitted the bill perfectly.

"[The program helps] him to get a job, maybe IT or programming"

Matthew and Sukesh enabled Richard to make gradual progress towards his goal of engaging with the community again. They went to movies, ate at restaurants, drank coffee at cafes and did a wide range of other activities out of the home. When Richard was tired, the carers kept him company in the house where they played video games or watched TV together.

The process of helping Richard re-engage with the community took a great deal of effort. Richard remained physically frail and frequently ended up back in intensive care. He still required a full-time carer (sourced from another program) to watch over him while he sleeps to ensure that he is breathing.

During the early days, Richard felt intensely embarrassed going out because of the way that other people stared at his respirator. Through persistence on the part of his carers and uncle, Richard has slowly built up his confidence to reach out to other people and leave the safety of his home. He has recently started a TAFE course and aims to pursue a career in IT or programming that fits with his physical circumstances.

"It understands our culture...this makes a big difference, done miracles"

The *Self Managed Model* option allowed Richard to pursue his goals despite his physical circumstances preventing him from entering a centre-based program. Underlying this success was that the funding "respected the role of the family in [their] culture", enabling the family to direct the funding when Richard could not. Richard was able to receive a tailored carer program that could meet his needs, nurture his interests, and adapt to his variable schedule. Over time, these supports gradually helped to lift Richard out of depression and restore his interest in life.

4.1.3 Critical Success Factors

Alignment of program aims to the goals of the service user

The key success factor in this case study was that the *Community Participation* program aligned with Richard and his family's goal of re-engaging with the community and having Richard rediscover a purpose in life. This alignment ensured a common understanding between the service intermediary and the service user. In cases where there was no alignment, there was tension between the program aims and the goals of the person with disability or their family which can hamper efforts to achieve positive outcomes for the service user.

Nous identified three sources of misalignment:

1. ***Mismatch between program's age-based guidelines and person's stage of living with a disability***

   In one case, a 37 year old man with an acquired brain injury was placed in the *Life Choices- Self-Managed Model* program due to his age. LC is aimed at getting people with a disability out of the home and participating in the community. The program therefore restricts funding to supports and services that directly relate to this aim. However, this person was still in the early stages of living with his disability: he was non-verbal; lived with a severely intellectual disability; had no motor control beyond minor limbic movements, e.g. arms were locked in a bent position; and required a full-time carer.

   His father requested that the LC funding be used to purchase rehabilitation equipment and modifications to the family car for wheelchair access, but both were denied under the guidelines. Consequently, the bulk of the funding was not spent and the family has not achieved their goals of physically rehabilitating their son – the first stage of getting him out of the house. As the father stated: "The thing I really want, the thing the boy really needs, I can't have...so don't keep ringing me to spend the money. I don't know how to spend the money!"

2. ***Use of ISP as non-specific funds for people unsuitable for centre-based or other programs***

   Some service users and their families expressed surprise that they received funding from the ISP. They suggested that these funds were provided because the person with a disability was unsuited to centre-based or other specialist programs, rather than because they had the capacity and desire to be at the centre of the decision-making process. One such case involved a 22 year old girl with a genetic disorder that manifests as paranoid-schizophrenia. She also had a long history of negative experiences with disability services. Now in a group home and unwilling to enter a centre-based program, she was enrolled into *Community Participation – Self-Managed Model* following a series of complaints by her family to ADHC. However, she has displayed minimum interest in community participation despite trying a vast range of activities, preferring to use her weekly visits to the family home to watch DVDs. Meanwhile, her family are struggling with home renovations designed to provide a more suitable environment for her when she visits, raising the question of whether a different existing program would be more closely aligned to the family's goals.

3. ***Misunderstanding of service user goals***

   There is the potential for ISP assessment panels to mistakenly assume that the goals of a particular person with a disability or their family matches that of their cohort, or even to misunderstand the goals of a cohort. For example, the *Extended Family Support* program is aimed at families with children aged 0-18 at risk of relinquishing care. The perception by service intermediaries and service users is that the aim of this one-year program is to provide emergency funding in order to prevent relinquishment by the family.

However, several families who had received *Extended Family Support* said that the funding arrived too late and for too short a period to significantly influence the family's decision to relinquish care. Said one mother of a child with a disability: "There's no repairing things after the damage has been done … after it's all gone belly up suddenly all this help comes along … there's this attitude that while you still have a functioning family you don't need the help".

Families also indicated that preventing relinquishment may not always be the best option for the child. In one case, a child living with an intellectual disability and autism spectrum disorder was behaviourally challenging in the family home but much happier in the highly regulated environment of a special-needs residential school. "No normal family could maintain the program at [the school], it was so structured" said the mother of this child. *Extended Family Support* funding was able to purchase supports for the child's sibling and pay for home renovations to assist with OH&S during home visits. However, the funding was unable to assist with the primary goal of the family: to find a suitable group home for the child with a disability after graduation.

4.2 Case study 2: Getting started

4.2.1 Key elements

Overview	Young woman with Down syndrome aimed to find a day program that is flexible and self-managed.
Situation	She had no previous experience with disability services and no social contacts from school because she was home-schooled.
Capabilities	∘ Her parents work in disability services and were familiar with the system ∘ Older brother had previous experience with the Transition-to-Work program
Decision supports	∘ Intermediary used a step-by-step process for family to complete application forms ∘ Service intermediary also had a child living with Down syndrome and was very knowledgeable about the disability ∘ Visual representation technique used to communicate with the service user and work out her goals ∘ Workshop on inclusion provided an opportunity for her family to talk to other families on the same funding and exchange information/ideas
Outcome	Actively participates in volunteer work and is a competitive athlete (archery). People have gotten to know her and her abilities. She is more confident and independent.
Critical success factors	∘ Sufficient time to become familiar with funding and the extent of its flexibility ∘ Good relationship with service intermediary who clarified guidelines and enabled service user to articulate her goals ∘ Mechanism to exchange ideas and information between families in the same program

4.2.2 Narrative

"We were told it was flexible, but how flexible is flexible?"

"It suits our lifestyle and what we expect."

Helen[10] is the youngest child in a family of six children living in regional NSW. She is also a foster child along with one of her foster brothers, and both of them live with a disability. Helen has Down syndrome, a genetic disorder that causes both cognitive and physical impairment. Both foster children were home-schooled.

Though both parents work in disability services, Helen had no previous experience with specialist disability supports through her school years. However, the older foster sibling had previously been involved with the *Transition to Work* program. This was a negative experience for the family, who felt disempowered due to the service intermediary's defensiveness when questioned. The family resolved that they would not repeat this experience with Helen. They decided to seek a day program that offered greater flexibility and self-management.

[10] Names have been changed to protect the identity of participants

After several months, the family heard about the *Community Participation – Self-managed Model* program through another family with a child already in the program. They applied and were accepted. The family opted for a service intermediary with extensive experience in delivering the self-managed model on the assumption that they would be more knowledgeable about the program than an organisation that was new to the scheme.

"She sat down and talked to her using totally different visual representation…better way of interacting so they were her words not mine."

The early months were difficult. Despite their extensive experience in disability services, the family was overwhelmed by the amount of administrative paperwork and information that was presented at the initial meeting with the service intermediary. Progress was made when these challenges became apparent to the service intermediary, who then arranged for the collection of forms, brochures, and guidelines to be broken up and sent incrementally to the family via email with step-by-step instructions. This occurred over the course of ten months.

There was a second challenge to be overcome: while Helen's family and friends could speculate on what her goals and interests were, she was unable to articulate them herself. A second service intermediary was able to resolve this barrier using a novel visual representation technique. Through this technique, Helen was able to make her goals for the program known: archery and volunteering.

"Talking to other families about what worked and didn't work was a really good support"

The intermediary also ran a workshop on community inclusion for the families of people in the *Community Participation – Self-Managed Model* program. In addition to being a good source of information from service intermediaries, speakers, and other sources of information, this workshop also allowed the families to meet each other and communicate in an informal forum. Helen's family found it useful to participate in a free exchange of information on what could be purchased through the program, what worked and what didn't work. These discussions helped them form their own ideas about how Helen's funding could be used and also provided a source of emotional support.

