National Disability Insurance Scheme

Summary: Participant Survey on Self-Management

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1. Introduction

The National Disability Insurance Agency (NDIA) has developed a <u>self-management policy</u>. Through this policy, we want to promote a simple, effective and consistent approach to self-management that improves participant outcomes and experience.

To support the development of this policy, we completed:

- A narrative review of the literature on the effectiveness of self-managed budgets as well as facilitators, barriers, and environmental elements that might influence success.
- 2. An environmental scan of prior research and evaluation, including work undertaken by the Independent Advisory Council and through Information Linkages and Capacity Building projects.
- 3. Analysis of NDIS data on self-management uptake patterns.
- 4. Disability sector consultation and engagement, including engagement with service providers and subject matter experts, focus groups and a survey with NDIS participants, their families, nominees or carers.

This report is a summary of feedback we received from the participant survey. You can find reports on the narrative review and focus group engagement on the NDIS website.

We used feedback from the <u>Participant Survey on Self-Management</u> to help us develop the self-management policy. We also worked directly with participants, their families and carers through focus groups, the NDIS Participant Reference Group, an external Self-management Reference Group, the <u>Independent Advisory Council</u> and <u>Participant First</u>.

Thank you to the NDIS participants, carers, and family members who participated and shared their experiences about self-management.

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 managed) or a registered Plan Management provider (Plan managed) 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.

2. Participant Survey

Participants and nominees were asked to complete a short online survey to help us better understand the:

- · benefits of self-management
- challenges for participants who self-manage
- supports and resources that would help participants self-manage their plans

The survey was available on the NDIS website from 10 February 2022 until Monday 14 March 2022. We promoted this survey through various stakeholder networks, including the <u>Disability Representative and Carer Organisations Forum</u>, our newsletters, social media channels and Partners in the Community. Monash Health Human Research Ethics Committee approved the survey.

We received 806 unique online survey responses from participants (45 percent) and nominees (55 percent). Nominees answered the questions in relation to the person that they support. Almost half of the survey responses were from participants or nominees in New South Wales and Victoria (49 percent). Most of the participants were between 45-64 years of age (63 percent).

The most common disabilities represented in the people who completed the survey were Autism (18 percent), intellectual disability (16 percent), physical disability (16 percent) and neurological disability (14 percent). More than one disability type could be selected.

Participant and nominee demographics

Who responded	Number	Percentage of total
Participant nominees who are currently self-managing	388	48%
Participants who are currently self-managing	314	39%
Participant nominees who have previously self-managed	13	2%
Participants who have previously self-managed	11	1%
Participant nominees who have never self-managed	37	5%
Participants who have never self-managed	43	5%

Age of the participant (years)	Number	Percentage of total
15-18	4	1%
19-24	12	1%
25-34	30	4%
35-44	128	16%
45-54	246	30%
55-64	267	33%
65+	115	14%
Blank	4	1%

Disability Type	Number	Percentage of total
Acquired Brain Injury	46	4%
Autism	223	19%
Cerebral Palsy	60	5%
Developmental delay	48	4%
Hearing impairment	44	4%
Intellectual disability	191	16%
Psychosocial disability	71	6%
Vision impairment	59	5%
Other physical disability	193	16%
Other sensory disability	55	5%
Other neurological disability	163	14%
Other	51	4%

Note: the total listed in this table exceeds the total number of survey responses, this is due to respondents selecting multiple disability types.

Participants that identify as belonging to the following communities	Number	Percentage of total
Aboriginal and Torres Strait Islander	22	1%
Culturally and Linguistically Diverse (CALD)	48	6%
LGBTQIA+	55	7%

Location of the participants	Number	Percentage of total
South Australia	72	9%
New South Wales	193	24%
Western Australia	89	11%
Victoria	201	25%
Northern Territory	8	1%
Australian Capital Territory	1	0%
Tasmania	16	2%
Queensland	146	18%
Blank	80	10%

3. What we heard

The survey results show a correlation between having experience of self-management and a positive interpretation of the benefits of self-management. The most significant benefits for those with experience of self-management were being able to choose registered or unregistered providers and using funding flexibly to get better outcomes.

