Participant engagement in the development of a self management policy

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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 NDIA policies, guidance, practices and priorities are informed by trustworthy and robust evidence so that decisions can be based on an understanding of what is important both for participants and the Agency. Our research is based on a collaborative approach in which we engage with participants and other key stakeholders to address scheme priorities. Our collaborative approach helps us to develop tailored approaches to the translation of the research. This includes developing resources for participants and providers to engage with best practice, as well as for partners in the community and other government departments to understand and apply evidence into their practices.

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## Acknowledgements

The NDIA acknowledges the Traditional Owners and Custodians throughout Australia and their continuing connection to the many lands, seas and communities. The NDIA pays respect to Elders past, present and emerging, and extends this acknowledgement and respect to any Aboriginal and Torres Strait Islander people who may be reading this Report. The Research and Evaluation Branch would like to acknowledge the broader NDIA team and the NDIS Participant Reference Group members who assisted in the development of this participant consultation project. The Branch gratefully acknowledges the NDIS participants, carers, and family members who participated and shared their experience.

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## Contents

[Abbreviations 4](#_Toc113629468)

[Glossary 4](#_Toc113629469)

[Why did we do this engagement activity? 5](#_Toc113629470)

[What did we do? 6](#_Toc113629471)

[Who took part? 6](#_Toc113629472)

[What did we find? 7](#_Toc113629473)

[Making the decision to self manage your plan 7](#_Toc113629474)

[Learning how to self manage 8](#_Toc113629475)

[Using payment systems and processes 10](#_Toc113629476)

[Accessing and paying for supports 13](#_Toc113629477)

[Being responsible and accountable 17](#_Toc113629478)

[What next? 19](#_Toc113629479)

## Abbreviations

**ABN** Australian Business Number

**IAC** Independent Advisory Council

**LAC** Local Area Coordinator

**NDIA** National Disability Insurance Agency

**NDIS** National Disability Insurance Scheme

**PRG** Participant Reference Group

## Glossary

**ABN** The Australian Business Number is a unique number used to identify a business or company to the Australian Government.

**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.

**NDIA-managed** A type of plan management where the NDIA pays providers on behalf of a participant

**NDIS participants** When referred to in the findings includes NDIS participants, family, carers and other supporters who spoke to the participant experience.

**Plan-managed** A type of plan management where the NDIA pays a plan manager who then pays providers on behalf of the participant

**Self managed** 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

## Why did we do this engagement activity?

The NDIS Self management Strategy was developed in 2019 to guide the Agency’s approach to self management. The strategy 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

Since the development of the initial Self management Strategy in 2019, the NDIA has completed the rollout of the NDIS and is transitioning 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, and ensuring better value for participants and the scheme into the future.

The establishment of an effective Self Management Policy will support the Agency to achieve key aspirations and strategic goals outlined in the [Corporate Plan (2022-2026)](https://www.ndis.gov.au/about-us/publications/corporate-plan), [Participant Service Improvement Plan](https://www.ndis.gov.au/about-us/policies/service-charter/participant-service-improvement-plan) and [Participant Service Charter](https://www.ndis.gov.au/about-us/policies/service-charter) including:

* Making plan budgets more flexible so participants can use their funding as they wish.
* Enabling plan flexibility to support participants to make their own decisions on the reasonable and necessary supports they require to achieve their goals (Corporate Plan 2022-2026).
* Making it easier for participants to self manage their plan, with the right support and controls in place.
* Enhancing efficiency and effectiveness of processes and systems.
* Evolving payments and claims processes to reduce manual payment activity and increase information to allow better decision-making for participants.

To support the development of a self management policy, the Policy, Advice and Research Division of the NDIA Policy and Advice Branch and Research and Evaluation Branch undertook a multi-phase process that included:

1. A [narrative review](https://www.ndis.gov.au/community/research-and-evaluation/self-management-research) of the literature to explore the effectiveness and cost 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 ILC projects;
3. Disability sector consultation and engagement, including engagement with service providers and subject matter experts, and focus groups and a survey with NDIS participants or their family, nominee or carer.

This report provides the findings from the focus groups with NDIS participants or their family, nominee or carers, which was undertaken as part of phase 4 of the process. The information collected from the focus groups, presented in this report, directly contributed to the development of the online survey. The results from the survey have been provided in a separate report available on the [NDIS website](https://www.ndis.gov.au/community/have-your-say/participant-survey-self-management).