"This has allowed it to be more about her interests rather than what her friends wanted"

Helen spent her funding on a carer to help her pursue her two main interests: archery and volunteering. She has been a keen archer for many years and trained regularly with national and international-grade athletes in the sport. Helen also volunteered at the local library. Through these activities she engaged with both her local community as well as the wider Australian and international archery community.

"People that she volunteers with have seen her for what she can do"

Prior to the program, Helen relied on her mother to communicate. *Community Participation – Self Managed Model* provided her with the opportunity to interact with people on her own. She is now recognised as a valuable part of the team, whether in the course of her volunteering efforts or during archery practice. People in the community are used to her and know how to communicate with her. They see her as an independent person. Helen aims to qualify for the Olympics, a monumental achievement and one that the family believes will be supported through the CP-SMM.

"A self-managed program is not for everybody. It is right for families who have a sense of their goal and doesn't work if child can't be independent."

Helen's family cautions that while the program worked for her, there were difficulties throughout the process. Even with their extensive experience in disability services, they were overwhelmed with information at the start of the program. They suggested providing program participants with the information and scheduling the initial meeting prior to commencing the program. Helen's mother indicated that it took around a year for the family to fully understand the flexibility of the program. Even with these improvements, she concludes that it can only work if the service user is capable of being independent.

In Helen's case, this program has enabled her to be more mature and confident by supporting her to be independent and communicative with people outside of her family.

4.2.3 Critical Success Factors

Sufficient time to become familiar with funding and the extent of its flexibility
It took ten months for the family to become familiar with the funding in terms of the guidelines, the potential offered by its flexibility, and the extent of self-management required of the family. This was despite both Helen's parents being well-versed in disability services through their professional exposure and the experiences of her older brother.

Service intermediaries reported that it took 6-12 months for families to become familiar with their funding. In this instance, the *Community Participation – Self-Managed Model* funding consists of recurrent funding over several years, sufficient for most families to gain confidence in its use.

However, other ISPs that are subjects of this evaluation have shorter funding periods, typically one year. These programs may not provide sufficient time for the service user, their family or carer to familiarise themselves with the full implications of the person centred approach before the funding runs out. In one case, an Aboriginal family with a child living with global developmental delay took nine months to become familiar with the funding and begin purchasing supports and services. However, their funding – *Early Start* – lasted for only one year and left the family under considerable stress as they attempted to spend the funding in the remaining three months. They suggested that unspent funds in these cases either be renewed or rolled over into the following year.

Good relationship with service intermediary who clarified guidelines and enabled service user to articulate her goals
The service intermediary plays a crucial role as the main source of ideas and guidance for the service user, their family or carer in the ISPs. For Helen, this role included providing administration support during the early stages of the funding as well as innovative communication techniques that enabled her to articulate her goals.

The relationship between the service user and service intermediary was particularly important for older service users such as those in the *Older Carers* program. Carers supported by this program have typically cared for dependents with disability for many years without significant support from disability services. They tend to be conservative with the supports and services that they purchase. Often, they were reluctant to spend all of the funding. It was important in these situations that the service intermediary and/or support planner understood the carer's situation. Often, this took the form of encouraging the carer to think broadly about what their funding could be used for, then providing the necessary logistical supports to ensure that these supports and services were purchased. The personal connection between the service user and the service intermediary/support planner was also important. As one carer put it, "It all depends on the person".

In contrast, tensions between the family of the person with a disability and the service intermediary can result in negative experiences for all parties involved. In one interview, a mother who had an adult child living with autism in a group home described how she clashed repeatedly with the service intermediary over the purchase of supports and services. She accused the service intermediary of bypassing her in favour of the group home managers: "There is a huge gap in the understanding; in the expectations of the program and what it means to the families and the service users…we have to break through the preconceptions of who he is and who I am". Negative comments were made regarding their competence: "I don't think they know how to provide the *Self Managed Model* to someone in a group home … it comes down to understanding their level of independence"; as well as their probity, "It's been nothing but hard word and graft … nothing positive have come out of this thing at all". After three years

in the program, the family remained unsatisfied with the funding and felt that none of their goals have been achieved.

Mechanism to exchange ideas and information between families in the same program

Most of the service users, families and carers that were interviewed reported that their early ideas on how to use the ISP funding were very limited. While in some cases these ideas came from the service intermediary, other families found great value in meeting other families on the same funding, as well as local community and disability groups. Specific mechanisms mentioned by participants included: "circle-of-support" sessions with close friends and family facilitated by the service intermediary; support groups for parents in the same ISP; information seminars run by the service intermediary; and informal links with local playgroups, community or disability groups.

Such links were often crucial, particularly in situations where there was limited rapport between the participant and the service intermediary. In one case where an Aboriginal family was caring for a child living with autism, the mother purchased only one type of service – speech therapy – and did not spend all of the funding available in her *Early Start* funding. This was despite the intermediary suggesting a range of supports accessed by other families on the same program which had resulted in positive outcomes. This was due to the mistrust that the mother had for disability workers in general, "They don't care; he's just a number to them". As a result, she relied heavily on a small group of her friends for advice and was not exposed to more innovative uses of the funding that were being tried amongst families in *Early Start*.

4.3 Case study 3: Settling In

4.3.1 Key elements

Overview	Older carer in her 70s with a disabled husband and daughter with the goal of accessing respite and support with home maintenance to help her provide care
Situation	She was under increasing strain from her carer duties. Both she and her husband have become frailer with age, and she has developed medical problems herself
Capabilities	• Highly connected with the local community • Experienced in engaging local tradesmen and supports • Previously worked as a volunteer with Home and Community Care
Decision supports	• Guidelines from ADHC support planners • Assistance with generating ideas • Support in researching local supports and services • Logistical and financial management of invoices from service providers and tradesmen
Outcome	She was able to set up a regular schedule for respite through the funding, and outsource some of the home maintenance duties that she now finds difficult to do alone. Some of the funding was also used to pay for home maintenance that had lapsed over the decades due to lack of time and funding. Most significantly, she installed a new disability-friendly bathroom suitable for her husband and herself after she was diagnosed with cancer.
Critical success factors	• Control and flexibility over the payment of invoices, including delayed payment for services pending quality inspection of work done • Flexibility to enter into joint purchases with others, such as her neighbours

4.3.2 Narrative

"[The best thing] is that I can get respite whenever I need it, I don't need to worry about forking out for it. I really and truly know that I can do what I want to do"

"I had a couple of medical problems and I just thought things have got to change"
Margaret[11] lives in a regional NSW town and has been a full-time carer for the past 28 years. Her husband, Bill, experienced a cardiac arrest leading to short-term memory loss that later developed into vascular dementia. Her daughter was also injured in a car accident a year after this event, acquiring a brain injury that put her in a coma for eight months and left her with a significant disability. While Margaret's daughter was able to move out and live semi-independently several years ago, Margaret remains the primary carer for Bill.

Now in her mid-70s, Margaret has developed medical problems of her own. Several years ago she was diagnosed with cancer. Although she is now in remission, Margaret has come under stress as both she and her husband become frailer with age, decreasing her ability to care for him even as his needs increase. In desperation, Margaret contacted Home and Community Care – where she had previously worked as a volunteer – and they provided a small amount of support in the form of a house cleaner.

[11] Names have been changed to protect the identity of participants

Further, they put her in contact with ADHC and a newly-arrived service intermediary. The latter assisted Margaret in applying for the *Older Carers* funding, which was approved two years ago.

"I was thinking about going away, and I thought here's my chance!"
The first thing that Margaret was able to do was to place Bill into a private respite centre for a week so she could take her first holiday in decades. This took the immediate pressure off her and enabled her to experience the potential of the funding. Respite would become Margaret's main use for the funding over time, transitioning from the occasional holiday during the early years to a regular schedule that she can use to help plan her arrangements.

Beyond respite, Margaret struggled with generating ideas for what to purchase with the funding and the degree of self-management that this entailed. She relied heavily on a series of ADHC support planners to guide her through the supports and services that she could purchase. The support planner also helped to coordinate local suppliers and tradesmen, and handled the invoicing and logistics for the home renovations. The connection and support that Margaret received from the support planner was an important part of the *Older Carers* program for her.