The results also showed that participants and nominees that had self-managed in the past identified that having the time to do administrative work was the most significant challenge. Those that had never self-managed identified that the most significant challenge was getting support to self-manage when they needed it.

Participants and nominees also provided feedback on the types of support and resources that would help them self-manage their plans. This included:

- Information sessions and training
- Video tutorials
- Access to mentors and expert organisations.

This feedback will be used to inform ongoing improvements to self-management resources and the implementation of the self-management policy.

3.1 Benefits of self-management

We asked participants and their nominees about what they thought were the most important benefits of self-management.

We did this by asking them to rate the following benefits as providing 'no benefit', a 'small benefit' or a 'big benefit':

- Funding flexibility
- Understanding budget
- Controlling supports
- · Choosing any provider
- Changing providers
- Employing their own staff

All groups of respondents rated these options as a significant benefit. However, participants and nominees with experience of self-management gave all of these identified benefits higher ratings than participants and nominees without self-management experience.

All groups of respondents reported being able to choose any provider to deliver supports was a significant benefit to self-management. However, this was the highest rated benefit by participants and nominees that were currently self-managing their funding (94 percent).

Participants and nominees who were currently self-managing their plans reported directly employing workers as the least beneficial part of self-management (with only 66 percent selecting this as a 'big benefit').

Table 1: What are the most important benefits of self-managing?

Answer	Currently self- managing	Previously self- managed	Never self-managed
Funding flexibility			
Big benefit	90%	88%	49%
Small benefit	6%	13%	31%
No benefit	2%	4%	10%
Understanding budget			
Big benefit	86%	50%	36%
Small benefit	9%	38%	24%
No benefit	1%	0%	28%
Control supports			
Big benefit	85%	67%	25%
Small benefit	10%	4%	28%
No benefit	3%	25%	36%
Any provider			
Big benefit	94%	83%	60%
Small benefit	4%	8%	19%
No benefit	1%	0%	11%
Change provider			
Big benefit	86%	71%	49%
Small benefit	8%	13%	23%
No benefit	2%	8%	18%
Employing own staff			
Big benefit	66%	71%	36%
Small benefit	11%	13%	25%
No benefit	11%	13%	24%

3.2 Challenges for participants who self-manage

We asked participants and their nominees about what they thought were the biggest challenges of self-management. We asked them to rate the following challenges as being 'no challenge', a 'small challenge' or a 'big challenge':

- Rights and responsibilities
- Budget tracking
- Knowing what can be purchased
- Knowing what supports cost
- Finding and arranging supports
- Processing payments
- Keeping records
- Using the myplace portal or my NDIS app
- Support with self-management
- Time spent on administration

Overall, participants and nominees who had experience in self-management gave all these challenges lower ratings than participants and nominees who had never self-managed. For example, only 7 percent of participants and nominees who were currently self-managing rated making payments as a significant challenge, but that increased to 46 percent of those with some self-management experience in the past, and 64 percent of respondents who had never self-managed their funding. There were similar trends for how respondents rated the challenges of keeping records, using the mobile app and tracking their budgets.

Participants and nominees who currently self-manage identified that finding the right supports and navigating what can and cannot be purchased as the most significant challenges.

Participants and nominees that had self-managed in the past identified that having the time to do all of the administrative work was the most significant challenge. Those that had never self-managed identified that the most significant challenge was getting support when they needed it.

Table 2: What are the biggest challenges of self-managing?

