# Consultation summary: Supporting you to make your own decisions

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**ndis**

National Disability Insurance Scheme

# Contents

# 1. CEO introduction

The National Disability Insurance Agency (NDIA or 'we') are developing a Support for Decision Making policy that will guide the way we support National Disability Insurance Scheme (NDIS) participants to make decisions.

We want to improve how we support people with disability to make decisions that affect them and the opportunities available to do this. We developed our consultation paper [Supporting you to make your own decisions](#) by working with the NDIS Participant Reference Group, the Independent Advisory Council and members of the Intellectual Disability Reference Group, academics, and members of our [Participant First Engagement Initiative](#).

To help us get this right, we asked for your feedback about our ideas in consultation sessions, through an online survey and through written submissions during a 12-week consultation period held between 21 June and 10 September 2021.

We have received a significant amount of interest in our proposed approach from people with a disability, families, carers, disability representative organisations, service providers, government departments, academics and health professionals.

You told us when you think we're heading in the right direction, and you told us when you think we need to change track or stop completely. You gave us hundreds of recommendations and specific actions to improve support for decision making for people with disability. This report summarises the feedback you provided to us and where improvements can be made.

With your help we are building a shared understanding of the key opportunities and barriers that need to be addressed. We will use what you have told us to co-design our Support for Decision Making policy and plan in partnership with people with disability and the disability community. We know that this will be a significant cultural change that we can influence, and that we need to work with you to make happen.

We thank you for the time and effort you have put into providing us your feedback and we look forward to working with you.

Regards,

Martin Hoffman
Chief Executive Officer

# 2. What we will do with your feedback

We want to improve how we support people with disability to make decisions that affect them and the opportunities available to do this.

We have produced this report to provide a summary of the feedback we have received during the consultation period. We have also made available the submissions from people who have provided their consent to do so. These submissions can be viewed on our [website](#).

We have done this so you are able to see what people have told us during consultation. We encourage you to have a look at these submissions to see what others have said.

The feedback you have provided will be an important part of what we will be using to develop a new Support for Decision Making policy. The next steps we will take to do that are explained below.

## 2.1 Next steps

Following the release of this report and the submissions we received, we will undertake a co-design process to finalise our Support for Decision Making policy. The image below shows where we are up to in this journey.



*Figure 1.* Support for Decision Making co-design process

Your feedback highlighted the importance of co-designing the Support for Decision Making policy and implementation plan with us. We will undertake the co-design process in line with

our ongoing commitment to include people with disability when developing changes to the NDIS. We will be guided by the work of the Co-design Advisory Group, which is made up of members of the NDIA, the Independent Advisory Council, and Disability and Carer Representative Organisations. You can read more about [our approach to co-design](#) on the NDIS website.

During the co-design process, we will use the feedback you gave us during the consultation period to build a strong and shared understanding of problems you experience and difficulties you face. Throughout the co-design process, we will have an in-depth look at the recommendations and potential solutions you provided.

We know that it will take time to create cultures and environments where people with disability can make decisions with the right support when they need it.

We understand that some feedback asks us to act quicker and to make improvements to how we support people with disability to make decisions now.

We recognise that co-design can sometimes take time, but we think working together in this way will improve Support for Decision Making for NDIS participants.

In the meantime, we will continue to make improvements to our existing systems, processes, guidance and decision making to improve the current NDIS experience. We are also working on ways we can engage with other government departments to provide opportunities for participants and decision supporters to try new ways of making decisions, and support initiatives that build skills for people with disability and decision supporters.

Following the co-design process, we will release the Support for Decision Making policy. It will include concrete actions alongside an implementation plan that will enable us to deliver on the vision we all have for supporting people to make decisions under the NDIS.

# 3. How we received your feedback

We received your thoughts, experiences, and insights in different ways, including through:

- online survey
- written submissions
- online events  across Australia
- targeted conversations with people who might benefit most from Support for Decision Making
- direct conversations with sector representatives and peak bodies
- direct conversations with participants through the NDIA's Participant First Initiative.

We asked you to give us your thoughts in ways that worked for you. Some of the feedback included direct email correspondence, creative responses (such as drawing pictures), and one-on-one conversations.

## 3.1  Consultation events

During the consultation period, we held **2 public information sessions** for communities across Australia. Our community engagement teams also held **16 national online consultation sessions** for participants, nominees, families and carers, providers and other interested individuals and organisations.

We also consulted with participants, families and carers **through 3 focus group sessions** with members of our Participant First initiative, and targeted conversations with groups and organisations of people who might benefit most from support for decision making.

We spoke to people from all around Australia about Support for Decision Making and the vision and ideas outlined in the consultation paper: Supporting you to make your own decisions.

The consultation paper and the survey questions were created with advice from the **Independent Advisory Council**, the Intellectual Disability Reference Group and other key stakeholders.

In recognising the major impact of COVID-19 on your ability to provide feedback, we extended the consultation period by 2 weeks. We also increased the opportunities to conduct information sessions virtually or in person, with adjustments based on restrictions and COVID-safe practices.

## 3.2 Online submissions

In response to NDIA's request for feedback, we received **280 unique submissions\*.** This included:

- 195 survey responses
- 85 written submissions (of which 35 were received by email).

Of these:

- 182 responses were from individuals (people with disabilities or people who support people with disabilities)
- 98 responses from organisations (including disability organisations, NDIS service providers, advocacy organisations and peak bodies).

\*An analysis of responses was also undertaken on transcripts and notes taken at engagement activities. However, demographic data was not captured for every attendee and therefore not included in this count.

**Responses from individuals**

Table 1 below displays information from 165 individuals who responded to the online survey only. It shows we mostly heard from people identifying as participants (31%), family, friends, or carers (29%) and nominees (12%). In this question, people could select more than one identity.

**Table 1. Identity of individuals who responded to the online survey**

| Who responded | Number | Percentage of individuals* |
|---|---|---|
| Participant | 70 | 31% |
| Family, friend or carer | 66 | 29% |
| Nominee | 27 | 12% |
| Allied Health worker | 18 | 8% |
| Community member | 15 | 7% |
| Other | 12 | 5% |

| Who responded | Number | Percentage of individuals* |
|---|---|---|
| Guardian | 10 | 4% |
| Disability Support worker | 8 | 4% |
| Total responses | 226* | 100% |

*Individuals could select more than one identity.

Table 2 below displays the number of individuals who identified with three specific groups when responding to the online survey. It shows we heard from a very small number of people who identified as Aboriginal or Torres Strait Islander (2%), culturally and linguistically diverse (1%), or from rural or remote regions (5%). In this question, people could select more than one identity.

**Table 2. Individuals who identified as Aboriginal or Torres Strait Islander, culturally and linguistically diverse, or from rural or remote regions**

| Who responded | Number | Percentage of individuals* |
|---|---|---|
| Rural/remote | 8 | 5% |
| Aboriginal or Torres Strait Islander | 3 | 2% |
| Culturally and linguistically diverse | 1 | 1% |

*Individuals could select more than one identity.

Table 3 below displays information from 165 individuals who responded to the online survey only and identified as having a specific disability or impairment. There were 37 responses (13%) where individuals identified as having a disability or impairment. For this question, many people selected more than one identity.

**Table 3. Individuals who identified as a person with a specific disability or impairment**

| Who responded | Number | Percentage of individuals* |
|---|---|---|
| A person with a psychosocial disability | 11 | 7% |
| A person with a communication disability | 10 | 6% |
| A person with a cognitive impairment | 8 | 5% |
| A person with an intellectual disability | 8 | 5% |

*Individuals could select more than one identity.

**Responses from organisations**

Table 4 below displays information from the 84* organisations who responded to the online survey and/or gave us a written submission. It shows we mostly heard from organisations identifying as peak bodies (30%), NDIS service providers (21%) and advocacy organisations (17%).

