

NDIS Quality and Safeguards Commission

Quality and Consumer Consultation Insights Report: Information

December 2023



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The more I know, the more empowered I am

The National Disability Insurance Scheme (NDIS) was designed toward the provision of a stronger voice for consumers shaping the services they receive, and who provides them. The NDIS Commission and the National Disability Insurance Agency (NDIA) work cooperatively with a number of intermediaries to support people with disability who engage with the NDIS.

Information empowers NDIS participants by providing clear understanding of their rights and the services available to them. Information enables participants to exercise choice and control over their supports. Informed consumers play a vital role in the decision-making process.

Key Insights

The more I know, the more empowered I am

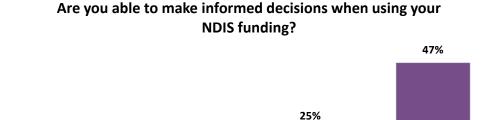
- Participants shared that there were a number of complexities to being empowered, with many telling us they did not have enough information to manage their NDIS plan or to make informed decisions when interacting with providers.
- Providers felt they were responsible for providing information to participants as consumers, although did not always have the right information available.
- Participants primarily used recommendations and trusted networks. Recommendations from people with lived experience and family connections were highly valued. Peer recommendations and experiences of those who work in the sector, including current workers or support coordinators, were highly regarded.
- Participants were highly in favour of implementing new systems that recognised the quality and safety of the service to help inform choice.
- Participants wanted access to better online systems to find providers and information about services, including geographic location, services offered, participant reviews, staff qualifications and training/specialty.

Provider definition

In this report, we have used the word 'provider' as a general description of any person or entity delivering NDIS services and supports to participants. We encountered a variety of service relationships and observed them to be varied (and sometimes complex). When participants told us about a 'provider' of services, this included workers considered as an employee; contractors; subcontractors; casual employees; organisations; or sole proprietors.

More definitions and terms used in this report can be found <u>here</u>.

47% of the participants who completed our survey said they had enough information to make an informed decision. However, many explained a number of complexities in being supported and empowered.



21%

Other

8%

I don't know

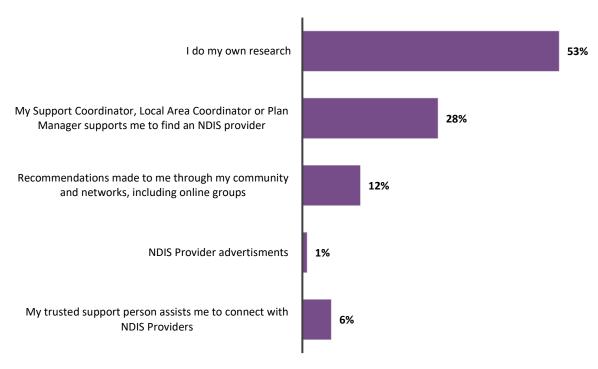
Those who selected the 'other' option told us that limited choice and control and relying on supports for information added to the complexities

No

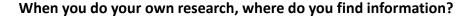
Yes

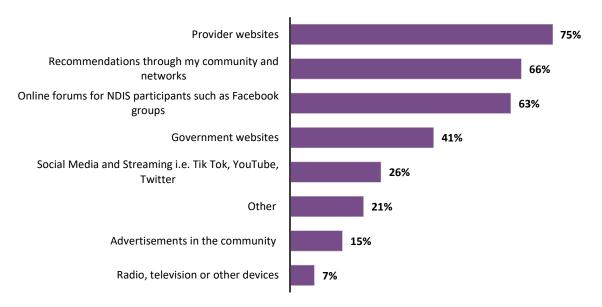
Most (53%) of the participants who completed our survey did their own research to find information.

Where do you go for information about accessing NDIS supports?



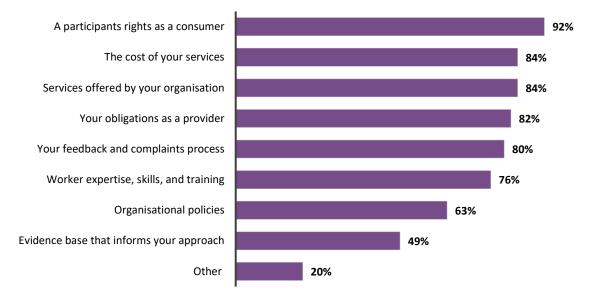
Provider websites was the highest selected avenue to find information, followed by recommendations and online forums.