More information about the development of the policy can be found on the [NDIS website](https://www.ndis.gov.au/participants/using-your-plan/self-management/self-management-policy).

The key aims of the consumer consultation and engagement was to understand what NDIS self management is like for participants, what participants say would help them to make an informed decision about whether to self manage or to enable them to successfully self manage, and how the experience and processes can be improved.

## What did we do?

In September 2021, eight focus groups were conducted with a total 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. Each focus group lasted up to one hour, and were conducted in MS Teams online.

We aimed to talk to 40-60 participants to help reach data saturation on themes and topics (i.e. no new themes arise from the data). Participants heard about the research through the NDIS Participant First Participant Engagement team, and the NDIA website.

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

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. Identifiable information was removed from the focus groups transcripts, and responses were grouped into key themes using computer software (NVivo).

The focus group research was approved by the Monash Health Human Ethics Committee (RES-21-0000-491A).

## Who took part?

Eighteen NDIS participants and 17 family or carers engaged in the focus groups. Three participants were also staff members of the NDIA or a disability organisation. Participants lived across Australia, although most lived in either Victoria (37%) or New South Wales (34%). Most participants (66%) lived in metropolitan areas. Participants had a variety of disabiltiies, including physical disability, intellectual disability, psychosocial disability, or autism. Sixteen participants were currently self managing, eight had previously self managed, and 11 had never self managed.

## What did we find?

In the focus groups participants discussed how they made the decision to self manage. They described what information, training and supports they found helpful, or could be helpful, when deciding and setting up self management. Barriers to self management included needing to have sufficient time and organisation skills to self manage. The flexibility to choose the services and items they wanted to purchase, and how and when they wanted to receive them were positive elements for participants who were currently self managing. Most participants said they found it hard to know what services or items they could and could not claim in their plan, and there was a lack of clear and reliable information available to help make these decisions. Participants gave many suggestions about how to improve the uptake of self management and how to make it easier to self manage, which have been included in this report.

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

*Mary, currently self managing*

### Making the decision to self manage your plan

Participants told us they liked the autonomy and flexibility self management offered, and they were more likely to self manage when encouraged by their plan manager and/or their social circles from the start of their first plan. Participants told us that:

* the process of self managing helped to build their skills and confidence to self manage;
* it 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 needs (e.g. replace a tyre on a wheelchair during the Christmas holidays);
* it can help overcome difficulties in finding suitable providers (e.g. to avoid long waiting lists for NDIS providers, to overcome geographical limitations, and to have flexibility to choose non-NDIS registered providers); and
* it was important to know that self management was an option, and that information was available when deciding whether or not to self manage.

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| “So I just think it [self management] needs to start with a frank and open conversation with the individual.”*Jade, currently self managing*“One, I have a degenerative condition, I require a different piece of ability equipment very quickly. The other reason is I live in rural [state] 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 wanna be waiting months and months for my paperwork to be reviewed. I need the equipment when I need it.”*Veronica, currently self managing* |

There were several suggestions for how participants can be helped to make the decision to self manage, such as:

* Local Area Coordinator (LAC) and NDIA Planners being more experienced in how to promote and explain self management to participants, to remove the fear that self managing was difficult;
* LACs and NDIA plan managers could show participants how to self manage using the myplace portal with a ‘learner’ profile and give example templates for keeping track of invoices and payments;
* participants could have the opportunity to try self management with support for a period of time, with the option to ‘back out’ if they decide it was not right for them; or
* having an opportunity to discuss self management with other participants who are already self managing.

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| “I think one of the biggest problems … some of the LAC's have no idea how to self manage because some of them have never gone into the portal. So it's really hard for them to even explain how to self manage, because there isn’t like [a] dummy one that they - LACs - can play with, so then they know how to show a participant.”*Bella, currently self managing*“From my experience with LACs, they tend to have a few pet plan managers that they try to funnel people through to, and or they try to push people into agency managed. It seemed to be very clique-y… there wasn't a sort of, like, ‘here are your options, you can choose from all these people go and talk to them, see who you like’, it was ‘no, you've got this or this’, and you're like, ‘eww, I don't like either of those’ [laughs]. … So I probably at that time could have self managed or managed for him at that point, but I felt unequal to the task.”*Frankie, never self managed* |

### Learning how to self manage

Participants told us about a few different ways they learned how to self manage. Participants told us:

* learning how to self manage was easier when you already had skills in budget management;
* some participants learned by themselves using the NDIA *Guide to Self management*, or using information from websites or peer support networks (e.g. Facebook pages);
* a small number of participants had access to a plan support co-ordinator who helped them to learn how to self manage;
* some participants had been able to attend an education session or workshop offered by their LAC to learn about self management. For other participants, their LAC did not offer education and support for learning how to self manage; and
* that the NDIS call centre often did not give clear information and support about self management.