*This number is different to the unique submissions (98) as 84 organisations uploaded written submissions and/or completed the online survey.

**Table 4. Responses from organisations by organisation type**

| Who responded | Number | Percentage of organisations |
|---|---|---|
| Peak body | 25 | 30% |
| NDIS service provider | 18 | 21% |
| Advocacy organisation | 14 | 17% |
| Disability organisation | 11 | 13% |
| Government department or service | 9 | 11% |
| Other | 6 | 7% |

| Who responded | Number | Percentage of organisations |
|---|---|---|
| Research organisation | 1 | 1% |

**Responses by location for individuals and organisations**

Table 5 below displays information from 257* individuals or organisations who completed the survey or emailed a written submission. It shows we mostly heard from people who reside in New South Wales (25%), Victoria (21%), and Queensland (16%).

*This number is different to the unique submissions (280) as 23 individuals or organisations uploaded written submissions and also completed the online survey.

**Table 5. Responses by location**

| Who responded | Number | Percentage of total |
|---|---|---|
| New South Wales | 63 | 25% |
| Victoria | 55 | 21% |
| Queensland | 41 | 16% |
| Western Australia | 29 | 11% |
| South Australia | 23 | 9% |
| National | 22 | 9% |
| Australian Capital Territory | 11 | 4% |
| Tasmania | 5 | 2% |
| Not specified | 4 | 2% |
| Northern Territory | 2 | 1% |
| Other jurisdictions* | 2 | 1% |

*Other jurisdictions includes the territories of the Indian Ocean and Norfolk Island. This number also includes non-disclosed locations.
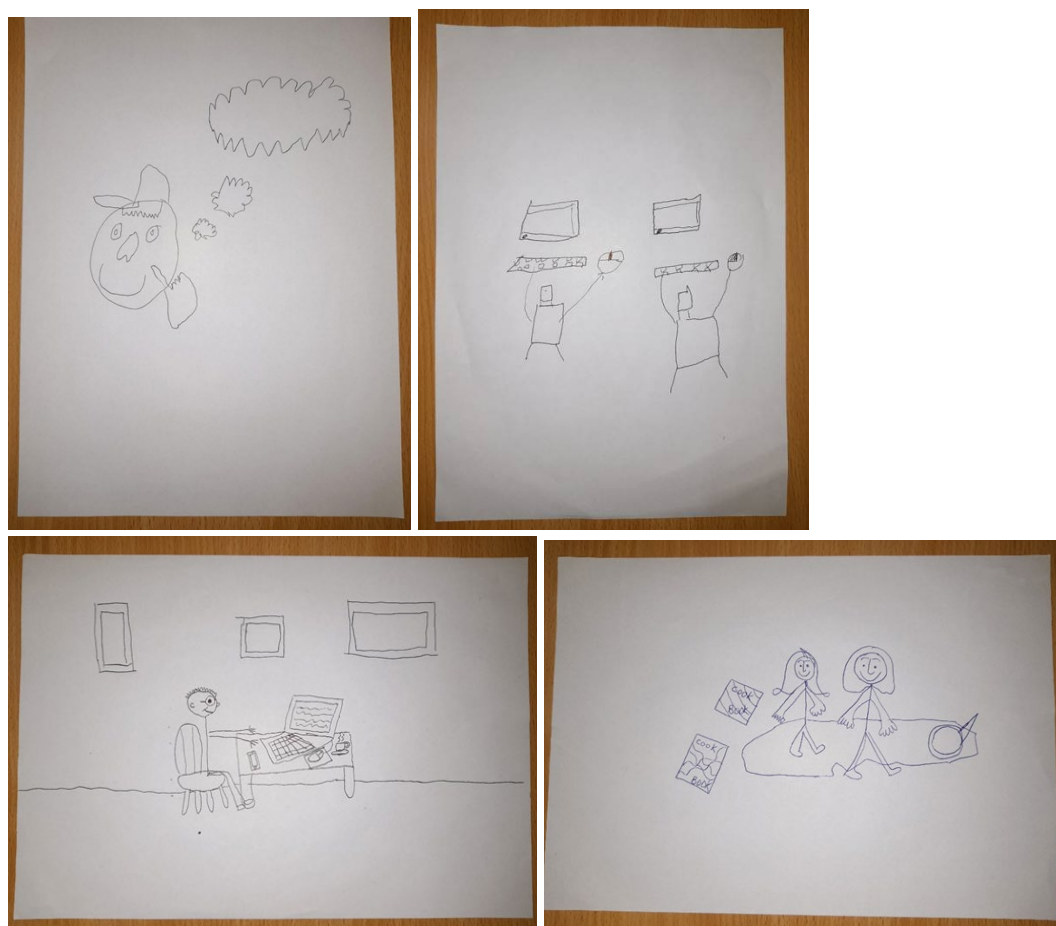
# 4.  What you told us

Your feedback came to us in many different ways and gave us many ideas and opinions on how we could make Support for Decision Making work.

We received feedback from a range of individuals and organisations including people with disability, carers and family members, those who act as Nominees, disability representative organisations, advocacy organisations, service providers, allied health professionals, the legal profession, academics and government (including Guardianship and Trustee bodies).

Overall, you told us that it is important that we have a policy about how we support people with disability to make decisions and that you want us to work with you and others to get this right.

You shared some of your thoughts in pictures, like the drawing below about who or what helps you make decisions:



*Figure 2. Drawings about who or what helps you the most when making decisions.*

## 4.1    General themes

There were a number of themes that stood out as being important to you. These were:

### 4.1.1   Co-design the policy and plan

You told us it is important we co-design the policy and implementation plan with the disability community.

### 4.1.2   Reconsider the policy approach and language

You told us that we need to:

- Recognise that everyone draws on people or information to help make decisions and that some people may **need support for most or all decisions** they make.
- Consider adopting the Australian Law Reform Commission's National Decision-Making principles.
- **Focus on the support a person needs** to make decisions, and the impact of the environment on their decisions, rather than their capacity.
- **Take a person-centred approach** rather than rely on 'typical' life stage transitions that may not map onto the experiences of individuals (in context of intellectual disability, cognitive impairment and or psychosocial disability).
- Recognise that decision-making **happens on a continuum** or could be represented as a spectrum.
- Define and use 'supported decision making' as a word which can be used for process, resources, and tools.
- Make our information so everyone can understand.

### 4.1.3   Look at the broader context and don't reinvent the wheel

You told us that:

- You want **us to lead** as well – that what we say and do in supporting people to make decisions is important and can impact others. And that what we do, can impact you.
- We need to **learn from you and other existing work** and not re-do things that have already been done. This includes encouraging the role of Information, Linkages and Capacity Building (ILC) in supporting people to make decisions (the ILC program provides funding to organisations to deliver projects in the community that benefit all Australians with disability, their carers and families).
- You also want us to **work with others** to get this right – from the disability community to other government departments.

- We need to **be clearer** about how our work on Support for Decision Making (including Nominees) fits in with legal frameworks focused on Guardianship and Trustees and how it fits with all the work that we are doing to make our decisions or improve supported decision making with and for people with disability.

### 4.1.4   Uphold the rights of people with disability

You told us that we need to **understand and explain** the rights of people with disability better and **uphold** people's right to make decisions.

### 4.1.5   Recognise the importance of relationships

You told us that **relationships** – trust, respect, collaboration – are key to supporting a person with disability to make decisions.

### 4.1.6   Enact effective support for decision making

You told us that:

- Making decisions **within the NDIS could be easier** if our information was easy to find and understand and our systems were easier to use. You also said we need to communicate with you in the way that works for you and check you have understood.
- **Effective** Support for Decision Making needs time, funding, choice of decision supporters who are skilled.