"I was being quite conservative with the money...didn't want to be extravagant in case it comes around again...didn't want to make it cost the Earth"
A central issue was that Margaret was highly capable of self-management, being heavily involved in the local community, but had received no support from disability services for most of her life as a carer. She was therefore conservative with her spending and reluctant to rely on the funds as a permanent part of her future, particularly in the event that the funding ceased. She also mentioned that she "[doesn't] really have ideas", and relied upon other people to help her decide on which supports and services to purchase. Over the course of a year, her support planners were able to slowly acclimatise her to the possibilities offered by the funding.

"Everybody's different"
These other supports fell into two groups: assistance with maintenance duties to relieve pressure on Margaret, and home renovations for OH&S reasons. Maintenance on her home had lapsed over the years due to Margaret's duties as a carer and, later, her medical problems. She therefore engaged contractors to repair her fence; paint the front door and exterior of her house; perform heavy gardening duties such as bush-trimming and weeding that she was no longer able to perform; and clean the large front windows of her home.

The other major purchases she made were home renovations, of which the most important was the installation of a disability-friendly bathroom in the home. Bill had a series of falls in the old bathroom that had left him hospitalised for several weeks. Margaret's cancer had also made her more vulnerable to injuries. The combination of the new bathroom and a new pacemaker for Bill succeeded in preventing him from falling again for the past two years, which has significantly contributed to Margaret's emotional well-being.

One factor that enabled Margaret to use her funding effectively was the quality of her relationship with her support planners. They calculated the amount of respite that she could access, coordinated teams of tradesmen for her renovations, and arranged for a joint purchase with her next door neighbour for a new fence. The emotional and managerial support from the support planners was important to Margaret in indirect ways. For example, they gave her the freedom to delay payment to tradesmen for work performed until the results could be inspected by a knowledgeable third party. Support planners also assisted Margaret with researching local supports and services.

"The one complaint I have with this program is the staff turnover and lack of local staff...this is my big bugbear"

The only major complaint by Margaret was the high turnover in ADHC staff. Each replacement planner required the relationship-building to begin anew. A compounding factor was when the replacement is not local, as is the case with her current case manager who is located in a distant town. Margaret felt that a non-local manager would not able to assist her adequately with finding local support services, nor would they be able to respond quickly and appropriately to her queries.

4.3.3 Critical Success Factors

Control and flexibility over the payment of invoices, including delayed payment for services pending quality inspection of work done; advance payments; flexibility to enter into joint purchases with others

It was important for Margaret to have a flexible purchasing process for supports and services through funding that she could control. This combination of control and flexibility enabled her to implement the tailored support plan that she developed with the ADHC support planner, without encountering any additional barriers related to the actual purchasing.

Margaret was able to use the flexibility in the funding to pay for supports that would not have been possible under previous disability programs, such as a private respite centre for her husband, her holiday, or her home renovations. She was also able to control the manner in which the payments were made to tradesmen and respite providers, including delaying payment to check renovation work and entering into a joint purchase with a neighbour.

Other participants in the ISPs have also relied upon the flexibility and control in purchasing to achieve their goals in these projects. One Aboriginal family with a child living with global developmental delay was able to use some of her *Early Start* funding to make advance payments for occupational therapy and speech therapy for the year after the end of the funding. Another family on *Extended Family Support* used their funding to fund OH&S upgrades to her home as part of a larger series of renovations, thus reducing overall costs.

In cases where the flexibility of the funding has fallen short of expectations, families have had to dip into personal funds to pay for supports. There were two principal barriers: 1) bans on particular purchases or funding types, and 2) lack of choice in moving away from the invoicing/reimbursement model.

For example, one family who were receiving the *Extended Family Support* funding were able to expend funds on holidays, respite, carers, and items for other family members, but were refused permission to purchase adult nappies for the person with a disability. The service intermediary decided that the nappies would not directly support the family through their time of crisis, unlike the other supports they were receiving. However, the nappies were expensive and the family preferred to use their funding to ease their financial stress rather than to spend it on a holiday.

Financial stress can be a common and overriding concern for families caring for a person with a disability. For these families, a reimbursement model leaves them out-of-pocket and places them under stress. They may also limit their purchases to supports and services that can be invoiced or inexpensive enough for them to afford personally. The uncertainty of whether their purchases would be reimbursed adds further stress. Such was the case for a large CALD family caring for a child living with global developmental delay in *Early Start*. While they preferred to purchase educational equipment and therapeutic aids for their child, they chose to access physiotherapy and speech therapy because these could be invoiced directly to the service intermediary and limited their purchases of items such as orthopaedic shoes which had to be reimbursed. The time required to arrange invoicing (typically two weeks) also prevented the family from taking advantage of short-term sales of services or equipment that they wanted to access, effectively forcing them to pay higher prices than otherwise necessary.

4.4 Case study 4: Flexibility

4.4.1 Key elements

Overview	A young person with multiple disabilities on the *Community Participation – Self-Managed Model* program aimed to hire carers to take him out for social activities, rebuild connections with school friends, and participate in the community.
Situation	His severe physical needs required him to have two carers at all times who were trained to handle him safely and respond to epileptic or anxiety attacks. Appropriate carers could not be recruited to provide the frequency and duration of care needed.
Capabilities	• Person with a disability was enthusiastic about building social connections • Strong project management skills by the father to support self-management • Family had access to informal network of capable carers
Decision supports	• Followed family instructions to hire, roster, and fire carers • Employed carers recommended by family who were not contractors • Expert advice in taxation, workplace law, and OH&S regulations • Managed and reported multiple funding sources • Budgeted and tracked carer hours for family • Coordinated large number of carers on flexible and variable schedule
Outcome	The family was able to engage and train an informal network of carers drawn from a range of atypical sources. This alternative approach was enabled by the flexible HR, financial and OH&S arrangements offered by the service intermediary.

Critical success factors	• Program and service intermediary guidelines that allow service users to engage supports in innovative ways
	• Service intermediary:
	  • had the ability to quickly change support plans to respond to changes in circumstance or crisis
	  • had the capability to support service user in hiring and firing carers sourced from family, close friends, or from unusual places (e.g. school networks) without contractor status
	  • understood relevant taxation, employment, and OH&S legislation
	  • could manage timesheets and rosters for large numbers of casual carers
	  • possessed regular and customisable budget and financial reporting processes that could support multiple funding sources and purchasing pools

4.4.2 Narrative

"If it wasn't for the program in this form we would have been in deep strife"

"What option was there?"
Robert[12] is 22 years old and in the 'exceptional' category of funding support with multiple disabilities. In addition to paraplegia, Robert is legally blind and unable to read print or identify objects in pictures. He has diminished speech capabilities and lives with severe physical disabilities that prevent him from venturing outside without intensive supervision. Although Robert is intellectually impaired and has similar cognitive abilities to that of a young teenager, he also has a talent for languages and is able to speak English, German, French, Spanish, and Italian. He also has an acute sense of hearing coupled with a love of music and perfect pitch.

Robert attended a normal public school where he was able to make friends and have a social network despite the difficulties posed by his disabilities, including the need for a full-time teacher's aide to be present at all times. These social contacts collapsed following his graduation, as there were insufficient supports for him to leave home and maintain links with school friends.

Robert's family had researched a range of centre-based programs for *Community Participation*. None were suitable. None of the centres could accommodate Robert's physical needs, which requires the presence of two full-time carers trained to deal with the unique challenges of keeping Robert safe in outdoor settings. Robert desired connections with people in his own age group who share his interests and are enthusiastic about spending time with him. His family decided that the only way for Robert to reach his goal was to find some way of meeting his need for appropriate carers. As a result, Robert entered the *Community Participation* program with *Self Managed Model* option.

"Give me a pool of people who are young, smart and interested in working with Robert"
Carers with the requisite skills to care for Robert were in short supply, particularly in the regional area where the family resided and for the frequency and periods of time that he required. A large pool of carers was necessary - teacher's aides and other carers throughout Robert's childhood tended to burn out after three weeks if assigned to him full-time.

The family's experiences in the early months of being in the program were largely unsuccessful as they and their service intermediary failed to find the requisite number of suitable carers. Despite extensive advertising and recruitment efforts through the service intermediary, only one carer was found during the first three months of being in the program. The family ultimately discovered that this carer was unsuitable after four months. It appeared that formal support mechanisms were not going to deliver what was needed for Robert to achieve his goals.

