



Research for the development of a self-management policy: Summary report

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Research and Evaluation Branch
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About the Research and Evaluation Branch

The Research and Evaluation Branch is responsible for ensuring that the work of the NDIA is informed by high quality evidence. Our works helps the Agency to understand what works, what doesn't work, and the benefit to participants and the Agency.

This document

This report presents research findings from the self-management policy project.

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Contents

Abbreviations	4
Glossary	5
Background	6
What is self-management?	6
What did we do?	6
What did we find?	7
Who decides to self-manage?	7
Learning how to self manage	8
Payment systems and budget management	9
Accessing and choosing supports	9
Outcomes of self-management and managing risks	10
What next?	12
References	13

Abbreviations

Abbreviation	Term
LAC	Local Area Coordinator
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PRG	Participant Reference Group

Glossary

Term	Definition
Agency Management	A type of plan management where the NDIA pays providers on behalf of a participant.
My NDIS mobile app	The my NDIS mobile app works alongside the myplace portal so that participants have a more accessible and user-friendly way to view their personal details and self-managed budget, and make and manage claims using their mobile phone.
myplace portal	The myplace portal is a secure website developed for participants, their nominees and contacts to help view and manage a participant's NDIS Plan.
NDIS participants	When referred to in the findings includes NDIS participants, family, carers and other supporters who spoke to the participant experience.
Plan Management	A type of plan management where the NDIA pays a plan manager who then pays providers on behalf of the participant.
Self-management	A type of plan management where the NDIA provides a participant with funding so that they can buy supports that will best help them meet their plan goals.

Background

The National Disability Insurance Scheme (NDIS) Self management Strategy was developed in 2019 to guide the Agency's approach to self management. Since then, the NDIS has transitioned from a period of rapid growth to a more mature operating environment. The focus is now shifting towards improving the experience for new and existing participants.

The National Disability Insurance Agency (NDIA) has developed a [Self-management Policy](#). Through this policy, we want to promote a simple, effective and consistent approach to self-management that improves participant outcomes and experience.

The policy supports the primary principles of the NDIS, giving participants:

- flexibility, choice and control over their supports
- greater independence and opportunities for social and economic participation
- access to high quality, innovative supports

To inform the development of this policy, the Research and Evaluation Branch carried out research to better understand self-directed approaches for people with disability used in similar schemes around the world and conducted focus groups with NDIS participants, their families or nominees to hear their experiences.

This summary report provides the findings from the research and focus groups.

More information about the development of the policy can be found on the [NDIS website](#).

To read the Participant Survey on Self-Management report, visit the [NDIS website](#).

What is self-management?

Self-management is when a participant, child representative or nominee manages the funding for supports under a participant's plan rather than having the NDIA (Agency Management) or a registered Plan Management provider (Plan management) manage the funding for supports on their behalf. They may self-manage all or part of their plan funding.

More information on self-management is available on the [NDIS website](#).

What did we do?

We collected information and research about self directed budget management from a variety of publications from all over the world. The key topics included:

- Who can self-manage, including eligibility and assessment practices and supports required to enable self-management,
- The role of social and environmental factors in self-management, including user-led organisations and peer support networks, and family and circles of support,

- Facilitators, barriers and challenges of self-management, including information access and training needs, and
- Outcomes of self-management for people with disability and their support networks, and Risk assessment and safeguarding processes.

We also held eight focus groups of 35 NDIS participants, carers, nominees and/or child representatives. Four focus groups consisted of members who were currently self-managed, two groups had previously self-managed, and two groups that had never self-managed. The focus group research was approved by the Monash Health Human Ethics Committee (RES-21-0000-491A).

Participants in the focus groups were asked questions about:

- What they liked and did not like about self-management,
- What made self-management more difficult than it needed to be, and
- How they did or would like to learn how to self manage.

The NDIS Participant Reference Group (PRG) and members of the Independent Advisory Council worked with the researchers to make sure the consultation and engagement process, interview questions, and findings were relevant to NDIS participants.

What did we find?

“I employ different people from the community that are just really good at interacting with me.”

Mary, currently self-management

Who decides to self-manage?