### 4.1.7   Recognise disability-specific and culturally-specific needs

You told us that:

- We need to ensure **what we do works** for people who have complex communication or support needs, people with intellectual and psychosocial disability and people who interact with multiple service systems like health, justice and child protection.
- We need to **better understand the perspectives** of Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities.

### 4.1.8   Explain our approach to safeguards

You told us that:

- We need to provide **more detail** about the safeguards in the policy;
- The NDIS Quality and Safeguards Commission should have a role in ensuring people are supported to make decisions.
- **Making sure people are getting the support they need** to make decisions (accountability) is very important.

## 4.2 Specific feedback

You also gave us your feedback for the specific questions we asked. We have summarised this feedback below under the following groups and captured more detail of your responses in Appendix A:

- Helping you make decisions
- Choosing decision supporters
- Capacity building for decision supporters
- Disability or culturally specific considerations
- Conflict of interest, undue influence and dignity of risk
- Implementation plan.

Many of the submissions also included recommendations and actions for us to consider. We are working our way through the detail of these and have summarised them in this report in Appendix B. The suggestions provided in the submissions related to legislation, policy, design and implementation of Support for Decision Making.

### 4.2.1 Helping you make decisions

**Summary**

Our vision spoke about how we want you to have more opportunities to make decisions and have the information and resources you need to do this. There are a range of supports and resources that can help you make decisions or identify and communicate what you want. These options do not take away your right to make your own decisions and range from having clear information to having a person to help you make decisions.

You told us that having people to help, who are working together with you, is one of the best supports for decision making. You told us that making processes simpler and information more accessible would give you more opportunities to make decisions. You also said that providing information about options in advance was important so people can make an informed decision. You also said having time to make decisions is one of the best ways to improve how we support people to make decisions.

You told us that all resources, information and communication need to be accessible and easy to understand and that the NDIA needs to make sure our processes are easier to follow. You said that the types of support that would be useful are peer support groups, real examples and scenarios of decisions, information sessions and workshops. You said that

funding would be needed for these supports and other initiatives that can build your skills to make decisions or to support someone to make decisions.

You gave us some specific examples of information and resources that help you make decisions. In particular:

- decision process trees, including, for example, an app
- circles of support or microboards
- dedicated hotlines or people to call when making decisions
- a single point of call for Support for Decision Making resources.

You also gave us specific feedback on how we can improve what we do to support you to make decisions. You said that we need to improve how we listen to people with disability. You told us that it is really important you get consistent advice and timely responses, because if you don't, these are barriers to confidently making decisions. You told us about the things that impact decision making, like capacity to make decisions, access to support and the imbalance of power. You told us that capacity to make decisions was impacted by an understanding of decision making, being informed about the decisions you were making and having the confidence to make decisions. You also told us you wanted us to focus on the support someone needs to make decisions not their capacity.

**Examples of what you said**

*[Good Support for Decision Making means]…'I am heard, understood and respected. So often I am not respected – I am right down to the little things. Right down to when the staff are in my house – they do things their way which is not what I want. I want to be supported this way. Or what are the consequences if we do it your way. If it is bad for me or another person, then I need to know why.'* (NDIS participant)

*'Explaining my options. Helping with leading after I make my own choices, as I need a push to get started, and help when it becomes overwhelming with paperwork etc.'* (NDIS participant)

*'Having a consistent approach and for the [person with disability] to feel informed and empowered to know where to look, when seeking support for making decisions*.' (Family member of an NDIS participant)

*'Support is decision specific and time specific and, like for each of us, we use different supports for different decisions'* (Family member and nominee of a person with disability)

### 4.2.2   Choosing decision supporters

**Summary**

In our consultation paper, we talked about the importance of having the right people around you to help you make decisions. There are many different types of decision supporters. Some are formal which means they do it as a job or they do it officially. Some formal supporters are paid to provide support but some formal supporters do not get paid, like nominees. Others are informal which means they do not have an official agreement to help you make decisions.

A decision supporter is a person who:

- helps a participant to practice making decisions
- helps them improve their skills, and
- builds a person with disability's capacity to make decisions.

You told us family members and advocates are usually the people you turn to help you make decisions, but that family might not always be the best choice in all decisions and someone independent of family might be more suitable. You want to have the choice of decision supporter depending on the decision you must make and the people you have in your life.

You told us that good communication skills are a key aspect of a good decision supporter, and that checking for understanding is a large part of this. You have told us that decision supporters should not have conflicts of interest and should not have a financial gain in any of the decisions being made. You told us that you would like decision supporters to have accredited training, have a diversity of experience and understanding of disability, be culturally aware, and to understand the rights of people with disability, especially dignity of risk.

You also told us that the most important thing about a person who supports you is the relationship you have with them, that you can trust them and that they trust you.

**Examples of what you said**

*'Listen to what I want.'* (Person with disability)

*'Again, all of the above are needed as the situation will depend on individual circumstance. Sometimes a person may not have any family or friends in which case they will rely on paid supports. Paid supports need to ensure minimum conflict of interest. There are not enough Independent Advocates to provide support for decision making as it is not an advocacy issue. Support for decision making for an NDIS participant in relation to NDIS supports should be covered by the NDIS.'* (Individual)

*'For Anangu from the remote NPY Lands of central Australia, support needs to be from workers they know and trust and who have a good understanding of Anangu culture and lifestyle.'* (Aboriginal Community Controlled Organisation)

*'In the unfortunate case that a person has no family or friends or comes from an abusive family or a toxic environment, then assistance should be received by both medical professionals (such as a GP) and other resources such as those options listed here, and then the individual should be the main influence in the decision making process.'* (NDIS participant)

## 4.2.3 Capacity building for decision supporters

**Summary**

In our consultation paper, we talked about how we need to help the people around you support you to make your own decisions. We aim to increase your involvement in decision making and reduce substitute decision making by building the capacity of your decision supporters, the Agency staff and Partner staff. We believe we can do this by building their capacity to recognise and enable your will and preference in decision making.

You told us about the attributes and characteristics of decision supporters and that being directed by you, knowing you well and having guidelines and examples of good Support for Decision Making were important. You told us that the most important thing for decision supporters to know are the rights of people with disability. You also told us that decision supporters could better support you to make decisions by having easy access to support themselves, such as a hotline to call, or accredited training.

You also told us many things that we could be doing to improve how we support decision making of you and your decision supporters. You said that we need to focus on providing options and opportunities for decision making. You said that we need to fund decision supporters, advocates and circles of support. Specifically, within participant plans, we need to fund supports for decision making and ensure greater flexibility of plan funds.

**Examples of what you said**

*'They need to know the person and understand what their will and preference is. They need to declare any conflict of interest. They need to be aware of their own unconscious bias and fully support the idea that people can make decisions even if they need support to do so. They need to have a good understanding about different ways people communicate. They*

*need to be able to accept that sometimes people may make bad decisions or decisions that the decision supporter would not make themselves.'* (Individual)

*'Training programs fall short by being too prescriptive with instructions - they would benefit from a values-based approach to training rather than such prescriptive methods that train team members to constantly refer to source material. The material has its place and is very beneficial, but a long-term values based skew on training will go very far.'* (NDIS participant)

*'Parents/carers of children with disabilities feel overwhelmed in making decisions. Families need help to make these decisions and to help their child to make decisions. Keeping their child involved.'* (Parent of a child with disability)

*'If we are focused on building skills for a person to make decisions independently we need to start in the early years. Parents/carers need support to be able to this - this needs to be in built into the package for parents/carers support to do this.'* (Parent of a child with disability)

### 4.2.4   Disability or culturally specific considerations

**Summary**

Our consultation paper acknowledged that sometimes people with specific disabilities or cultural backgrounds will have different considerations and ideas about decision making. Aboriginal and Torres Strait Islander or Culturally and Linguistically Diverse people may understand and approach disability and decision making differently. Also, about 60 percent of adult NDIS participants have a disability that may affect the way they think.