Answers	Currently self- managing	Previously self- managed	Never self- managed
Rights/responsibilities			
Big challenge	18%	50%	53%
Small challenge	47%	25%	31%
No challenge	33%	25%	13%
Budget tracking			
Big challenge	9%	46%	60%
Small challenge	35%	29%	31%
No challenge	55%	25%	8%
Knowing what can be purchased			
Big challenge	27%	54%	60%
Small challenges	53%	29%	33%
No challenge	19%	13%	3%
Knowing support costs			
Big challenge	12%	25%	54%
Small challenge	37%	54%	33%
No challenge	49%	21%	11%
Finding/arranging supports			
Big challenge	32%	50%	60%
Small challenge	41%	29%	23%
No challenge	26%	17%	15%
Payment processing			
Big challenge	7%	46%	64%
Small challenge	22%	25%	26%
No challenge	71%	25%	9%
Keeping records			
Big challenge	7%	50%	61%
Small challenge	32%	29%	26%
No challenge	60%	17%	10%
Portable app usage			
Big challenge	6%	21%	44%
Small challenge	25%	42%	33%

Answers	Currently self- managing	Previously self- managed	Never self- managed
No challenge	63%	25%	18%
Support with self-management			
Big challenge	22%	58%	69%
Small challenge	34%	25%	18%
No challenge	37%	8%	6%
Administration time			
Big challenge	21%	71%	68%
Small challenge	40%	21%	21%
No challenge	37%	0%	5%

3.3 Supports and resources to help participants selfmanage their plans

Only 10 percent of those currently self-managing their plans reported getting help from support coordinators, and 13 percent of participants and nominees who had self-managed in the past reported getting help from plan managers.

Participants and nominees who were self-managing considered video tutorials, information sessions, and the NDIS website as the most useful resources in learning how to self-manage. This group reported that the least helpful strategies were self-managing part of their plan or self-managing for a shorter period.

Participants and nominees who didn't have self-management experience reported regular check-ins, mentoring, and support to try self-management as the most helpful ways to learn how to successfully self-manage.

Participants and nominees that have self-managed in the past, or those that have not self-managed, found the majority of learning resources helpful.

All respondents reported that the least helpful resource is information on social media.

Table 3: What would be helpful when learning how to self-manage?

Answers	Currently self- managing	Previously self- managed	Never self-managed
NDIS website			
Very helpful	36%	50%	24%
Helpful	46%	29%	48%
Not helpful	11%	13%	18%
Information and training sessions			
Very helpful	40%	63%	41%
Helpful	40%	25%	29%
Not helpful	12%	8%	14%
Video tutorials			
Very helpful	41%	63%	29%
Helpful	40%	29%	38%
Not helpful	9%	8%	11%
Starting small			
Very helpful	10%	42%	39%

Answers	Currently self- managing	Previously self- managed	Never self-managed
Helpful	25%	33%	30%
Not helpful	48%	21%	14%
Chance to try			
Very helpful	11%	38%	43%
Helpful	27%	38%	23%
Not helpful	44%	13%	14%
Regular check-ins			
Very helpful	28%	46%	49%
Helpful	39%	21%	26%
Not helpful	23%	33%	9%
Help from organisation			
Very helpful	27%	63%	41%
Helpful	32%	21%	29%
Not helpful	28%	13%	10%
Self-management mentor			
Very helpful	37%	58%	45%
Helpful	36%	38%	15%
Not helpful	17%	4%	18%

Table 4: What would help you to self-manage?

25% 42% 21% 38% 38% 21%	25% 44% 18% 33% 36%
42% 21% 38% 38%	44% 18% 33% 36%
42% 21% 38% 38%	44% 18% 33% 36%
21% 38% 38%	18% 33% 36%
38% 38%	33% 36%
38%	36%
38%	36%
21%	4.407
	14%
50%	34%
25%	35%
17%	11%
67%	43%
25%	25%
4%	13%
50%	53%
42%	30%
8%	6%
63%	45%
29%	33%
8%	11%
	49%
50%	26%
	50% 42% 8% 63% 29% 8%