People with any type of disability can self-manage when they have the support of someone close to them who has relevant skills and knowledge about self-management (Harkes, Brown and Horsburgh 2014a; Turnpenny et al. 2021). Support can come from a circle of support made up of friends, family, neighbours, or health professionals, or with the help from an appointed plan nominee or independent representative or guardian (Fleming et al 2019; Harkes, Brown and Horsburgh 2014b; Lakhani, McDonald and Zeeman 2018).

The majority of people with disability choosing to self manage have a physical disability (Leece and Leece 2006). People with psychosocial disability are less likely to use self-management because the fluctuations in mental health symptoms makes it difficult to consistently manage a budget (Hamilton et al 2017; Webber et al 2014).

Participants in the focus groups told us they liked the autonomy and flexibility that self-management offered. As found in the research (Harkes, Brown and Horsburgh 2014b; Mitchell 2012), the participants we interviewed said they were more likely to self manage when encouraged by their plan manager and/or their social circles right from the start of their first plan. Participants told us that self-management:

- helped to build their skills and confidence to self manage,
- offered greater financial control, an opportunity to use their budget in innovative ways, and provided flexibility to purchase items or services efficiently in response to urgent situations, and
- can help overcome difficulties in finding suitable providers by having the flexibility to choose non-NDIS registered providers.

Participants told us that it was important to know that self-management was an option, and that there was information available when deciding whether or not to self manage.

“I have a degenerative condition, I require a different piece of ability equipment very quickly. The other reason is I live in [a] rural [area] and there aren't a lot of providers, so I can go where I need to go... A walker might be no good tomorrow, I might need a wheelchair and I don't want to be waiting months and months for my paperwork to be reviewed. I need the equipment when I need it.”

Veronica, currently self-management

Learning how to self manage

Both the literature review and focus group participants told us that self-management was easier to start doing when you:

- have access to information and advice in an accessible format (Lakhani, McDonald and Zeeman 2018)
- have assistance from support groups and user led organisations (Duffy 2005; Strong 2012),
- were given opportunities to learn how to self manage (Fleming et al 2019)
- could talk to people who are already using self-management (Williams, Porter and Marriott 2014), and
- already had the skills to manage a budget (Carey, Crammond and Malbon 2019).

Some participants told us how valuable it was to have a plan support co-ordinator who helped them to learn how to self manage. Other participants said they attended an education session or workshop offered by their LAC to learn about self-management. A number of participants volunteered that they learned to self manage by themselves using the NDIA *Guide to Self-management*, or using information from websites or peer support networks.

“I definitely think having face to face [training]. When I started self-managing I had a face to face - in those days when we could face to face - session with the LAC and that really helped because she actually kind of physically took me through self-management and how to set it up and that was really great.”

Priya, currently self-management

Payment systems and budget management

All participants interviewed who were currently self-managing, or had self-managed in the past, had used the *myplace portal* to view and manage their plan. A few self-managing participants had also downloaded and used the *my NDIS mobile application*.

The research and participants agree that having simple paperwork requirements and administration processes to monitor payments, to support decision making and for quality assurance is helpful for self-management (Harkes, Brown and Horsburgh 2014a; Laragy, Sanders and Brophy 2015; Verhaeghe 2020). Some participants said that the process of self-management can be harder if you are not a naturally organised person.

“I think you need to be very organised and, I guess, probably also guidance around having a very clear and repeatable process in terms of...which invoices needs to go to which category. I think once you have a repeatable process in terms of doing that, everything should fall into place”

Lukas, never self-management

Participants need and want clear purchasing guidelines, including what can and cannot be purchased, that also allows for maximum flexibility and creativity (Dickinson 2017; Fleming et al 2019; Hutton and King 2018). Having access to staff with expertise in self-management is also important (Henwood and Hudson 2008).

Accessing and choosing supports

When a person is able to choose their own support workers they can recruit people who they get along with (Manthorpe et al 2011). Many people rely heavily on personal contacts, social networks and 'word of mouth' to recruit support workers (Manthorpe et al 2011; McNeill and Wilson 2017). Others choose to 'poach' agency staff, or employ family and friends if it is permitted (Arksey and Baxter 2012).