Sometimes these participants will need extra help to make decisions. This includes participants with:

- acquired brain injury
- intellectual disability or cognitive impairment
- psychosocial disability
- other episodic or degenerative disabilities.

You told us that we need to make sure how we talk about and provide Support for Decision Making is inclusive and accessible for people with disability and their decision supporters. You told us we need to demonstrate we understand the cultural considerations of this work. You made it clear that relationships and knowing the person are key to helping people with disability make decisions. You also told us that our policy needs to demonstrate a stronger understanding of the needs of people with complex communication or support needs and people with disability who are engaged with multiple service systems including youth justice,

out of home care, justice and primary health. You also said our policy needs to reflect the perspectives of Aboriginal and Torres Strait Islander communities and Culturally and Linguistically Diverse communities.

**Examples of what you said**

*'Decision making is not a linear process and people's capacity to make decisions can depend on their circumstances at the time (health). Sometimes people want a break from making decisions.'* (Person with disability)

*'Firstly it is important to understand that there is very wide variability in terms of Aboriginal and Torres Strait Islander communities. Cultural competence for the specific community is the basic requirement. Then all the variables related to the individual disability need to be taken into account.'* (Family member, nominee and guardian of a person with disability)

*'Resources need to be readable, and comprehension ensured. Resources will need to be flexible for individuals with a range of disabilities, to support them to read, digest, engage with curiosity and move towards decision making.' (NDIS service provider)*

### 4.2.5 Conflict of interest, undue influence and dignity of risk

**Summary**

In our vision, we imagined an Australia where people with disability have the freedom to make their own choices, where your right to make decisions is not limited because of your disability.  You have the right to take risks, to learn from your experience and use this experience in future decisions. This means making decisions where the outcome is not clear. This is called 'dignity of risk' and is an important part of building your decision-making ability. It is also part of what makes us human.

We also talked in our consultation paper about the concerns we had previously heard around the potential for conflicts of interest and undue influence when you make decisions.

You overwhelmingly told us that the rights of people with disability to make decisions for themselves is the most important thing we need to uphold. You told us that we need to provide more detail about safeguards and dignity of risk in our policy and that we need to put safeguards in place to help reduce risk, conflict of interest and undue influence. You made it clear that decision supporters should be independent from the decisions being made and exposure and experience in making decisions is key to reducing the risks involved. You also told us that having a knowledgeable independent advocate and strong circles of support

help safeguard you from conflict of interest and undue influence, and provide you with the space to take risks in your decision making.

You told us that it was very important that NDIA staff and Partners understand and demonstrate disability awareness, rights of people with disability, the concept of 'dignity of risk', and listening skills. You said this might be done through increased training.

**Examples of what you said**

*'That they may make a decision based on what they think will please other people and not what they need or what.'* (NDIS participant)

*'Regular in-home checks, consulting the person with a disability and those involved in supporting them make decisions. Talking with them about their decision making process in relation to specific decisions they have made. Clear guidelines around the level of family involvement in a person's care - as support worker only not decision-making support as well as support worker and family member.'* (Disability support worker and family member of a person with disability)

*'In helping people from the remote Aboriginal communities of Central Australia (Anangu), to make decisions relating to the NDIS and their plans, conflict of interest is best reduced through the presence of advocates who visit or live in communities and who are trusted by Anangu. Advocates need to have a good understanding of Anangu culture and community lifestyle. They should be known to and trusted by the person they are supporting. They should have a thorough understanding of the implications of the choices Anangu may make so that they can assess and explain any issues that may arise for Anangu from the support given them.'* (Aboriginal Community Controlled Organisation)

*'People with disabilities have the right to make decisions including those that are of a high risk, however, it is important that participants have the supports in place to help them to cope with any consequences that they may encounter.'* (Advocacy organisation)

*'The proposed policy should provide more detailed information about undue influence and abuse. It should identify 'red flags', such as where a nominee requests the cessation of services to isolate the participant. The NDIA should consult with people with disability and their representative organisations to develop a comprehensive list of 'red flags'.'* (Peak body for people with disability)

### 4.2.6  Implementation plan

**Summary**

In our consultation paper, we identified a range of actions we might be able to take to improve Support for Decision Making. You provided us with feedback on these actions, which was mostly positive. You also gave us a lot of other ideas and said sometimes we had things right and sometimes we were not clear enough. Some of the key things you told us where that we need to work in partnership with you, that the rights and autonomy of people with disability need to be upheld, that our staff need to be skilled in supporting people to make decisions, and the implementation plan needs both funding and to be specific in its actions and intent. You want us to reconsider how we measure success in relation to nominees – you want us to have a stronger appointment and review process.

You also told us that we need to make sure we incorporate Support for Decision Making throughout the whole access and planning process.

You provided us with many specific suggestions for the implementation plan, and for Support for Decision Making in general, these can be found in this report at Appendix B.

**Examples of what you said**

*'[We] think it is good the NDIA supports the rights of people with disability to make their own decisions.'* (Organisation of people with intellectual disability)

'*The plan should talk about money for supported decision making projects. The plan should be clear about who pays for supported decision making*' (Organisation of people with intellectual disability)

'*Replace the current nominee arrangements to allow participants to nominate decision supporters. This should include clear guidelines around the role, responsibilities and duties of decision supporters*.' (Joint submission from a peak organisation and service provider)

'*The plan says supported decision making should start at age 16. This is too late*' (Organisation of people with intellectual disability)

'*There needs to be a way to make support for decision making a formal process for the most vulnerable people who have no one in their lives, and for people who have identified they would like this support. There needs to be funding for this so that someone can facilitate for decision supports.'* (Individual)

'*The adage 'it's difficult to dream if you're not allowed to dream' rings true in this context. Support providers predominate the lives of people with [intellectual disability], controlling every aspect of their life. Monosupport should not be allowed.'* (Person with a disability)

*'Strongly promote training about [supported decision making] as a key skill and competency for support workers/ peer workers/ recovery coaches etc. Help understanding that [supported decision making] is an opportunity that people can utilise to maximise their independence. Promote help seeking of participants regarding [supported decision making].'*
(Peak body)

# Appendix A – Your responses to our online survey

Below we have summarised the responses to the survey questions we asked as part of the consultation. The consultation survey questions were designed to provide the NDIA with a greater understanding of the views of individuals and organisations.

We received online survey responses from individuals, including people with disability who are NDIS participants, family members, carers, those who act as Nominees and individuals who work in the disability sector and allied health. A range of organisations – including peak bodies, disability organisations, advocacy organisations and government and research organisations also submitted online survey responses.