Providers told us they provide a range of information to participants. However, 43% stated they did not think providers published enough information for participants to make informed decisions.

What information is provided by your organisation to participants?



Navigating the current system is challenging

Participants told us that accessing information often presents a number of challenges. Some participants shared with us that they struggle to comprehend the wealth of information available, especially coming from a number of different sources and not a single point of truth. Participants noted that there is also a high volume of technical terms and jargon within the NDIS, which is further complicated by inconsistent definitions for key terms between agencies and providers:

"NDIA information often has contradictions, does not match legislation and is not specific enough to make well-informed decisions."

Participants that are part of diverse communities, found particular difficulties in navigating the system. Culturally and Linguistically Diverse (CALD) and First Nations participants often encountered language barriers that affected their ability to understand detail. Information was not always readily accessible in their preferred language or did not consider cultural nuances. Additionally, participants told us information was not targeted to particular cohorts and their needs. For example, young participants expressed frustration with being grouped with older people:

"Have an understanding that people who are a younger with disability are going through a different time and system to the older people with disability so they may see things differently."

Participants shared that the reliance of digital channels for information access also presented problems for those with limited digital literacy. Accessibility concerns in the provision of information was also raised for those with vision, hearing and cognitive disabilities. Not providing information in accessible formats often meant participants had to rely on others to gather information for them, leading them to feel disempowered:

"Should not have to rely on people having guardians to speak for them to get their needs met."

Participants told us that they have limited knowledge about the roles and functions of the NDIS Commission and, to a lesser extent, the National Disability Insurance Agency (NDIA) that made navigating the system difficult. This included limited understanding as to what the relationship between the agencies were, the responsibilities and differences of each were, and who was best to approach. Participants shared that knowing about the scheme was important as it empowers them to understand their rights, make informed choices, and advocate for their needs:

"Having knowledge of how the system works makes you feel safe. Knowledge is power."

Participants that had engaged with the NDIS Commission did not always have positive experiences. Participants stated that the lack of personalised support from the NDIS Commission made it feel irrelevant. Other participants spoke of using the resources provided by the NDIS Commission to support them in asserting their rights. Many participants were supportive of the regulatory functions and the need for the NDIS Commission to help participants know where to turn in case they had concerns about service quality, safety, or rights violations:

"The NDIS Commission is necessary. Every service needs a 'watchdog'."



I need more than service information

Participants told us about the need for a deeper understanding of service providers beyond just the services they offer. Participants wanted greater access to comprehensive organisational policies, especially in relation to consistent information handover, guaranteeing continuity and quality of care. Participants told us that a provider's service quality is measured by the presence of clear communication protocols and detailed service agreements; their absence raises concerns about the provider's commitment and professionalism. Additionally, participants highly valued operational transparency, and wanted more insight into any internal changes or developments that might impact their service experience:

"Learning about services and keeping up to date with changes in the organisation that may impact on clients and carers."

Participants emphasised the importance of communication between service providers and participants regarding the scope, details, and nuances of the services offered. This included clarity of approaches to therapeutic supports and the level of experience providers had. Participants were keen to be apprised of finer details of a provider, such as costs associated with services, the training level of all staff, and the service's track record:

"Information from providers/support workers about what their experience is working with different clients could help with choosing the supports."

Participants shared they had trouble when engaging services and being able to comprehend the information they were given. Participants expressed a clear preference to have processes, terms, and conditions explained plainly and in easy to read formats. Participants told us they found themselves signing agreements or documents without understanding what they were signing. They found organisations did not take the time or invest in actually breaking information down and supporting them with decision-making. This was not just intimidating for participants but also disempowering:

"Having the service agreement explained to me, not getting me to sign something that I do not understand."

Participants said do not just want to be passive recipients; they want to be informed, empowered partners. Participants told us they do not just want information—they also seek guidance. Having

oversight of and understanding the various service options available to them is seen as crucial to choice and control. Participants expressed that it is not just about knowing what exists, but also understanding what aligns best with their specific needs and goals. Participants want to be informed about all facets of a service, even from aspects that might not directly align with their immediate goals:

"Know about all the services available even if they (provider) don't think they are relevant to the identified goals."