"All recruitment is through word-of-mouth…jobs go from one sibling to another…it is a small town"
A breakthrough was achieved through a chance encounter between Robert's father and an ex-colleague's son, Alan, who was studying nursing at university while also working a part-time carer. Alan was able to put the family in contact with an untapped pool of young people who had the skills to care for Robert and were interested in working with him on a flexible part-time basis.

Over the course of nine months, a loose network of carers around Robert started to develop: carers from agencies who had worked with him previously; university students and local contacts that had cared intermittently with Robert throughout his high school years; and this new pool of nursing and education students through Alan.

[12] Names have been changed to protect the identity of participants

"Professional but with an understanding of the issues in our own minds"
To make this network of carers work, Robert's family relied heavily on their service intermediary to offer flexible supports that went beyond the typical decision support mechanisms that are normally provided. The family were free to make hiring decisions about the carers, which was crucial to ensure that the carers were a good fit with Robert and were able to handle his needs, even if they did not possess the formal qualifications that would normally be required.

The service intermediary was able to put the carers on their payroll and manage their timesheets as employees. The demands on HR support were not inconsiderable, with 10-12 carers on the payroll at any given time, and a regular turnover of carers as they graduated from university and passed on their roles to friends, siblings, and other family members. It was equally important for the service intermediary to be able to support the family's decision to fire carers when it emerged that they were inappropriate or unsuited to the role, without the family being placed under additional stress.

In total, carers were employed for about 90 hours per week, in two shifts of six hours per day with overlaps of three hours. As the CP-SMM program is only able to fund 40 hours of care, the family was able to supplement the funding pool managed by service intermediary from personal funds. The complex nature of these arrangements was supported by the regular and flexible financial reporting processes at the service intermediary that allowed the family to accurately track their remaining funds and plan their supports and funding levels accordingly.

The ability of the service intermediary to quickly and flexibly alter arrangements depending on Robert's medical needs was critical. This enabled carers to be rescheduled when Robert was in hospital.

"All those milestones in life, he is now part of it, he gets exposed to it, he gets included in it"
For Robert, this informal network of carers has evolved into a social group that enables him to rebuild links with his school friends, participate in the community, and experience the milestones of young adult life. He is invited to parties, graduations, and weddings; plays cards in university cafes while conversing in French or Italian; and goes out for meals at restaurants and clubs with his carers and friends. This social group has persisted even as carers enter and leave, with most of them staying in contact with Robert several years after they have moved on.

"Self-management is an option not a universal answer"
The *Self Managed Model* worked for Robert because the family had the capability to manage the funding and it fitted well with the goals that Robert was seeking to achieve. Robert's father stressed that "the family must be able to formulate a valid vision for community inclusion for the person with a disability". There must be clear and realistic goals for what to get out of the program and detailed plans to achieve this, both of which require enormous effort on the part of the family. "If not", he suggested, "centre-based options may be more suitable".

4.4.3 Critical success factors

Guidelines that allow service users to engage supports in innovative ways (e.g. training students in TAFE/university in client-specific skills as carers)
Robert was able to engage carers who were not formally qualified but could be trained through informal links with existing carers because of the flexibility provided by the service intermediary to hire staff. A similar situation occurred in another case where a deaf-blind service user was finding it difficult to hire specialist carers. She was able to work with a local TAFE to cross-train students studying hand-over-hand sign language in specialist care techniques in order to become suitable carers for deaf-blind people.

Ability to quickly change support plans to respond to changes in circumstance or crisis
As Robert was frequently in hospital, it was important that carer schedules could be changed at short notice when Robert became ill in order to prevent funds from being needlessly wasted.

Capability to support service user in hiring and firing carers sourced from family, close friends, or from unusual places (e.g. school networks) without contractor status
Robert's success with overcoming an acute lack of suitable carers was because his service intermediary could handle the HR and OH&S hurdles involved in hiring and managing a large number of informally-sourced carers. In cases where the service intermediary has been unable or unwilling to provide these capabilities, efforts by the service user to tap into alternative sources of support failed to be realised. In one case, a mother of a child with a disability residing in regional NSW was unable to hire potential carers that she had discovered through non-traditional channels due to the refusal of her service intermediary to employ these carers through the ISP.

Understanding of relevant taxation, employment, and OH&S legislation
The service intermediary was sufficiently sophisticated in matters relating to taxation, employment laws, and OH&S legislation to employ a large number of casual staff as carers without formal qualifications or being registered as independent contractors. This was critical in enabling Robert's family to engage their informal carer network.

Management of timesheets and rosters for large numbers of casual carers
10-12 casual carers were hired by Robert's family for up to 90 hours per week, in a complex pattern in which carer schedules overlapped with each other to provide two carers for Robert at any given time. This required a significant level of HR support from the service intermediary in the management of timesheets and rosters.

Regular and customisable budget and financial reporting processes that can support multiple funding sources and purchasing pools
Robert's family was able to supplement the ISP funding from personal funds, and receive regular updates on their budget in terms of carer hours and where the funds were being drawn from. This was crucial for them to confidently predict how much care could be provided for Robert, and to add funds to the funding as required.

4.4.4 Success factors identified in other cases

Expertise in specialised disability areas (e.g. autism or early intervention) to assist in exercising informed choice
While not an issue for Robert and his family, service intermediaries who are expert in the disability of the service user were commonly cited as a key advantage in our interviews with service users and service intermediaries, especially those in *Early Start.* One mother of two boys with autism spectrum disorders was able to engage a range of innovative supports and services beyond direct therapy after hearing suggestions from her service intermediary. Conversely in another case, a mother of a child with global developmental delay struggled to find the right mix of supports for her child as her intermediary was inexperienced with this disability at the time. She was restricted to a small number of direct therapies for eight months of her one-year funding before additional research enabled her to find a better mix of supports for her child.

Educational procedures to build capability in service users/families/carers to research supports and services independently

Other families have also indicated that they need quite basic support in order to effectively make decisions. One service intermediary cited an example of a CALD family caring for a child with a disability who was unable to articulate the supports that they wanted. On closer inquiry it was discovered that the mother was computer-illiterate and nervous about calling services directly for information. This problem was readily solved by educating the mother in basic computer skills, which boosted her confidence and enabled her to independently research supports for her child.

4.5 Case study 5: Reaching goals

4.5.1 Key elements

Overview	Mother of two boys living with autism spectrum disorders aimed to use the *Early Start* funding to obtain disability supports and services
Situation	The boys were to start school in a year, and the mother wanted them to speak before this point so that they could make friends
Capabilities	∘ Previous experience with "Helping children with autism" program ∘ Mother was highly capable of self-management and could independently research supports and services
Decision supports	∘ Service intermediary assisted the mother in generating ideas ∘ Support groups that helped her meet other families on *Early Start* ∘ Option to pay in advance for recurrent services that would continue after the funding ended
Outcome	First boy started speaking before entry into school; second boy was on track to do so by Jan 2012.
Critical success factors	∘ Funding duration coincided with major transition point for the service user

4.5.2 Narrative

"I wanted him to make a friend"

"I was juggling therapies because I was running out of money"
Vanessa[13] is a young mother with two boys diagnosed with autism-spectrum disorders: Darren and David, aged 5 and 4 respectively. She was under financial pressure to fund sufficient supports and services for her sons and had previously accessed the "Helping children with disability" program which provided $12,000 for the family to pay for therapies. As this funding came to an end, Vanessa became increasingly active in looking for alternative sources of support. Through her contacts in a local support group for children with disability, a disability services advocate referred Vanessa to the *Early Start* program. They were approved and were reapproved a year later, giving them two years access to the funding.

"We knew what we wanted – speech therapy"
The goals that Vanessa had for her children were for them to speak before entering school, "so that they could possibly make a friend". Darren was to start school in a year, with David following the year after. For the first year that she was in the *Early Start* program, Vanessa used the most direct approach she could think of to achieve this goal – speech therapy, regularly and frequently. She spent half her funding on Darren, entirely on speech therapy, and set aside another portion to pay a forward invoice for additional therapy in the following year. For her younger son, David, she purchased autism-specific early intervention therapies to give him the best possible advantage in the penultimate year before he too started school.

[13] Names have been changed to protect the identity of participants

"I didn't really feel like I had any other options … then she asked me: 'is there anything else that we can do?'"