## Question 1

**We asked:** How can we help people with disability make decisions for themselves?

**Your response:** The majority of what we heard was that having a person help (26%), having information (22%) and resources (22%), and having decision guides (20%) would help people with disability make decisions. You also told us that other things (9%) that could help including providing options and opportunities for decision making, peer support groups, scenarios and examples, and making the NDIS easier to navigate.
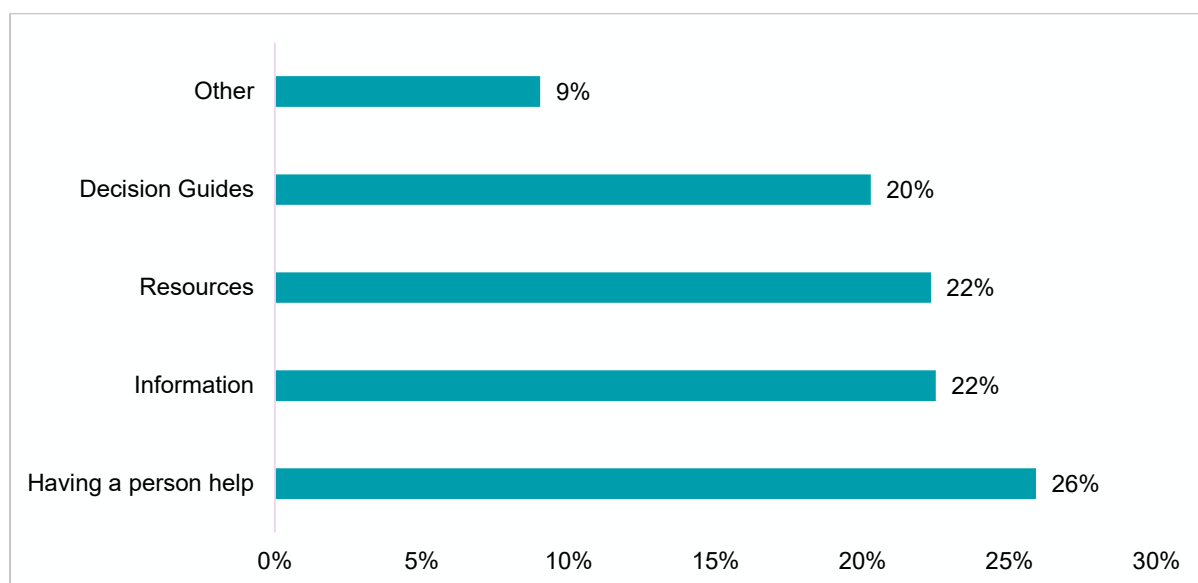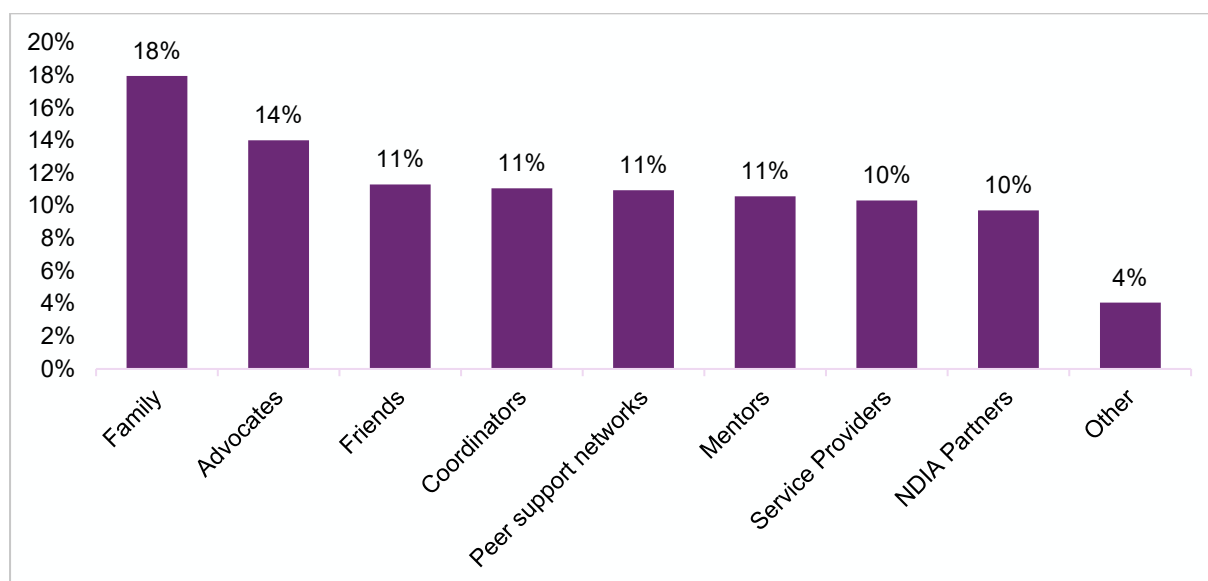


***Figure 3.*** *Responses identifying how to help people with disability make decisions for themselves*

## Question 2

**We asked:** Who are the best people to help you (or a person with a disability) to make decisions? We call them decision supporters

**Your response:** The majority of what we heard was that family (18%) and advocates (14%) were the top two best options for a decision supporter. All the other options were identified as equally useful in helping to make decisions: friends (11%), coordinators (11%), peer support networks (11%), mentors (11%), service providers (10%) and NDIA partners (10%). There were also a number of other responses (4%) which identified that medical professionals, carers, support workers, legal services and education services are also important decision supporters.



*Figure 4. Responses identifying who are the best people to help people with disability make decisions*

## Question 3

**We asked:** What should they (decision supporters) do to help with decision making?

**Your response:** The majority of responses were related to the attributes and characteristics of decision supporters. With knowledge and experience of the decision supporter being the most important attributes.

Some of the key themes included:

- The person with disability should direct all decisions
- Decision supporters need to know the person with disability.
- Decisions supporters need to provide opportunities for decision making

- The decision supporter's communication (in the preferred format), information gathering and decision-making skills are of high importance.
- Decision supporters need to be aware of dignity of risk so that people with disability can learn about the impact and consequences of decisions.
- Self-determination is key to all decisions.
- Decision supporters need to help ensure there is the appropriate amount of time to make decisions.
- There is a need for an absence of a conflict of interest between the decision supporter and the person with disability.

## Question 4

**We asked:** How can they (decision supporters) get better at helping?

**Your response:** The responses to this question were mostly in agreement, with low variability between the options. You advised that decision supporters can get better at helping people with disability by getting to know the participant well (34%), by having resources and information about providing decision support (26%), and by doing training on decision support (26%). You also advised of other things (11%) that decisions supporters can do, including focusing on skill development around communication, decision making, prioritisation, and information and resource gathering.
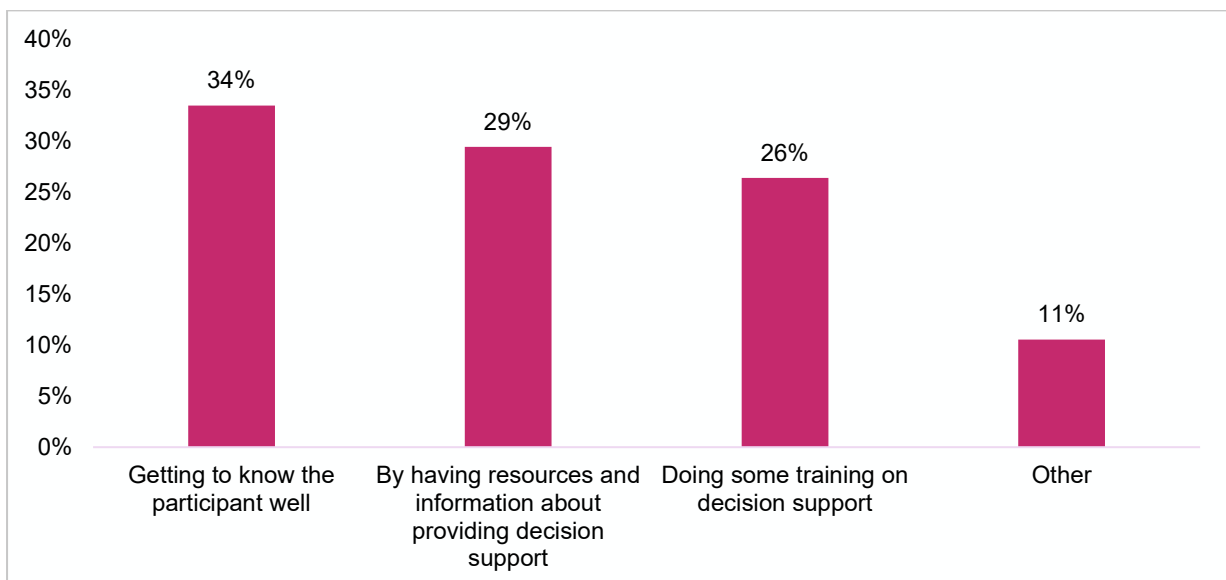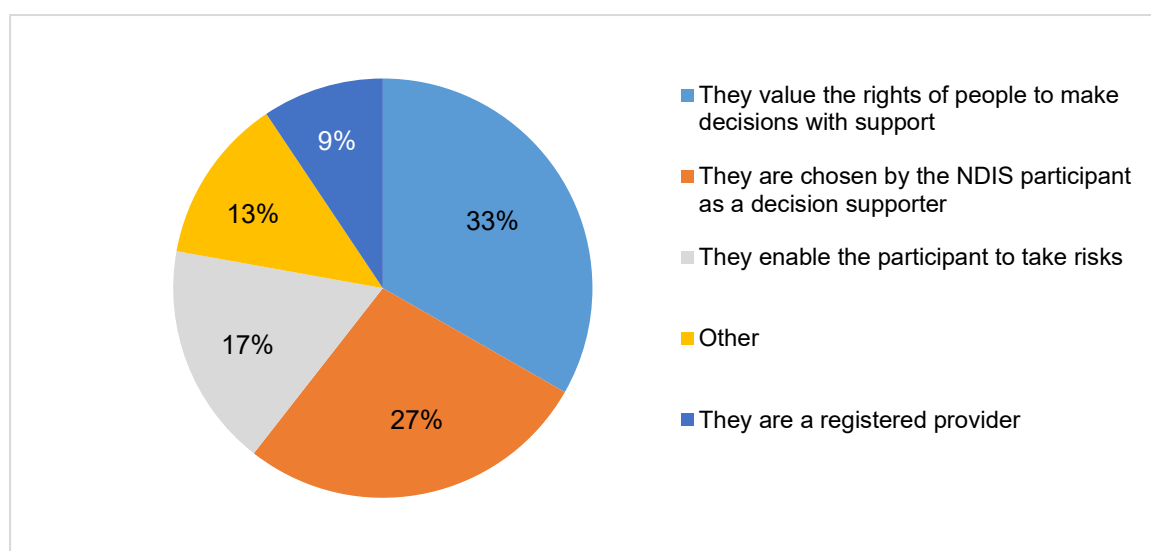