	Currently self-	Previously self-	
Answers	managing	managed	Never self-managed
Not helpful	21%	13%	11%
Employee management	0%	0%	0%
Very helpful	26%	50%	48%
Helpful	32%	42%	19%
Not helpful	28%	8%	13%
Facebook, Instagram, and Twitter			
Very helpful	13%	17%	6%
Helpful	28%	38%	26%
Not helpful	44%	46%	49%
Budget tools or accounting programs			
Very helpful	31%	54%	48%
Helpful	34%	33%	25%
Not helpful	24%	8%	9%
Online chat or phone about SM			
Very helpful	42%	54%	51%
Helpful	36%	38%	23%
Not helpful	12%	8%	9%
My place portal or NDIS app			
Very helpful	34%	67%	46%
Helpful	32%	25%	21%
Not helpful	16%	4%	6%

Respondents were asked what could make paying for supports easier. Participants and nominees that are currently self-managing reported that the most beneficial improvement would be the ability to pay providers directly from their NDIS budget (49 percent of respondents said this would be very helpful). In this group, the least helpful was training in collecting and organising receipts and invoices, with only 12 percent rating this as very helpful.

Participants that previously self-managed reported that the most helpful improvement would be training in collecting and organising receipts and invoices, with all respondents in this group rating this option as very helpful. However, nominees in this group preferred the ability to link invoices and receipts to payment requests.

Table 5: What would make paying for your supports easier?

Respondent	Participants		Participant nominees	
Answer	Currently self- managing	Previously self- managed	Currently self- managing	Previously self-managed
Notification: Payment				
Request processed/money is				
paid into nominated account				
Very helpful	28%	64%	28%	54%
Helpful	36%	27%	35%	46%
Not helpful	26%	9%	27%	0%
Making payment directly to providers from their budget				
Very helpful	49%	73%	51%	54%

Respondent	Participants		Participant nominees	
Answer	Currently self- managing	Previously self-managed	Currently self- managing	Previously self-managed
Helpful	22%	9%	24%	38%
Not helpful	16%	9%	13%	8%
Linking invoices and receipts to Payment Requests				
Very helpful	37%	64%	43%	62%
Helpful	27%	18%	29%	31%
Not helpful	20%	9%	15%	0%
Training: collecting and organising receipts and invoices				
Very helpful	12%	100%	13%	31%
Helpful	32%	18%	34%	54%
Not helpful	44%	9%	42%	8%

Respondents were asked what would help when deciding what to buy and how much to pay. Participants and nominees that are currently self-managing reported that information about the NDIS Pricing Arrangements and Price Limits as the most helpful option, with 81 percent rating this as very helpful or helpful.

Participants and nominees who have self-managed in the past, or those that have not self-managed, found the majority of options helpful.

Table 6: What would help you when deciding what to buy and how much to pay?

Answers	Currently self-managing	Previously self-managed	Never self- managed
Information and guidance from the NDIS			
Very helpful	32%	42%	35%
Helpful	49%	46%	45%
Not helpful	12%	13%	9%
Online networks where I can find, compare			
and review providers Very helpful	36%	33%	53%
Helpful	43%	63%	28%
Not helpful	13%	4%	9%
Talking to other participants to find what work for them	S		
Very helpful	31%	50%	38%
Helpful	42%	42%	43%
Not helpful	17%	8%	10%
The ability to try out supports/change them if they are not right for me			
Very helpful	49%	67%	61%
Helpful	38%	25%	23%
Not helpful	8%	8%	6%
Information on Facebook, Instagram and Twitter			

Answers	Currently self-managing	Previously self-managed	Never self- managed
Very helpful	13%	17%	8%
Helpful	29%	33%	24%
Not helpful	41%	46%	54%
Information about the NDIS Pricing Arrangements and Price Limits			
Very helpful	44%	63%	49%
Helpful	43%	29%	36%
Not helpful	9%	8%	9%
A Support Coordinator or Plan Manager			
Very helpful	26%	71%	63%
Helpful	26%	17%	25%
Not helpful	36%	8%	8%
A NDIS Planner or Local Area Coordinator			
Very helpful	20%	46%	40%
Helpful	38%	25%	29%
Not helpful	29%	29%	16%
An online chat or phone service for self- managers			
Very helpful	37%	50%	41%
Helpful	40%	29%	33%
Not helpful	13%	17%	15%
Other organisations that offer support to self- managers			
Very helpful	24%	50%	34%
Helpful	32%	33%	31%
Not helpful	25%	8%	18%

Participants and nominees that have experience with self-management have a greater awareness of the NDIS Code of Conduct and the NDIS Quality and Safeguards Commission compared to other NDIS safeguards, such as guidance on NDIS worker screening checks, NDIS Restrictive Practices and Behaviour Support.