Darren responded well to the therapy and made great progress in his speech development. When the *Early Start* funding was renewed for the second year, Vanessa was initially inclined to use the funding similarly to way she used it in the first year. However, she recognised that she had not used the funding in the first year to its full potential in terms of using the flexibility in the funding to explore a range of different supports and services; developing her own understanding of the disability system; or increasing her capacity to self-manage supports or services for her children. Following the successful, though limited, use of her funding in her first year, Vanessa became interested in using her funding more creatively in the second year.

Her service intermediary provided some suggestions for alternative approaches to reach Vanessa's goal of having David speak before school. Perhaps as importantly, Vanessa was invited to a seminar run by the intermediary that put her in touch with other families who were also on the same program. Beyond the emotional support of meeting other people in the same situation, her discussions with other families inspired her to undertake a more creative mix of supports and services for David.

Vanessa maintained a regular schedule of speech therapy for David but at a lower intensity than she had purchased for Darren. On top of this, funds were used to purchase equipment that were designed to help with the children's sense of balance. Other purchases included early intervention activities specific to children living with autism such as weighted vests and blankets to keep them secure while walking or sleeping, and an iPad loaded with interactive software for kids. Supplementing the autism-specific supports were activities such as swimming lessons. The funding was also used to educate Vanessa and her husband in speech therapy techniques so that they could provide therapy to David directly in the home.

"I could direct the way my kids were learning, how they were progressing"

A key advantage of the *Early Start* funding was that Vanessa was able to access the supports that she felt she needed for her children and direct the way that they were learning. In particular, she was able to choose the speech therapist that had a good rapport with her children despite the therapist not having ASD-specific accreditation. The lack of accreditation had prevented Vanessa from hiring this therapist under her previous "Helping children with autism" funding and also increased therapy costs, as accredited therapists charged significantly more for their services.

Vanessa admitted that her goals had been achieved in both the first and second years of the *Early Start* funding, despite the widely different range of supports that were purchased. The most important aspect of the funding was the timing: they enabled her to purchase the supports that she needed in the year before her children started school.

Both years of the funding have resulted in success. Darren is in primary school and has vastly improved speech skills. David is halfway through his final year before school and is on track to speak before he enrols in the new year.

4.5.3 Critical Success Factors

Funding duration coincided with major transition point for the service user

Vanessa's success with the *Early Start* funding hinged upon the funding supporting her children through to the start of school, the next transition point in their life. For other families in ISPs that run for a fixed one-year term such as *Early Start* and *Extended Family Support*, the funding period has not always coincided so neatly with the transition point.

For one *Early Start* family caring for a 2 year old girl with developmental delay, the funding started when she was one and was due to finish well before she could transition to school. The family were therefore reluctant to engage in recurrent services/supports such as therapy, as they were not confident that they could maintain these therapies with their family income after the program finishes. Consequently, they skewed their purchases towards items such as orthopaedic shoes as opposed to services.

Similarly, families in *Extended Family Support* tend to receive this large and non-recurrent funding for only one year, typically less than the length of time required to lift them out of crisis. For one family with a son with a severe intellectual disability, this funding arrived well after they had relinquished care of their child and was of insufficient duration or amount to enable them to re-establish primary care for him. In another case involving an 18 year old child living with multiple disabilities, the family were placed under mounting stress as their funding ran low while they waited for confirmation of further disability support. While their funding was ultimately renewed, they retained concerns that it would not see them through his high school years and to his transition to adult life.

5 System case study: meeting decision support needs

This evaluation interviewed six service intermediaries to find out their experiences with providing decision support mechanisms for people with a disability, their families and carers in the ISPs. A system case study is produced below to illustrate the success factors and challenges that have been identified through the pilot projects. These factors and challenges may have implications for the implementation of a person-centred approach to disability services in NSW.

5.1 Key elements

Situation	Service intermediaries struggle to provide the right decision support mechanisms to service users on the basis of need, while being constrained by fixed administration fees, few guidelines on decision support, and a lack of standardised techniques
Key Challenges	• high ratio of service users to service intermediary staff due to caps on administration fees • balancing the need to provide extra decision support to service users with high needs while not neglecting service users with less need • getting service users to understand their responsibilities in the ISPs and to manage their expectations • giving service users flexibility to decide on their supports and service while having a duty-of-care to make sure these are safe and appropriate for the person with a disability • ensuring that the decision support is provided at the right level for the person with a disability, not too much and not too little
Success factors	• early engagement with the service user, emphasising that the family will have to do a lot in the ISPs • step-by-step guidance through the ISP processes over 12 months, while encouraging the service user and their family or carer to make decisions and take responsibility • regular conversations to find out the goals of the person with a disability and discuss how their chosen supports can help them achieve these goals • suggestion to allow service users to choose the level of decision support provided to them and vary the administration fee to cover these

5.2 Narrative

"After four years, we're still learning about this self-managed model…still putting changes in place"

"Some people take more of your time than others"
Grace[14] has been working as a front-line staff member with a service intermediary for the past two years, providing support coordination and case management for 30 service users enrolled in various

[14] Names have been changed to protect the identity of participants

ISPs. Supporting this many service users takes its toll on her, and Grace regularly works overtime in order to keep up with the load.

Much of the support that she provides is informal, and services users or their families or carers regularly call her outside of normal hours when they have queries about the program or during emergencies. The people that she supports have widely varying levels of need: some rarely contact her except during their regular scheduled meetings, while others call her several times a week and require frequent check-ups.

"There is a prioritising aspect to balancing workload"

This level of workload is not unusual. Grace noted that several of her colleagues are supporting as many as 40 service users. These high ratios of service users to staff result from the limits posed by ADHC guidelines on the administration fees that the service intermediaries can charge, typically 12% of the service user's funding[15]. It is not economically viable for the service intermediaries to operate with lower ratios.

Low ratios are not necessarily a problem, notes Grace, if the service users all have relatively low needs. This is rarely the case, and inevitably service intermediaries prioritise their clients: those with high needs and/or at the beginning of their program are provided with more decision supports while those with low needs or have been in the ISPs for some time are given less support. Despite this, all service users pay the same rate for administration services and Grace notes that many people feel this is unfair.

"In the first 6-12 months there is a need for a lot of support…and small steps to build their confidence"

Regardless of their capability to make decisions and self-manage, Grace notes that every service user requires a relatively high level of decision support at the beginning of the funding to get them used to the person centred approach in the ISPs.

"There are generally three kinds of people who come in", says Grace, "1. People that have things they'd like to do, but can't tell you the underlying goal; 2. People who are just living with their disability and have no long-term goals; and 3. Those who are quite clear about their goals from the outset". She notes that the people who fall into the first two categories tend to have been in the disability system for a long time and usually have some form of intellectual disability, while those in the last category are often already well-supported by family and friends, with fewer immediate or pressing needs compared to most service users.

For all of her clients, Grace spends the bulk of her time helping them understand their rights and responsibilities in the ISP. "It is vital that information is provided from the beginning of the program on what supports will be provided, what the family is expected to do, and also the grey areas…when services are unavailable. There must be an early emphasis that the family will have to do a lot". For her, it is necessary that the service user and their family are guided step-by-step through the process of using their funding to build their independence and confidence. "You have to be there", she explains, "encouraging them through the management process, being available, being responsive, but being able to model the researching approach and help them do it rather than to do it for them".

Clarity is a must. "There is a need to have written materials after the conversations: the program, the person centred approach, and the contract. These set out the amount of funding, duration, how the budgeting and reporting works, etc." This is followed by a formal assessment conducted with the service user and their family or carer to determine their capacity to make decisions, manage their own supports, and refine their support plan. As a rule of thumb, Grace believes that it takes 12 months for a person to be comfortable in the ISPs so that they have the experience of going through one full funding cycle.

[15] 10% for ES, 12% for EFS, OC, and SMM

"It can be very difficult where there is this lack of understanding about the package"

There are occasional cases where service users do not understand their responsibilities even with the support that is provided. "Some people seem to feel that it's the government's job to look after them and their family", says Grace, noting that there is often a mismatch between the expectations of the individual and what the package can actually provide. "It is an expectation for some families that the funding will continue indefinitely…[or] the service user expects 18 hours of support to be provided by the support provider without consideration for cost or requiring any management by the service user".