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| “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 'cause she actually kind of physically took me through self management and how to set it up and that was really great.” *Priya, currently self managing*“… if you strike the right support coordinator then you know you have a very, a smooth sailing … If you find a good support coordinator then well, you know, you’re home and hosed really. That is key.”*Laura, previously self managed* |

Most participants said that once they had set up their own process, the procedure of self management was relatively simple.

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| “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, like, you know, what/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 managed* |

Participants gave several suggestions about how to support people who want to learn how to self manage, such as:

* having a short course (‘self management 101’) offered as a live workshop, or as online videos to complete at your own pace. Some participants said this should be mandatory for some participants, such as child representatives and parents;
* having access to clear information that showed step-by-step how to do each stage of claiming and record keeping;
* having the opportunity to trial self management for a set period of time (e.g. for 30 days or 3 months), with support and guidance given during this time, where the person offering assistance gently steps back once the self manager becomes more experienced and confident;
* LACs offering education sessions or support to self managers over telephone or email, as they would have better knowledge of what services are available in the local area than the NDIS national call centre; or
* having access to a plan support co-ordinator at the beginning to support them to set up self management processes.

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| “How about like a short course or a short video or a short small group training? I don't know… I think everybody’s situation is different.”*Tia, currently self managing*“I'm not sure that lessons online, videos, are always very helpful because, as someone said before, it's very hard to get feedback on specific questions. But yeah, I think some face to face lessons or… some tutoring or even, you know, putting them in touch with someone else who is self managing in their area to give some help on some of these things.”*Alec, currently self managing* |

### Using payment systems and processes

All participants 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*.

Participants told us about several things they liked about the self managing payment system and processes, such as:

* doing the self managing process yourself meant that you could easily keep track of what was left in your budget and how it was being spent;
* claims were usually processed within 24 hours of submission; and
* self managers could make sure that their providers were paid quickly.

Some participants said that the process of self management can be harder if you are not a naturally organised person. There were many things participants did not like about the payment system and processes. They said that:

* it can be time consuming to upload documents to the myplace portal;
* it can be clumsy to use your own records, the myplace portal and the my NDIS mobile app all at the same time;
* it was not easy to fix mistakes made in the myplace portal;
* it made it hard to keep track of payments if you were self managing for more than one participant, especially if the participants saw the same provider (e.g. a therapist seeing two children from the same family who each had an NDIS plan); and
* there were times when they could not access their budget because of technical glitches, or when a participant turned 18 and the parent lost access while waiting for the participant to get access.

“With the portal, I found that fairly easy to use, but it is quite tedious because once I put the payment request in, you put in the provider, the amount, etc. then I have to come out of that and go into the next one to view all your payment requests and upload the receipts and then upload the invoice, so I feel like I'm always double handling. So that's probably something that takes a lot of time. So when you've got four to five providers per child, times two, I'm dealing with ten different lots of invoicing and that comes in pretty much weekly, fortnightly. It can be, it can be challenging”

*Monique, currently self managing*

“I don't even think there was an option then to upload your receipts or attach a receipt with the claim… so that you could just upload it, hit submit, done, dusted. Don't have to worry about keeping it up. Receipts fade, you know things happen so to not be able to have that digital side of it and then have to go back and go, ‘Oh, what was that amount?’ Go check it with an invoice. It was impossible. And then if you're self managing on behalf of, like, I got 4 kids that were participants, it was impossible to be able to do that. Or and you couldn't ask for like a financial administrator or assistance or supports to be able to pay someone. So you're paying out of pocket for a bookkeeper or for administration, for people to track and log.”

*Anika, previously self managed*

“I suppose my concern with self management is that everything goes through the portal and I did have a friend whose son turned 18 and it took them three months to get her into the system or, not three months, three weeks or whatever. So you can't actually access any funds because it's all through the portal. Whereas with the plan manager you do have another person who's, who you can contact … they can do something. We haven't had that trouble, but that was that was just my concern. It's like if the Internet dropped out or something, then the funds are tied up to whether you can log into the portal.”