*Figure 5. Responses identifying how decision supporters can get better at helping*

## Question 5

**We asked:** How can we make sure the right people are helping? For example: that they are building the capacity of the person with disability. That they are considering what the person with disability wants.

**Your response:** the majority of what we heard was that the most important aspect of a decision supporter is that they value the rights of people with disability to make decisions (33%). You also indicated that the decision supporter should be chosen by the NDIS participant (27%) and should enable the participant to take risks (17%). There were only a small number of responses that indicated it would be okay if the decision supporter was a registered provider (10%). There were also a significant number of other things (18%) that you advised make a good decision supporter, including an absence of conflict of interest, knowing and understanding the person with disability, independence (no financial or other gain), being accredited or trained, and ensuring the decisions are made and directed by the person with disability.



*Figure 6. Responses indicating how to identify the most appropriate decision supporters*

## Question 6

**We asked:** What should decision supporters know about so they can better help people with disability make decisions?

**Your response:** The responses to this question were in agreement, with very low variability between the options. You advised that decision supporters need guidelines available (24%), scenarios or examples of good decision making (22%), information sessions available to them (22%), and support networks for both people with disability and decision supporters

(22%). You also advised of other things (9%) that decisions supporters need to know, including a strong understanding of disability, their local community, the disability sector, the NDIS and the rights of people with disability. Decision supporters also said they would like guides about how to be an effective decision supporter.
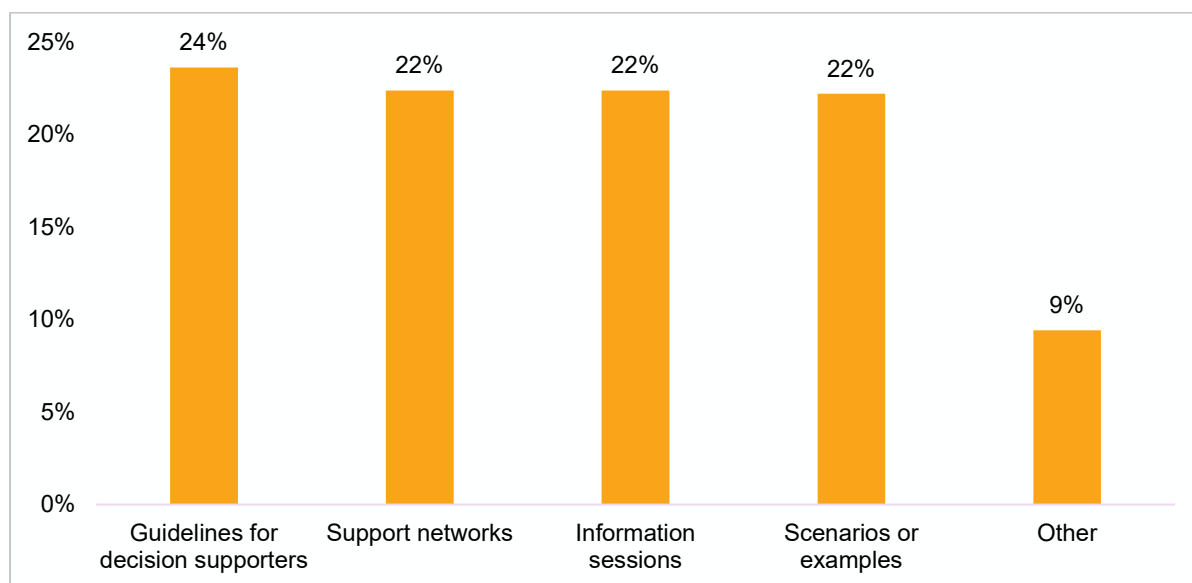


**Figure 7.** *Responses identifying what decision supporters need to get better at supporting*

## Question 7

**We asked:** Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?

**Your response:** Respondents answered this question by discussing what worked well when making a big decision and what did not work well. Over both types of responses, the most important factors in making a big decision were the time to discuss and make the decision, and the person with disability being heard and listened to by their decision supporters.

Some of the key themes included:

- That the formal and informal supports around a person with disability collaboratively work with the person to support them to make decisions.
- That the most important things a decision supporter can do are to:
  - take the time to assist with making decisions, discuss and consider options
  - listen to the person with disability
  - know and understand the person with disability
  - check for understanding when discussing decisions
  - make sure that options provided are relatable, open and transparent
  - make sure that person with disability directs all decisions

- That there are a number of ways that the NDIS can be improved, with a key focus on Agency and partner staff capability. In particular:
    - improved communication and listening skills
    - increased understanding of Support for Decision Making
    - understanding of varying decision support requirements of people with disability
    - understanding that there will be varying levels of decision making experience and that some people with disability may not want to be more involved in decision making
    - understanding how a person communicates and then ensuring that person is heard and understood
    - increased understanding and awareness of the rights of people with disability and the concept of dignity of risk
    - providing people with disability the time and space to make decisions
    - providing resources and information in accessible formats and through multiple sources; and
    - working collaboratively with the person with disability and their decision supporter/s.

## Question 8

**We asked:** What is the best way to support people with disability to make decisions about their NDIS plan? (This includes decisions about using your plan, making sure your plan works well and changing your plan).