Other people, especially those who have previous experience of disability supports, "are accustomed to having the service provider telling them what to do…it takes time for them to get accustomed to the idea of making their own decisions". She says that it is sometimes necessary for her to push back on requests to find local services and supports for her clients in order for them to do things for themselves and build their own confidence.

"How do we ensure that our clients are accessing safe services?"

One of the biggest challenges that Grace and other service intermediaries face is where their own responsibility lies in the provision of decision support to their clients. One example was a young woman who wanted to go to TAFE. "We hooked up all the meetings, we organised staff to support her, equipment for TAFE. She asked for exercise equipment. Community access – movies, so we'd arrange for the movie tickets/bus tickets. How do we tell the family that things like a laptop or iPad may not be legitimate supports if they are not currently at TAFE?" Refusing these requests can be confronting. "In some people's minds, they think 'why are there these limitations, it's my funding, it's my money!'" In these cases, she often feels that very little progress is being made for the people with disability. "They aren't really realising any goals, they are just floundering around".

The reverse has also occurred. "For example, one person wanted a bed, which we refused because it wasn't really fitting with the aims of the program [that they were enrolled in], but who's to say that it's not going to help her?"

Grace finds the uncertainty around the service intermediary's responsibilities and authority to be a challenge in providing advice about supports and services. "What's the level of proof," she asked, "that we as an organisation need to help us determine the validity of a request, what are the guidelines about meeting the spirit of the program, and also what information do we need from the service user? Time is a factor…going back to the guidelines to check when you receive a message on your voicemail or getting advice from my manager to test whether something can be approved".

She worries about the duty of care that service intermediaries have for their clients. "There's a lot of stories about using someone's uncle, etc., with great success [as paid carers]," says Grace. "If someone is a tutor and a family practitioner with an ABN (sole traders), this can work…however, there are questions around what the duty of care is…how legitimate are they, can we allow families to pay family members, what precedent does this set?" When it comes down to it, Grace tends to go with the family decision but notes that having a conversation is important.

"The plan has to follow the person rather than the person following the plan"

Ultimately, says Grace, decision support mechanisms – like the program itself – have to fit the needs of the service user. "Different people have different levels of need, and over time people get better at self-management". People with a low level of need require minimal support: "all decisions are implementation – what, who, when…they prefer to contact service providers themselves…there's no need to explain invoicing to them, often they pay for everything themselves and get reimbursed". People with high needs "always ask 'what do you think?', and need regular contact and are happy for someone else to take care of the lot".

The key thing is to make sure that the system supports this ability to tailor supports to the needs of the individual. “Funding amounts are very inconsistent…service users in similar circumstances often have widely varying amounts of funding”, says Grace. She adds that there is an issue of resource management for supporting clients as the assessment process for determining a person’s capability for self-management is not performed by the service intermediary but by ADHC, leading to discrepancies between the support that needs to be provided and the funding to provide these support. “There is a need for clearer and realistic guidelines for assessment as well as an appeal process to change the level of funding. This goes both ways…some service users need more funding while other service users could do with less.”

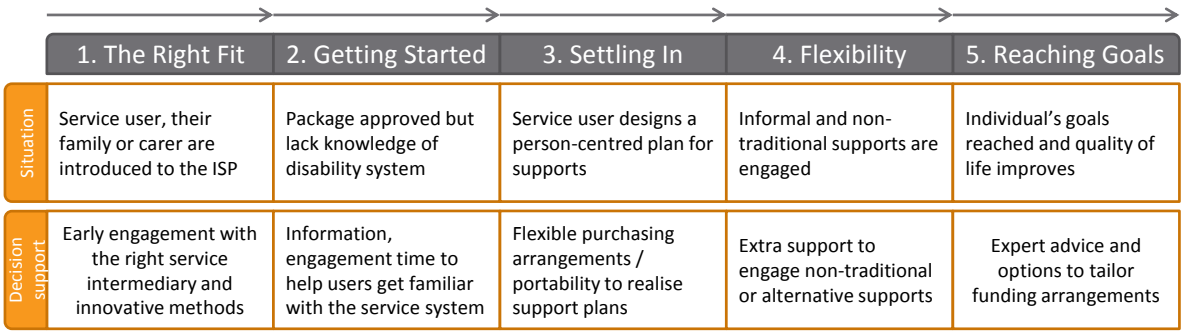
6 Implications and conclusions for the person centred approach

This evaluation describes the diversity of experiences of service users, their families and carers as well as the impact of decision support mechanisms in those experiences. This section provides conclusions in response to the following evaluation question:

How might the success factors in implementing decision support mechanisms be implemented as part of the broader person centred approach?

The conclusions are matched to the five phases that service users move through as they access and use services in a person centred system (Figure 9), as well as the findings from the system case study.

Figure 9: Decision supports for the journey through the service system



1. **The right fit**: Service users have indicated that one of the most important implications for a person centred approach is to ensure that the goals of the individual are aligned with the aims of their disability support program. Service providers involved with the ISPs say that the best outcomes are achieved through these programs when the person with a disability, their family or carer believes that the goals of the program are appropriate to their circumstances. Mis-alignment, by contrast, often results in less than ideal outcomes. It is anticipated that alignment will improve as NSW disability services move from a program model with narrow goals to a broader integrated support model. Some of the decision support mechanisms that have been suggested to improve 'fit' include:
    - engaging the person with a disability, their family or carer prior to the start of the program or funding to ascertain their goals. Service intermediaries indicate that this is particularly important for Aboriginal people. Some service intermediaries have specialist staff who are experienced in engaging Aboriginal communities
    - assisting people with a disability in articulating their life goals by providing translation services, visual facilitation techniques and other methods
    - selecting the right service intermediary when the service user first interacts with the disability service system. Specifically, a service intermediary that is able to provide the appropriate level of support for the service user, including any additional capabilities (e.g. HR, OH&S, complex financial management, etc.) and links to specialist service providers. This is to ensure that the service intermediary's supports, their location, and other factors are appropriate to the circumstances, capacity, and goals of the service user

2. **Getting started:** A common difficulty indicated by service users was that there is often a lack of information at the beginning of the ISP funding. Service intermediaries have similarly described the early stages of getting people started in the ISPs as an ongoing challenge. There are three aspects to this challenge:
    - users are confronted with a large quantity of forms, brochures, guides, and other materials in one meeting at the start of the funding
    - the person centred approach is very different to their previous experience of disability services
    - there is inconsistency in the way that different service intermediaries engage service users, and there are no standard techniques for assisting service users of varying capacity and knowledge about disability services

    Some of the decision support mechanisms that service intermediaries have had success with include:
    - early engagement before the start of the program with the person with disability, their family and carer to educate them about disability services, the level of funding, and the guidelines of the funding
    - a tailored approach to orient service users to the service system, with information provided progressively and innovatively
    - standard toolkits and training modules for service intermediary staff to assist them in informing service users and getting them familiar with the program
    - seminars and support groups that bring families on the same program or in similar circumstances together. This enables families to mutually support each other and generate ideas about which supports and services to access. Other approaches, such as “circles-of-support” – a facilitated support group consisting of close friends and family – may also be useful
    - processes to enable service users to change their plans as they become more familiar with the system
3. **Settling in:** Some service users were able to clearly articulate their goals and were highly capable, but encountered barriers as they sought to implement the funding into a tailored mix of supports and services. This was particularly the case for people who wanted to engage informal or non-traditional supports. They relied on decision support capabilities that were offered by some (but not all) service intermediaries. These capabilities included:
    - sophisticated HR and OH&S capabilities, including the ability to hire casual staff (e.g. carers and translators), management of timesheets and rosters, payroll facilities, etc.
    - financial management and budgeting processes that can coordinate multiple funding sources and accounts
    - knowledge of legal and insurance issues associated with non-traditional services or supports
    - expertise in specific disabilities or early intervention
    - capability to educate service users in tasks such as online research and basic budgeting/accounting to assist with self-management

    It is not expected that every service intermediary will have all of these capabilities. However, it may be important in a person centred system that intermediaries with the desired capabilities are available to all service users, particularly those in regional or remote areas.