Participants told us about the significance of having a personal interaction. Meeting with service providers and having face-to-face interactions helped build a foundation of trust and clarity. This was particularly important for parents who needed to make sure providers understood their child's needs and would be the right fit, which was hard to determine via email. Participants said personal interactions allowed for questions to be asked, where providers could be upfront about what they can offer including the scope of services, costs, and roles/options of staff:

"Knowledge and information and connection and for providers to meet them and explain about their services and the role of staff."

Never confident I have found all the information

Participants reported that having confidence about whether information is trustworthy is crucial for NDIS participants as they make decisions about service providers and supports. Participants generally expressed a level of mistrust for providers and information:

"The only way to trust anything is to use it for a few weeks. Nothing is set up to make sure providers are trustworthy."

Participants were aware of marketing strategies and sceptical of sources that seemed too good to be true. Our survey indicated only 40% of participants were aware of how to report misinformation. Participants noted trustworthy sources were those that provided clear and comprehensive information and were open about their data and methodologies. One participant commented:

"Online provider information is often not a true reflection of quality in our experience."

Participants expressed that information that is consistent across multiple sources is often more reliable. If participants found consistent feedback and reviews about a particular provider or service, it provided a level confidence in the accuracy of that information. Many participants used support coordinators or other professional services to assist with research on providers and finding services that aligned to their individual needs:

"Other trusted professionals whom are consistent with our values, beliefs, and philosophy of service recommendations."

Participants told us they often visit the official NDIS website and relevant government websites to access information and resources. However, some participants expressed frustration with navigating these sites and complained of finding inaccurate and out of date information. It was noted that rules and processes change so frequently, and governments have a responsibility to manage these changes. One participant expressed:

"The only information I trust is from the community, including my providers. Government websites

or providers' own websites are completely untrustworthy."

Other participants found official government websites offered comprehensive information about the NDIS's structure, guidelines, and registered service providers that they could reasonably assume was reliable. Participant told us they use these sites to verify provider credentials and learn about the NDIS standards and policies:

"Government websites, reputable advocacy organizations, and established provider directories are generally trustworthy sources."

Many participants told us they liked access to online directories to find providers. These directories were beneficial when they offered information about provider specialties, contact details, locations, and the services they offer. Participants told us that these directories are useful to find providers that match their specific requirements; however, they were often complex to navigate and did not have information that was specific enough or relevant to what they wanted to know:

"Frankly, the NDIS Portal is very difficult to understand or find what you are looking for."

Participants shared with us they really valued recommendations from friends who are also NDIS participants and support workers who are familiar with a participant's unique needs. Participants felt personal endorsements provided a level of trust and reassurance, making it more likely for participants to consider engaging a particular provider:

"Recommendations from people with lived experience and family connections are highly valued. Information from these trusted sources about both their positive and negative experiences of specific service providers are helpful."

Participants told us they frequently turn to their peer networks, which include fellow NDIS participants, disability support groups, or advocacy organisations. Participants felt these networks offered valuable insights and experiences. Peer networks enabled participants to gather firsthand information about different providers, services, and best practices. One participant shared:



"I know information is trustworthy when it is coming from someone I trust and respect, whose motivations for taking the position they have I understand. It is important that I can connect with them and their perspective, to understand if their advice/information is relevant to us. Intersectionality is so relevant here."

Participants told us social media platforms and online communities play a significant role in information sharing. Participants talked about joining online forums, Facebook groups, or Twitter communities to exchange experiences, seek recommendations, read reviews and feedback from other participants. These platforms offered a space for open and real-time discussions on service quality:

"I try finding information from more than one source saying the same thing about a provider. It is not full proof by any means."

Many participants discussed using reviews though Google and undertaking comparisons of provider websites to assess the safety and quality of providers. Participants shared this was an onerous process but that there are no reliable review sites for participants to review providers. Some

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participants also told us that the branding for NDIS was helpful initially but was now possibly misleading, as participants do not know if a branded provider has been officially approved or if they are just using the NDIS logo. On participant shared:

"I compare provider websites with participant's reviews and choose the providers who have the best comparison to my wants."

Participants were supportive of establishing a comparison and rating system on the NDIS Commission's website. Some participants expressed concern with the reliability of a rating system and the potential for being abused by those in power or for people to undermine a certain provider for unethical reasons. Participants felt a rating system that recognised the quality and safety of the service would help increase visibility of services and inform choice:

"A simple provider star rating system that considers all the available information to the Commission about whether each provider can walk the talk, or whether their practice does not cut it."