**Your response:** The majority of what we heard was that information and resources (25%), guidance tools (21%), practice (19%), and peer support networks (17%) would help people with disability make decisions about their NDIS plans. You also told us other things (16%) that could help including:

- making sure all information, guidance and tools are clear, accessible, easy-to-use and transparent in their processes.
- There was quite a consistent number of responses that indicated that the lack of flexibility around plan funding reduces the opportunities of people with disability to make decisions.
- You also said if we make it easier for you to interact with us understand and use your NDIS plan, you can focus on the decisions you need to make.
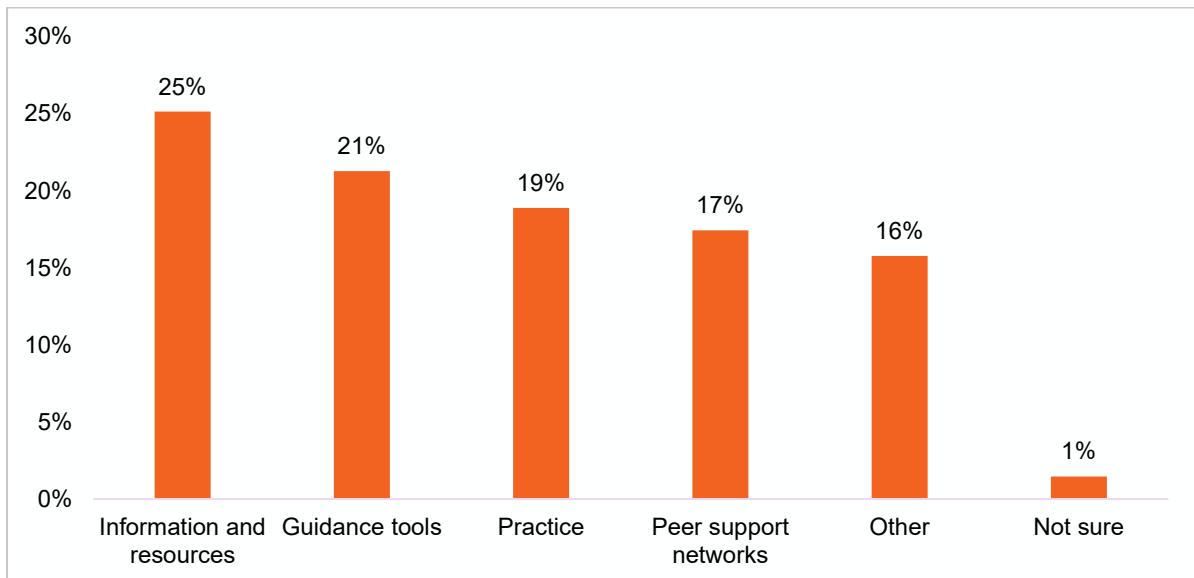
*Figure 8. Responses identifying the best ways to support people with disability make decisions about their NDIS plan*

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## Question 9

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**We asked:** Are there different things to consider for people with different disabilities or cultural backgrounds?

The options:

- an intellectual disability
- a disability that impacts how they think (cognitive impairment)
- a psychosocial disability
- a disability that impacts their ability to communicate
- from a CALD community
- from an Aboriginal or Torres Strait Islander community; or
- from the LGBTQIA+ community.

**Your response:** The responses were spread relatively evenly between the different disabilities or cultural backgrounds – so you want us to make sure we have an approach to Support for Decision Making which is responsive to all people with disability and cultural diversity. Most often you said that there were specific considerations for people with intellectual disability and cognitive impairment. Across all responses, there were quite similar themes, the major differences being that the responses to questions about disability-specific considerations had themes more related to accessibility, training, understanding and time; while the responses relating to cultural considerations had more to do with cultural awareness, co-design and knowing the person.
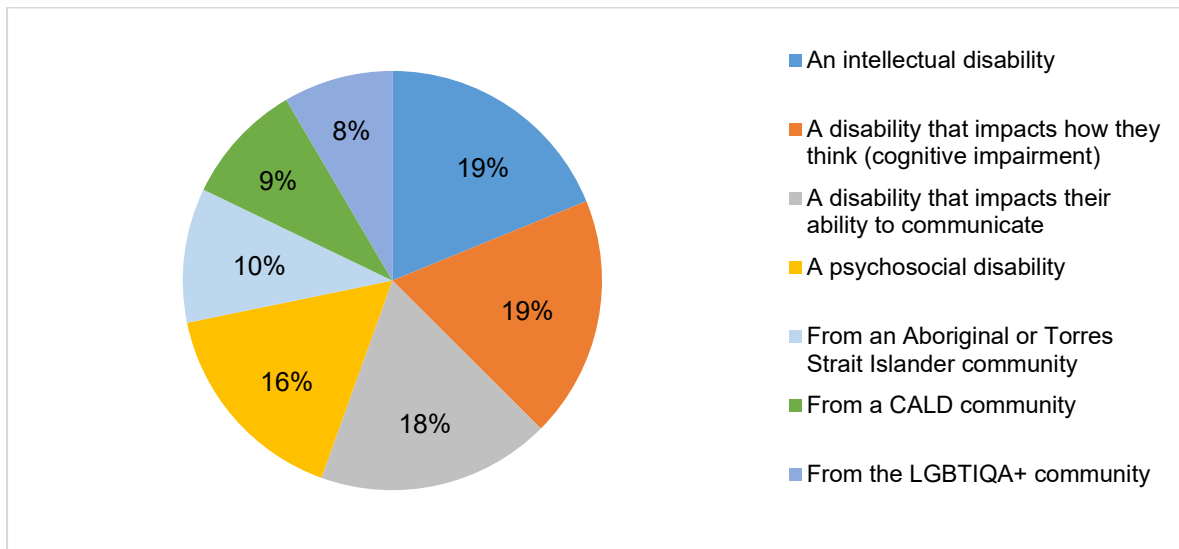
*Figure 9. Responses identifying the different disabilities or cultural backgrounds that require specific consideration*

Some of the key themes included:

- The characteristics of decision supporters were important to all of these groups, with a focus on their traits, motivation and communication skills. Specifically:
  - that decision supporters know and understand the person with disability
  - that decision supporters are culturally aware, and
  - that decisions supporters communicate in the person with disability's preferred format.
- There be a focus on the Support for Decision Making needs of people with disability, in particular the resources and content. Specifically:
  - that all resources are created with an understanding that decisions take time
  - that all resources are accessible to all audiences, and
  - that there is a particular focus on technology/communication aids to support people with disability.
- That Agency and partner staff capability is increased, with a focus on the following areas:
  - Cultural competence and awareness
  - Increased disability awareness and understanding
  - Support for decision making training for all staff
  - That it should not be assumed that people cannot make decisions
  - Human rights and dignity of risk, and
  - Co-designing with people with disability.

- That there be a particular focus on improving access to support and increasing the types and options of support. Specifically through:
    - Increased support networks and investing in micro-boards, and
    - Accessible Support for Decision Making resources.
- That the Agency build into all resources and communications the concepts of human rights and autonomy.

## Question 10

**We asked:** Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit. How can we help reduce conflict of interest?

**Your response:** The majority of responses were related to who the decision supporters were and their roles and responsibilities.

Some of the key themes included:

- That decision supporters should be independent from the person with disability and have no financial gain attached to the decisions.
- That there should be specific guidelines around the roles and responsibilities of decision supporters, which provide guidance about conflict of interest.
- That there should be audits and governance around decision supports, especially paid decision supporters.
- That circles of support or micro-boards could help reduce the conflict of interest, as there are more supporters to hold everyone accountable.
- That independent advocates are required as they often help reduce potential conflict of interest.
- That in all decisions the person with disability should be directing the action.

## Question 11

**We asked:** Undue influence is when a support person makes the person being supported do something they don't want to do by making them feel scared, by being mean or by threatening or lying to them. How can we help reduce undue influence?

**Your response:** Most responses to this question were to do with the decision supporters characteristics, role and responsibilities, and how the NDIA can ensure this is governed correctly.