4. **Flexibility:** Flexibility in purchasing arrangements and the portability of funding between service intermediaries was often mentioned as contributing to positive experiences for service users, their families and carers. A person centred system may want to consider implementing the following suggestions from service intermediaries to ensure flexibility:
    - easy portability of service user funding between service intermediaries or providers
    - rapid invoicing, quick reimbursements, and a facility to pre-approve some purchases in case of crisis or emergency
5. **Reaching goals:** A common theme was that service users do not typically plan according to the funding period of their program, but rather through to their next life stage. The implication is that a person centred approach may consider varying the period of funding for individuals depending on their circumstances, even if the total amount of funding over this period is unchanged. There were a number of decision support mechanisms mentioned by service intermediaries to assist people in reaching their goals, including:
    - budgeting advice to ensure that sufficient funds are available to support individuals through the entire funding period
    - option to pay in advance for recurrent services (such as therapy) that will be delivered after the funding period
    - expert advice and innovation in suggesting alternative supports, education, or equipment purchases that can provide long-term benefits to the individual with a disability. For example, investing in educational aids and speech therapy instruction for parents caring for a child living with autism
6. **Meeting decision support needs:** Service intermediaries found it difficult to provide the right level of decision support to service users, because service users were unable to choose the amount of these supports they wanted to receive. The administration fee that service intermediaries were able to charge for these supports was too low and placed stress on their staffing levels. This system created incentives for decision supports to be cross-subsidized between service users and for service intermediaries to 'cherry-pick' service users with low needs. Some of the mechanisms that were suggested to resolve these issues include:
    - allowing service users to choose the level of decision support provided by the service intermediary depending on their own capabilities and skills
    - enabling the administration fee to be varied for different service users depending on the decision supports that they require

Appendix A Glossary[16]

AA-SMM	Active Ageing – Self Managed Model. A program within SMM, one of the four ISPs in this evaluation.
ADHC	NSW Department of Family and Community Services: Ageing, Disability and Home Care
CALD	Culturally and Linguistically Diverse
Carer	A person of any age who provides informal care, help or assistance to a person with a disability
Case Management	An individualised, person centred and holistic approach to supporting people. It spans the range of life experiences and transitions across family, community, formal and informal services. Case management provides support and coordination aimed at strengthening families and promoting community inclusion in an open, responsive, flexible, respectful and accountable way
Case Manager	ADHC front-line staff responsible for developing a support plan for service users enrolled in EFS
Circle of Support	People that a person with a disability identifies as being their source of practical, emotional and spiritual assistance and guidance. This may include friends, family members, carers, colleagues, teachers, community and religious leaders.
Consultant	Front-line staff of a service intermediary coordinating supports and services for service users enrolled in ES
CP-SMM	Community Participation – Self Managed Model. A program within SMM, one of the four ISPs in this evaluation
Day Programs	Adults with a disability participate in day programs so that they can learn new skills, take part in activities they enjoy, achieve their goals and be part of the community
ES	*my plan, my choice*: Early Start. One of the four ISPs in this evaluation
EFS	Extended Family Support. One of the four ISPs in this evaluation
ISP	Individualised Support (demonstration) Project
KEQ	Key Evaluation Question
LC-SMM	Life Choices – Self Managed Model. A program within SMM, one of the four ISPs in this evaluation
Nous	Nous Group Pty. Ltd.
OC	*my plan, my choice*: Older Carers. One of the four ISPs in this evaluation
PCA	Person centred approach: an approach that recognises the 'person' as the focus and driver of action
PCS	Person centred system: a disability system that adopts a person centred approach

[16] Glossary terms sourced from Stronger Together: A new direction for disability services in NSW 2006-2016 [19]

Respite	Planned short-term or time limited breaks for families and other unpaid carers of people with a disability. Respite gives the carer a break from their usual care giving roles, whilst providing meaningful activities for the person with a disability. Respite may be delivered in centre based or flexible community based settings
Service Intermediary	Organisation or front-line staff member responsible for coordinating supports and services for a service user
Service Provider	Organisation directly providing supports and services to people in an ISP
Service User	An person with a disability, their family or carer who is the primary recipient of supports and services in an ISP
SMM	Self Managed Model. One of the four ISPs in this evaluation.
Support Planner	ADHC front-line staff responsible for developing a support plan for service users enrolled in OC
Therapy	A professional group that includes occupational therapy, physiotherapy and speech pathology, who have appropriate qualifications, training, skills and expertise. It provides services which are strength based and focussed on functional outcomes to promote access and participation in the community and to improve the quality of life and well-being of the person with a disability and their family/carer
Transition-to-Work	A two year program for young people with a disability leaving school focusing on employment and/or further education outcomes

Appendix B Key evaluation questions

The objective of this evaluation was to draw insights from the four ISP pilots that can be used to inform the implementation of a person centred system. Specifically, this evaluation aimed to learn about the experiences of service users and decision support mechanisms across the four ISPs. The conclusions will be primarily used to inform the development of a person centred system for people with a disability, their families and carers based on individualised funding arrangements.

Nous articulated two key questions that directed the evaluation towards this objective:

1 **What were the different experiences of service users, their families and carers in the Individualised Support (demonstration) Projects** ('typical' experiences and 'unintended consequences, successful and unsuccessful results, and whether clients are better off)?

   a. What were the types of services/supports accessed by service users, their families and carers before entry into the ISPs?
   b. How did types of services/supports change during their time in the ISPs?
      i. What types of services/supports, particularly non-traditional ones, were accessed through the ISPs?
      ii. Were support plans developed by service users, their families and carers, and how were these supported?
      iii. What were the experiences of service users, their families and carers in using the support plans?
   c. What happened in the ISPs, what worked and what didn't work?
      i. What were some of the positive experiences of service users, their families and carers in the ISPs? What did they feel were the features of the ISPs that contributed to these experiences?
      ii. What were some of the negative or challenging experiences of service users, their families and carers in the ISPs? What did they feel were the shortfalls in the ISPs that contributed to these experiences?
      iii. Were the experiences of service users, their families and carers in using the support plans positive or negative, and what could be improved?
      iv. Have service users, their families and carers experienced any unintended consequences in the ISPs, and if so, what were they?
      v. In what ways do service users, their families and carers believe their experience could have been improved?
   d. To what extent were the experiences of services users, their families and carers influenced by characteristics such as:
      i. The ISPs in which they were enrolled?
      ii. Age
      iii. Cultural background
      iv. Geographical location
      v. Gender
      vi. Living arrangements

vii. Nature of disability
viii. Previous service experience

e. To what extent do service users, their families and carers feel their skills and capabilities have been improved by the ISPs?

2 What role did decision support mechanisms play in the experiences of service users, their families and carers within the Individualised Support (demonstration) Projects?

f. What were the types of decision support mechanisms accessed by service users, their families and carers?

   i. Were some of these supports provided by services outside the ISPs, and if so, what were they?

g. How important were decision support mechanisms in shaping the experiences of service users, their families and carers?

   i. What were some of the positive experiences of service users in using decision support mechanisms? Which features of these mechanisms contributed to these experiences?

   ii. What were some of the negative experiences of service users in using decision support mechanisms, and what are some of the shortfalls in these mechanisms that could be improved?

   iii. What were some of the decision supports that service users felt they needed but were not provided?

h. To what extent did service users feel that they had a greater say in designing their support plans, and how did this give them more flexibility and choice in the services/supports received?

   i. What were some of the features of the decision making process that supported service users to have a greater say in the supports and services received?

i. To what extent do service users, their families and carers feel that their decision making capacity has been improved by the ISPs?

j. What did service providers feel were some of the success factors involved in implementing decision support mechanisms? How might these be implemented as part of a broader person centred approach?

Appendix C Detailed methodology

Nous conducted two data collection activities in order to answer the key evaluation questions posed by this project:

1. **Analysis of Existing Data:** Nous analysed a range of existing program data (see Appendix D) from earlier evaluations, the central records on service users, and data obtained from service intermediaries to:
    - understand current state of service delivery by the ISPs
    - understand the demographics, cultural/socioeconomic background, and other characteristics of service users, their families, and carers
    - understand the current issues and experiences identified thus far by service users, their families and carers (these were explored further in the interviews)
    - identify service users, their families and carers in the ISPs and service intermediaries that represent diverse experiences across a wide range of demographic and other characteristics

These were tested with ADHC to identify candidates for the structured interviews.