*Frances, never self managed*

Participants who had never self managed before were worried about:

* having to use household funds to pay for services when waiting for a claim to be paid;
* whether money coming in and out of your bank account affected a bank’s decision to give you a loan, and whether self managed funds are income on your tax return; and
* knowing how to manage the process, and how and what types of records they need to keep in case NDIS asks to see them.

“That would be my concern as a, you know, single parent, carer pension, with two adult disabled children, that you would be constantly overextending yourself, looking at your paychecks, waiting for them to come in. Looking at, you know payments for therapies to come in, and you would always be struggling financially, or at least mentally, about your finances.”

*Frankie, never self managed*

“And the other thing is just that probably being out of pocket, so when you’re paying amounts that’s, you know, $250 for therapy it adds up. You might be a $1,000 out of pocket, with all you’re claiming, so you need to have like a kitty or something to, you know, start you off and to keep it, and how to keep an eye on that.”

*Frances, never self managed*

“Hopefully, if you had $10,000 in, then you've paid providers with the 10,000 and you've got back your 10,000, hopefully you don't pay any tax, I'm guessing would, that would be the way it would work.”

*Denver, never self managed*

“Yeah, but then if you applied down the track for a home loan or something like that, they wanna see all your accounts and how does that, how does that look? You'll have to show ‘em that, your NDIS account, and does that go against you?”

*Aalia, never self managed*

“It does seem to be a lot, too much work, especially if you have sometimes limited capacity for processing information, which sometimes I do, so just being able to put the information somewhere and have someone say yes, that's OK, that's part of your plan, that's great, paid, not a problem. I would find things like holding on to receipts and documents and things like that would be difficult because, you know, you can only hold on to so much paperwork and receipts fade if they're, you know, photosensitive paper, that sort of thing. Yeah, you can, you can end up in trouble if you don't have everything documented and that needs to be an easy process at the point of user.”

*Frankie, never self managed*

Participants suggested several strategies to make the self management systems and processes easier, including:

* having access to clear information that showed step-by-step how to do each stage of claiming and record keeping. This information could be given as written guides or short videos;
* having access to example templates (e.g. Microsoft Excel spreadsheets) to see how claiming and payment processes can be recorded;
* the option to upload from your mobile phone the photos of receipts and invoices;
* to be able to access information when learning how to self manage (e.g. online videos, guides, learning workshops) and to ask questions once they were getting more experience with self management;
* the opportunity to learn ‘tips and tricks’ that other participants use which could help simplify the processes; or
* having an option where the NDIS pays service providers directly for each invoice.

“And you know you have somebody, a specific person who you can call or ask online, ‘What I need to do with that?’, or ‘how is that going?’ And probably the other, the last thing would also be if you’re not sure it gets paid, can I ask first or do I put it in and hope for the best?”

*Marc, never self managed*

### Accessing and paying for supports

Participants told us that they liked how self management gave them flexibility to choose their own services and providers in ways that best suited them, and at a reasonable cost. They told us it is important to have timely access to the right providers that matched their needs, and to form and keep good relationships with them. What participants told us about accessing and paying for supports has been summarised below in three key areas:

1. Getting access to services at a good price
2. Making and keeping good relationships
3. Knowing what is permitted in the plan and who is best to provide it

Participants told us they used several ways to get information about how to use their plan, finding services and providers, and managing provider relationships. They told us they use a mixture of the following information sources and processes:

* NDIS Plan Management Guide, the NDIS website and myplace portal;
* Online support groups (e.g. Facebook), although many participants said they were cautious with the information shared on these sites, and other participants completely avoided online sites that were not linked to the NDIS or an NDIS provider;
* calling the NDIS National Call Centre;
* asking their LAC or support co-ordinator for advice as local area knowledge was seen as important for some people;
* experience, ideas and advice shared by friends, family and peers; and
* use of online labour hire platforms (e.g. Mable, HireUp).

Participants had some suggestions for how the NDIA could support self managing participants with accessing and paying for supports, including:

* a 1800 number dedicated to self management advice and support that is serviced by knowledgeable staff;
* a live Chat Bot function to answer basic questions, which can refer a person to other sources of support (e.g. an LAC or similar) for more complicated questions;
* an online forum for discussion, moderated by the NDIA, so that only correct information is provided;
* assistance to help decide what can and cannot be claimed in your plan, having access to a decision matrix using a traffic light system similar to a risk matrix (red = no, orange = maybe, green = yes); or
* participants who are not currently self managing wanted to have the opportunity to ask questions of participants who are currently self managing about how they found the transition from Plan and/or Agency managed.