“I love self-managing, I don't find any problems whatsoever. I did it because I wanted to hire my own workers rather than have a company [hire my workers]. So for the first year we stuck with the company line, and as we got familiar with it I said to everybody ‘who wants to come with me and we'll go solo?’ and they all said yes we will. So that's what we did.”

Chip, currently self-management

Participants told us that finding and choosing their own workers and services meant they could get value for money, and “more bang for your buck”. They said that not being limited to NDIS registered providers meant there were more providers to choose from in their local areas, and sometimes they could negotiate a lower price than the NDIS price limits. . This flexibility was very helpful if you lived in an area where there are few providers (e.g. in rural and remote Australia) or for services with long waiting lists (Lakhani, McDonald and Zeeman 2018; McNeill and Wilson 2017; Simpson and Douglas 2016).

“I can choose the providers and who I want to go with, and I can negotiate that rate. I've been able to...stretch my funding as much as I can.”

Sally, currently self-management

For some participants, having the dual role of both employer and support recipient can create challenges. For some participants, it can be difficult to discipline or dismiss a support worker who is not performing well, especially if they have formed a close relationship with them (Arksey and Baxter 2012; Manthorpe et al 2011).

Outcomes of self-management and managing risks

For some people, self-managing results in personal satisfaction and confidence, increased social and community participation, and improvement in physical and mental health (Hatton and Waters 2011; Glendinning et al 2008; Vergaeghe 2020). There is a greater sense of choice and control related to being able to decide how, when, where and by who support is provided (Fleming et al 2019).

In all focus group discussions, participants shared the view that being self-managed meant they were more responsible and accountable for the activity in their plan budget compared to when they use Plan Management or Agency Management.

“But if I get some flexibility in self-management then, definitely, [I] have to take some responsibility as well.”

Mathias, previously self-management

Participants said they liked the responsibility of self-management because it meant:

- they could be more flexible with their budget spending, and choose the providers that they wanted
- they could be innovative and adapt to changes in circumstances
- they had a sense of autonomy and independence in decision making, as well as the opportunity to 'use their brain'
- not having to interact with the LAC if they did not want to
- opportunity to develop and maintain relationships with the providers that they liked
- acknowledgement that they were the expert of their own life

"It was coordinating my own finances - that was the part I loved. I loved being able to manage that. ... It was too much work doing plan managed ... there was way too much to-and-froing for me. It was faster for me to self manage [my plan]."

Peli, previously self-management

For others, taking on the responsibility of self-management is too stressful and anxiety provoking, and they prefer to have some professional support (Davidson et al 2013). For some, delays in receiving payments can put personal finances at risk and increases feelings of insecurity and stress (Junne and Huber 2014).

"We don't want to find out that we've done something wrong down the track and, you know, seven years later they're after, you know, \$20,000 because we did something wrong and we were completely unaware."

Frankie, never self-management

Accidental or fraudulent misuse of funding when self-managing is rare (Friedman and Rizzolo 2016). Often purchasing errors have occurred when spending guidelines are not clear and self managers have inadvertently 'overstepped' what administrators consider to be reasonable purchases (Laragy, Sanders and Brophy 2015).

The main risks that have been identified for people who are self-managing their services include financial exploitation, receiving poor quality services, not receiving the necessary care or support services, or being harmed or neglected (Junne and Huber 2014; Laragy,

Sanders and Brophy 2015; Stevens et al. 2018). Monitoring for financial irregularities can help with identifying financial and other forms of abuse (Stevens et al 2018).

“I've had not so trustworthy support workers where ... how they are invoicing hasn't been reliable always ... some of them have charged more than what we negotiated.. So I've gone from a couple of times from an independent support worker to a provider ... I went to a provider that was NDIS registered because I at least know that they've gone through the right processes to be accredited.”

Sally, currently self-management

What next?

The findings from this research and the Participant Survey on Self-Management have informed the Agency's development of the Self-management Policy.

The findings will also be used to develop a participant guide about plan management options, and training and resources to support participants who wish to begin self-management of their plan.

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