2. **Structured Interviews on the experiences of service users/carers/families and the impact of decision support:** 25 interviews were conducted with service users, their families and carers as well as six interviews with service intermediaries. These interviews were qualitative and focused on:
    - **Service users, their families and carers:**
        - their experiences and the services/supports accessed before and after entry into the ISPs
        - whether these experiences were successful, unsuccessful, or unintended, as well as the factors behind these experiences, particularly in terms of decision support
        - the extent to which their skills and capabilities were improved by the ISPs, particularly their capacity for decision making
        - the importance, positive and negative experiences, and shortfalls of decision support mechanisms, as well as any improvements that could be adopted
    - **Service intermediaries:**
        - the key aspects of the ISPs which produced positive experiences for service users, their families and carers, particularly those aspects that enabled people to have a greater say on the supports and services received.
        - the challenges they have faced in the implementation of the ISPs, particularly for decision support mechanisms.
        - the potential pitfalls that would inform the development of a broader person centred approach in NSW.

The interviews were primarily conducted face-to-face by two Nous consultants using a structured interview guide. Each interview was summarised into a standard template and de-identified.

Each consultant independently identified several key findings from each interview which were then synthesised into three consensus themes. The collection of findings across the entire dataset of interviews was then scanned for the five most significant findings which were:

- shared across a number of different service users
- identified as a critical factor for positive experiences in the ISPs

Nous produced a set of five case studies that illustrated the key findings by collating and comparing the experiences of service users, their families and carers as a result of ISP participation. The case studies highlight differences in services/supports accessed before and after entry into the ISPs, the diversity of experiences – positive and negative – and how these differ between demographic groups, and the critical success factors and challenges that have been identified.

This approach to the case studies enabled Nous to use the personal experiences of service users, their families and carers to develop insights into the development of a person centred system. We avoided the limitations posed by the absence of sufficient quantitative data on the ISPs by focusing on the diversity of experiences rather than attempting to derive generalised outcomes from a limited sample of interviewees.

Our case study approach used the following process:

1. **Code interviews:** Information was scanned from all interview participants and coded for emerging themes and key aspects identified in each interview[17].
2. **Pattern identification:** Patterns of experiences were found that can be used to identify representative experiences, critical success factors, and challenges.
3. **Assemble case data:** Case studies were repaired using Patton's[18] approach: raw case data was assembled; a case record was constructed (raw data condensed into a single record); and a primary narrative for each of the case studies was written based on the experiences of one participant.
4. **Highlight aspects:** Case studies were expanded into multi-case studies (Burns[19]) in which multiple instances within a setting were used to highlight different aspects as well as common features. Auxiliary data from other interviews were used to contrast against features of the primary narrative.

The findings were then tested in two focus workshops. The first workshop was conducted with ADHC front line staff and key stakeholders to test the methodology and the content of the findings to identify any gaps. The second workshop was held with nine support planners from ADHC and service intermediaries to retest the findings and obtain additional information that was missing from the structured interviews.

Limitations

There were a number of limitations to this evaluation:

- Quantitative and qualitative data for the ISPs were incomplete and of varying quality. In particular, demographic data was partially missing for EFS and no data was obtained from SMM through our data request. Consequently, the findings in this reports are indicative rather than comprehensive, e.g. the list of supports accessed by service users is not exhaustive.
- The interviewees selected in this evaluation were chosen for diversity of experience, rather than through random sampling. The experiences of service users highlighted in this report therefore do not necessarily reflect their frequency across the whole of the four ISPs. It is not possible to quantify the significance of specific experiences or implications, only that they were cited.
- This evaluation did not compare ISPs with non-ISPs, and hence cannot statistically determine whether a particular experience is caused or correlated to an aspect of an ISP. Such linkages are based on anecdotal evidence from the service users, their families or carers only.

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Appendix D Summary of quantitative data sources

Document	ISP	Source	Date	# of clients	Relevant Data Contained
FMS Oracle Report Extract 21/07/2011	Self Managed Model – CP/AA/LC	ADHC – Central Database	21/07/2011	308	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity • Service Intermediary • Service Type used by code • Funding Amount
FMS Report Extract 11 August 2011	Extended Family Support	ADHC – Central Database	11/08/2011	104	**Demographics:** • Age • Gender • Geographic Region • Primary Disability • CALD/Not CALD • Service Intermediary • Service Type used by code
OCP Demographics	*my plan, my choice*: Older Carers	ADHC – Central Database	16/08/2011	43	**Demographics:** • Age • Gender • Geographic Region • ATSI/Not-ATSI
De-identified data on AA, LC to ARTD	Self Managed Model – AA/LC	ADHC – Central Database	04/05/2010	96	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity • Service Intermediary • Establishment funding
De-identified data on AA, LC to Nous	Self Managed Model – AA/LC	ADHC – Central Database	04/05/2010	96	**[As above]**

Document	ISP	Source	Date	# of clients	Relevant Data Contained
Data Request: Early Start	Early Start	ADHC - Claudia Vianello. Manager, Stronger Together Implementation	07/09/2011	31	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity **Pre-ISP** • Types of Services/Supports **ISP** • Types of Services/Supports • Types of decision support
Data Request: Extended Family Support, Newcastle	Extended Family Support	ADHC – Suzanne Punshon, Manager Access – Case Management	05/09/2011	4	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity **Pre-ISP** • Types of Services/Supports • Frequency **ISP** • Annual Funding • Types of Services/Supports • Frequency • Service Intermediary • Support Plans, Provider and Type

Document	ISP	Source	Date	# of clients	Relevant Data Contained
Data Request: Extended Family Support, Hunter	Extended Family Support	ADHC – Toni Carson, Senior Practitioner Case Management	06/09/2011	6	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity **Pre-ISP** • Types of Services/Supports • Frequency **ISP** • Annual Funding • Types of Services/Supports • Frequency • Service Intermediary • Support Plans, Provider and Type
Data Request: Extended Family Support, Metro North	Extended Family Support	ADHC – Janet Koprivica, EFS Champion	31/08/2011	6	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity **Pre-ISP** • Types of Services/Supports • Frequency **ISP** • Annual Funding • Types of Services/Supports • Frequency • Service Intermediary • Support Plans, Provider and Type

Document	ISP	Source	Date	# of clients	Relevant Data Contained
Data Request: Older Carers	Older Carers	ADHC – Neil Harris, Acting Service Support & Development Officer, Northern Region	12/09/2011	42	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity **Pre-ISP** • Types of Services/Supports • Frequency **ISP** • Annual Funding • Types of Services/Supports • Frequency • Service Intermediary • Support Plans, Provider and Type
Review of the Self Managed Model	SMM	Nous Group	09/2010	96	**Demographics:** • Age • Gender • Geographic Region • Living Arrangements • Primary Disability • Ethnicity

Appendix E Nous strategy for selecting interviewees

The purpose of the structured interviews was to understand the diversity of experience amongst service users, their families, and carers across the four ISPs that were the subject of this evaluation. Nous used the following strategy in its selection of interviewees:

1. For programs that responded to the data request (ES, EFS, and OC):
    i. We selected 5 interviewees from each of the programs.

Program	Number of Interviewees (# from data request/MDS)
ES	5 (31)
EFS	5 (16)
SMM – CP	8 (179)
SMM – LC	5 (119)
SMM – AA	2 (8)
OC	5 (42)
TOTAL	30 (395)

    ii. A first cut interviewee selection was performed in which each of the key selection criteria – gender, age, disability, location, living arrangements, previous (pre ISP) support, form of planning support - was represented across the three programs (15 interviewees).
    iii. If possible, key characteristics within each program (e.g. living arrangements in OC) each had a representative amongst the interviewees.
    iv. The initial list was then iteratively checked against the overall demographic and service history/use information from the integrated dataset to verify that the major clusters within each criteria had at least one representative amongst the 15.
    v. If there was insufficient representation of a particular key selection criterion, an interviewee that shared several criteria-of-interest with other interviewees was replaced by a new interviewee that represented this new criterion.
    vi. These interviewees were then verified with the Project Control Group and subsequently passed onto the PAR champions to contact and arrange interviews.
    vii. Nous engaged the PAR champions through the interviewee confirmation process to a) refine the list of selected interviewees if the PAR champion believed other participants were more suitable and b) to find replacements in situations where an interviewee declined to be interviewed or could not be contacted.
2. In the case of SMM, we used a similar approach that was undertaken by the PAR champion and/or service intermediaries using the key selection criteria confirmed by the Project Control Group.

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