#### Getting access to services at a good price

Participants said that finding and choosing their own services to purchase from their plan budget meant they could get value for money, and “more bang for your buck”. By not being limited to NDIA-registered providers, they said that there were more providers to choose from in their local area, and sometimes they could negotiate a lower price than the maximum fees in the NDIA price guide. This was very helpful if you lived in an area where there are few providers (e.g. in rural and remote Australia) or long waiting lists (e.g. psychologists).

“… so that’s why we went to self management because it was a lot harder [to find NDIS registered providers] and then if you did find the provider, there was like a nine month waiting list.”

*Bella, currently self managed*

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

*Sally, currently self managing*

“I also found it [self managing] was more economical. You could actually get quotes for physiotherapy and, like, which turned out to be a lot cheaper than when they found out that you had NDIS funding.”

*Laura, previously self managed*

Participants said it was easy to check that invoices coming in matched the services received when you were self managing. This was more difficult when you were self managing for someone that you do not live with. Participants said that it was important to have providers who were trustworthy, and who would provide the service at the agreed price. Two participants said that a provider had made a mistake on their invoices by charging for services not delivered. Both participants felt they had taken appropriate action to fix this.

Some participants were worried they would lose the flexibility of choosing overseas providers if the provider supplying the product or service must have an Australian Business Number (ABN).

“… one of the services I have funding for is actually from overseas so they don't have an ABN so I don’t quite know, like, if they become mandatory over on the portal then I probably won't be able to use that service anymore.”

*Jade, currently self managing*

#### Making and keeping good relationships

Participants said that self managing helped them make and keep good relationships with providers. They said:

* they really liked being able to create their own team of providers;
* being able to choose the provider tends to give more certainty of the service being delivered when and how it is wanted;
* it is possible to try different support workers and find those who worked best with the participant, and to not be stuck in a contract with different workers often coming from different agencies;
* creating relationships with the same team of providers meant they had to retrain new staff less often, and reduced how often a participant would need to re-tell personal traumatising information; and
* self managed participants can make sure their providers were not waiting very long for invoices to be paid, and self managers can check that the invoices matched the services they actually provided.

“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. 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 managing*

“I found with agency managed [I] was very limited to the providers I was given, and it seemed to be like a revolving door. You would start to get to know a therapist and then they would leave, and then you get a new one, and get a new one, and that's very difficult when you have children on spectrum who find it very difficult to manage change… So I think being able to self manage and pick your provider gives you more certainty of service and, you know, the ability to manage that relationship much better.”

*Monique, currently self managing*

“I love the flexibility. I've been able to keep support workers for years, rather than getting random support workers from various agencies. I have also been able to try out different support workers or different services and haven't had to sign any type of contract. I can just get somebody who's good at something for a short period of time. And not use them again for ages.”

*Mary, currently self managing*

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“So it's basically between… myself and the LAC at the beginning of the process and then just directly with any people that I engage. So just the shorter lines of… when you deal with a lot of people you’ve just gotta add another person to the mix. So I'm glad to not have to add another person to the mix and provide those explanations. I’ve got a bit of trauma around medical intervention, medical management, so being self managed suits that trauma response that I get having to explain myself to people.”

*Tia, currently self managing*

#### Knowing what is permitted in the plan and who is best to provide it

Participants told us it was important to understand what had been included in their plan, the types of services and supports needed to help reach plan goals, and what services and providers are available in the participant’s area. They told us:

* during the planning stage, it is important to have enough information and knowledge to make sure what is needed is included in the plan.
* it can be difficult to decide what are the most appropriate services and supports to help them reach their plan goals, and what types of providers are most suitable to provide these. They said that the NDIS National Contact Centre and LACs are not always able to help answer this for them.
* where a participant wanted to use a provider as an innovative support, they were worried that this may be questioned (e.g. where the provider had an ABN that was associated with a business not directly related to the service they were providing);
* it can be difficult to find out what providers were available in their area and if they were qualified to provide a service.
* recruiting and interviewing providers can take up a lot of time, and it can be hard to know if they are qualified for the role. Some participants chose to use NDIS registered providers as they felt confident that the worker was accredited for the service that they were providing.
* being plan managed does not make it easier to get appropriate services if the plan manager lacks knowledge of local services, or does not know if a provider is suitable for a participant’s needs. But having experience with self management often means a participant is more confident to ask questions of their plan manager.