Table 7: Are you aware of the following?

Answer	Currently self- managing	Previously self- managed
NDIS Code of Conduct		
Yes	83%	88%
No	17%	13%
NDIS Quality and Safeguards Commission		
Yes	76%	88%
No	23%	13%
NDIS Worker Screening		
Yes	63%	79%
No	35%	21%
NDIS Restrictive Practices and Behavior Support		
Yes	61%	71%

Answer	Currently self- managing	Previously self- managed
No	38%	29%
NDIS Provider Registration and Practice Standards		
Yes	69%	63%
No	29%	29%

All participants and nominees, including those that have never self-managed, advised that if they were unhappy with a support they purchased, their most common strategy would be to address the providers directly. One of the least common approaches would be to do 'nothing'.

Table 8: What would you do if you were unhappy with a support you purchased?

Answers	Currently self- managing	Previously self- managed	Never self- managed
Nothing			
Always	1%	0%	6%
Often	4%	13%	6%
Sometimes	24%	42%	26%
Never	54%	38%	43%
Talk to the provider			
Always	55%	33%	39%
Often	24%	46%	26%
Sometimes	18%	21%	25%
Never	1%	0%	4%
Make a complaint			
Always	17%	4%	18%
Often	14%	33%	15%
Sometimes	53%	63%	45%
Never	6%	0%	10%
Talk to a Support Coordination or PM			
Always	14%	33%	30%
Often	11%	25%	30%
Sometimes	22%	25%	24%
Never	39%	13%	5%
Talk to my Planner/LAC			
Always	10%	13%	15%
Often	8%	8%	16%
Sometimes	31%	25%	30%
Never	41%	50%	24%
Talk to family/friend			
Always	27%	33%	33%
Often	25%	17%	20%
Sometimes	30%	38%	26%

Answers	Currently self- managing	Previously self- managed	Never self- managed
Never	13%	13%	14%
Cancel the support or go somewhere else			
Always	27%	13%	19%
Often	32%	38%	25%
Sometimes	33%	46%	41%
Never	2%	0%	4%
Contact the NDIS Quality and Safeguards Commission			
Always	7%	4%	11%
Often	4%	8%	4%
Sometimes	35%	63%	29%
Never	22%	17%	21%

4. Outcomes and next steps

We are committed to making it easier for participants, child representatives and nominees to self-manage with the right support and controls in place, including being able to easily change between plan and self-managed.

The new NDIS Self-Management Policy is one way we are working to address the challenges identified by participants and their nominees in this survey.

Overall, the most significant challenges related to finding the right supports, navigating what can and cannot be purchased, finding the time for administration responsibilities, and getting support to self-manage. The new <u>self-management policy</u> helps address these challenges by more clearly explaining the responsibilities participants, child representative and nominees have in self-managing their plan and how we can support and offer guidance to assist in them to meet these requirements.

As we continue to implement the policy, we are focused on improving resources for participants, their families, carers and nominees to help support them to self-manage their funding. This will include:

- Updating the NDIS website to include clear and accessible information on fund management options.
- Updating the existing self-management guide to include more practical advice on how to self-manage NDIS funding.
- Develop training for Agency and Partner staff to provide better support to participants and nominees.

We are also planning to continue working with participants, nominees and representatives from the disability community to:

- Develop a new participant guide about plan management options.
- Develop orientation and training resources for participants interested in selfmanagement.
- Update our internal systems and processes so that the right support and controls are in place for those that are wanting to try self-management.
- Develop targeted approaches to make self-management easier to understand and access for identified cohorts of people who are under-represented amongst selfmanagers.

To be notified of opportunities to be involved in this work or future consultations, you can join Participant First.