Terms and Definitions

Agency-managed participant: A participant whose NDIS funding is managed by the NDIA. Participants who choose to be Agency-Managed can only access supports and services from registered NDIS providers.

CALD: Refers to any person or group of people that are culturally and linguistically diverse.

Choice and control: A participant has the right to make their own decisions about what is important to them and to decide how they would like to receive their supports and who from.

Complaint: telling the NDIS Commission if you are unhappy with or have a concern about your current NDIS supports or services.

Confidence: a high level of trust. For example, you are confident your provider gives you correct information.

Consumer: see "participant"

Demographic information: Data about the features or characteristics that define an individual or group. For the purpose of the Own Motion Inquiry, this includes data such as location, age and disability type.

Dignity of Risk: is the right to make decisions about yourself and your supports including choosing to take risks.

Empowered: people having power and control over their own lives and confidence to make a decision.

Information: Knowledge provided to you or that you look for in relation to NDIS Supports.

Informed decision-making: have all the information and facts available related to the decision topic

Knowledge: Facts, truths, information provided to you or that you look for.

LGBTQIA+: Refers to a person's sexual orientation and/or gender identity and is an abbreviation for lesbian, gay, bisexual, transgender, queer (or questioning), intersex, and asexual (or allies), and more.

Market: A collection of providers offering products and services to NDIS participants. Also known as NDIS Market.

Misinformation: False or wrong information about the NDIS or NDIS services that is spread by accident or on purpose.

NDIS Market: The NDIS Market is the collective term for all Providers and Services available to NDIS Participants to purchase using their NDIS Plan funding.

NDIS participants: People with disability who receive NDIS funding to access services and supports from registered and unregistered NDIS providers.

Participant: A person who meets the NDIS access requirements.

Peak body: An organisation which represents organisations and members of the community in the disability sector.

Plan-managed participant: A participant whose NDIS Plan is managed by a provider who is registered with the NDIS Commission to deliver Plan Management. Participants who choose a plan management provider can access supports and services from both registered and non-registered providers for most supports.

Registered NDIS provider: A registered NDIS provider is a person or organisation that is registered with the NDIS Commission in accordance with section 73E of the National Disability Insurance Scheme Act 2013. NDIS providers must be registered to deliver some kinds of supports (e.g. implementing regulated restrictive practices in a behaviour support plan). NDIS Providers must be registered to deliver NDIS funded supports and services to participants in the NDIS whose NDIS plan is managed by the National Disability Insurance Agency (NDIA), See "Agency-Managed Participants".

Registration Process: Registration of NDIS providers is a process that aims to ensure the provision of safe and quality services by requiring providers meet quality and competency standards and engage in additional safeguarding practices such as reportable incidents. These standards are proportionate to the risk associated with the type of service delivery and the scale of the provider.

Registration status: Indicates if an NDIS provider is registered or unregistered. See also: 'Registered NDIS provider' and 'Unregistered NDIS provider'.

Safeguards: An appropriate measure or measures taken to protect participants from unnecessary risks or harm.

Self-managed participant: A participant that manages their own NDIS funding either fully or in part. Participants who choose self-management can access supports and services from both registered and non-registered providers for most supports.

Service types: Refers to groupings by type of services and supports delivered to participants. These are:

- Support at home: such as personal care, meal preparation assistance, medication and/or skill development to increase independence with daily life activities
- Household tasks: such as lawn/yard maintenance, gardening and/or cleaning
- Community access activities: such as travel/transport, appointments, shopping, social activities
- Therapeutic support: such as Occupational Therapy, Speech Therapy, Psychology etc.
- Behaviour Support: such as implementing behaviour support strategies"

Sharp practices: a range of practices involving unfair treatment or taking advantage of people.

Unregistered NDIS provider: A provider of NDIS supports and services that has not been registered with the NDIS Quality and Safeguards Commission.

Worker screening: The NDIS Worker Screening Check is an assessment of whether a person who works, or seeks to work, with people with disability poses a risk to them.

Worker/Support Worker: An individual who deliver's NDIS funded supports or services to an NDIS participant. A worker may be a NDIS Provider or employed or engaged by a NDIS Provider (registered or unregistered). 'Workers' includes but is not limited to employees, sub-contractors, independent contractors and sole traders.