“… some of the people that I employ their businesses, like they're doing support work for me, but one of the people I work with, in her other life, is a tarot card reader. So yeah, I'm afraid if I put her ABN in, because she does support work for me, we, you know, do some fitness things and she helps me organize different bits around my house, they’d be like ‘why are you going and getting tarot reading?’ It's like, I'm not, she's just being employed as a support worker.”

*Mary, currently self managing*

“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 managing*

“I haven't found a difference between plan managed and self managed because the plan managers actually don't help with anything. I think they're a bookkeeping service and they don't actually have knowledge of what services are available in your local area.”

*Priya, currently self managed*

### Being responsible and accountable

In all focus group discussions, participants spoke from the point of view that being self managed meant they were more responsible and accountable for the activity in their plan budget compared to Plan Managed or Agency Managed.

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

*Mathias, previously self managed*

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 (e.g., respond to COVID restrictions)
* 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

“I'm fairly financially minded so we set up a spreadsheet, run with it, account myself for it, keep the details I need. I know exactly where it is in any single moment in time, so the actual control of it is, it's crucial to me.”

*Tia*, *currently self managing*

“I like to be able to use my brain and that's what self managing helps do, you know, it kind of takes me out of my body, in the sense, it puts me in my brain and I can focus on that.”

*Nellie, currently self managing*

“Oh, it was coordinating my own finances [that I liked]. That was the part I loved. I loved being able to manage that. … It was too much work doing plan managed, it was the opposite to what someone else had said. There was way too much to-and-froing for me. It was faster for me to self manage [my plan].”

*Peli, previously self managed*

“I don't know if it's really manageable when you have executive functional issues, that's where I sort of sit … on the rails of whether or not giving someone else all the responsibility is good for me, or whether you know it's a self empowerment thing to do it for myself.”

*Frankie, never self managed*

For some participants, the added responsibility and accountability of self management was a negative. They told us that:

* being responsible for administering the plan, maintaining their records, and recruiting providers took too much of their time;
* they were not good at managing their personal finances, so having to manage a plan budget was too overwhelming;
* they did not like the possibility of making a mistake or wrong decision, as they thought this would mean they would have self management taken away from them, or that they would be unable to repay thousands of dollars if they made a mistake.

Participants who were confident with self management said they had good systems and processes in place, were generally organised and good at problem solving, were motivated, and had existing skills and supports available at the time of setting up self management. Participants who were currently self managing said that they would like support and input from the NDIA to self manage without too many ‘rules and regulations’ complicating the process.

Participants who had never self managed were concerned about how much time it takes to self manage. There was also a sense of not being comfortable with the added financial responsibility of self management, and a fear of making a costly mistake.

“The time it takes to chase up and collate all the invoices and record keeping. As we, the family, all work full time, we do not have the capacity time-wise to self manage the whole NDIS plan.”

*Adele, never self managed*

“We don't wanna find out that we've done something wrong down the track and, you know, seven years later they’re after, you know, $20,000 'cause we did something wrong and we were completely unaware.”

*Frankie, never self managed*

“If you're not organised, then that's probably where you need a little bit of help, you know, to get it set up and keep it running smoothly so that you don't have the worries that, you know, all of us have about risk and personal liability and ‘have I chased that?’, you know, in the middle of the night thinking ‘have I paid that’ or ‘have I done that’ so that it can all be ticked off so that you know it's been taken care of, 'cause it all lands on you.”

*Frances, never self managed*

“I see about [sic] the same problem because how do you need to secure that the bills get paid if you self manage it? And is there a risk if you approve the wrong bill and then the NDIA comes and says no, it doesn't get paid, you know, where is there the issue for you? Or is there even a liability for you that you can be fined because you should never have put it through or something like that?”

*Marc, never self managed*

## What next?

The insights provided in the focus groups, as summarised in this report, were used to develop an online survey for NDIS participants and their supporters to further explore the key themes with a wider range of participants, including making the decision to self manage, learning to self manage, using payment systems and process, and accessing and paying for supports. The results of the survey have been provided in a separate report.

The findings from the evidence reviews, focus groups and survey, and with input by the Participant Reference Group and Working Groups have all informed the Agency’s development of a self management policy.