Some of the key themes included:

- That decision supporters needed to be independent from the decision being made, whether financially or otherwise.
- That NDIA staff need training to identify undue influence and help to counter it.
- That independent advocates are a prime example of a decision supporter who can help to reduce undue influence.
- That there needs to be adequate monitoring, evaluation and audits of decision supporters, both formal and informal.
- That decision supporters can both heighten or reduce undue influence. For example, by acting according to the person's will and preference and not another party or their own views and by ensuring there is separation of roles or duties.

## Question 12

**We asked:** What are your concerns (if any) around people with disability being more involved in making decisions for themselves?

**Your response:** Many people did not have concerns about people with disability being more involved in decision making. The majority of responses were related to the risks of decision making, the rights and autonomy of people with disability and the various things that impact decision making.

Some of the key themes included:

- That decision making is a skill that is learned and that providing opportunities for people to make decisions will increase their understanding of the risks around decision making.
- That consideration needs to be given to understanding the capacity of people with disability to make informed decisions.
- That there needs to be greater understanding and training around autonomy and the dignity of risk.
- That the types of decision supporters involved can increase or decrease the risks around decision making. The characteristics of a decision supporter who decreases risks are that they:
    o provide opportunities for decision making
    o listen to the person with disability
    o aim to ensure the person with disability is independent, and
    o ensure decisions are directed by the person with disability.

## Question 13

**We asked:** What else could we do to help people with disability to make decisions for themselves? Is there anything missing?

**Your response:** The majority of responses gave feedback on ways in which the NDIS and the Agency could improve in order to support people with disability to make decisions. There were also a number of responses that discussed the specific Support for Decision Making needs of people with disability, the barriers and what decision supporters could do to help.

Some of the key themes included:

- The need to incorporate Support for Decision Making throughout the access and planning process.
- The need to ensure that all communications related to the NDIS are accessible and that the environment and context of decisions are accessible.
- The need to make it simpler to engage with the NDIA so that people can have greater choice and control and focus on the information they need to make decisions.
- To include funding for decision supports and Support for Decision Making in a participant's plan.
- The need for our staff to provide consistent advice and not assume someone cannot make decisions.
- To ensure a strong focus on listening to people with disability is ingrained in all things that Agency and partner staff do
- That there is a strong overall focus for messaging and information to the disability community (inclusive of the NDIA) around the rights of people with disability.

## Question 14

**We asked:** Do you have any feedback on our proposed actions in Appendix C of the paper?

**Your response:** The responses that addressed the actions in our 'Proposed next steps' (Appendix C) were mostly positive, with a significant amount of constructive feedback on areas that could be improved.

Some of the key themes included:

- A need for the Support for Decision Making policy and implementation plan to be co-designed.
- That the rights and autonomy of people with disability are respected and understood by the whole of the NDIA.

- A need for increased training and awareness for Agency and partner staff in:
  - Cultural awareness
  - Disability awareness, and
  - Communication and listening.
- That we should focus on the support someone needs to make a decision rather than assessing someone's capacity to make a decision.

# Appendix B – Your suggestions

In your feedback to us, you provided a lot of suggestions on how we can improve Support for Decision Making. We have put your suggestions into groups related to general ideas, legislation, policy, design and implementation of Support for Decision Making.

## 1. General – Ideas that we need to always consider

**Communications and Engagement**

- Provide the revised policy framework in plain English and tailor the information to the individual's requirements so that all participants, their families and carers can access the information.
- Keep listening to feedback from people with disability to continuously improve the NDIA's creation of accessible information.
- Co-ordinate external consultations so they do not occur all at the same time.
- Develop an "opt-out" system where participants automatically receive information about Support for Decision Making and are supplied with options and follow up around accessing this support.
- Check-ins to include relationship and trust building with participants.
- Provide communications and information in formats other than online or paper.
- Explain major policy changes and the impacts these might have on the disability community.
- Identify clearly how participants with autism fit into Support for Decision Making.
- Highlight the intersection between decision support and advocacy.
- The Australian Government provides additional communications funding to a peak Aboriginal Community Controlled Organisation, so that they can continue to expand their NDIS communications work for Aboriginal and Torres Strait Islander participants, their communities, families and carers.
- Plan management services should demonstrate provision of person-centred communication and engagement training for NDIS accreditation – this should be a registration requirement.
- Easy Read should always be accompanied by graphics to give readers optimum information.
- Always provide options for engagement via face to face, personalised contact.
- Listen to people with disability. Prioritise people with disability, their families and carers as critical sources of information in any communication and engagement process.

- Engage with empathy and respect at a pace set by people with disability, their families and carers.
- Practice a trauma-informed approach in any communication and engagement process.

## 2. Legislation – The rules for what we do

- Strengthen the NDIS Act 2013 in its enacting of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) articles 3, 4 and 12.
- Amend Australia's declaration entry under the UNCRPD with a clear and prominent statement that 'substitute decision making is replaced with supported decision making',
  - Make sure the NDIA understands that this will require small steps and changes so that decision-support systems and legal structures can continuously change and improve to meet this aim.
- Clarify and align the NDIA's Support for Decision Making work and legislation relating to Trustees and Guardianship.
- Remove the single-point entry for appointment of plan nominee.
  - Instead put in place a collective model (featuring a community circle of supporters) with appropriate safeguards and dispute resolution features.
- Collaborate with the Attorney-General's Department to:
  - put in place a national register for enduring powers of attorney (EPOAs) in relation to financial matters and for all enduring instruments, and
  - lead the harmonisation of laws about enduring powers of attorney and other advance decision-making instruments.
- Make sure NDIA is meeting the legal requirements of the states and territories around guardianship and administration law.

## 3. Policy – The ideas that guide what we do

**Concepts and approach**

- Re-consider the approach from 'assessing a person's capacity' to focusing on the supports someone needs to make decisions.
- Provide more clarity about how we propose to 'assess a person's capacity' or need for a nominee.
- Consider decision making as relational interdependent and changeable, rather than individualised and independent.

- Describe decision making in the Decision Making Capability Framework in a more true-to-life way.
- Presume capacity for supported decision making.
- Focus on the support needed to make choices rather than the outcome of the choices.
- Recognise that learning to make decisions starts in early childhood, and the policy should include reference to Child Representatives.
- Start supported decision making before the age of 16 – extend the Framework to provide for Young People (13 – 17) as well as young adults.
- Embed Support for Decision Making in all areas of the Agency, not an isolated policy.
- Acknowledge and discuss the role of carers in Support for Decision Making and identify how we will support carers.
- Recognise that support is required at the community level in aspects such as community attitudes, community awareness to reduce barriers.
- Include more aspirational key principles.
- Strengthen the human rights basis of the proposed policy, including the right to exercise legal capacity to make decisions.
- Clearly convey a human rights-based approach from the start of a participants and family's experience with the NDIS.
- Define supported decision making, recognising that decision-making happens on a continuum or could be represented as a spectrum.
- Recognise that a number of people can be decision supporters.
- Acknowledge that Support for Decision Making can be resource intensive.
- Take a person-centred approach rather than over reliance on 'typical' life stage transitions that may not map onto the experiences of individuals (in context of intellectual disability, cognitive impairment and or psychosocial disability).
- Differentiate between Support for Decision Making and supported decision making.

**Systemic considerations**

- Look at systemic barriers to supported decision making within the NDIS and how to overcome them.
- Continue to acknowledge the ongoing need for independent advocacy around NDIS issues.
- Introduce a pre-planning process prior to the NDIS planning meeting for individuals who live with an Intellectual Disability.
- Introduce simplified and standardised service agreements.

- Provide education of what is possible around an ordinary life outside of care, as expectations can be lower than the rest of society.
- Look at how an NDIS framework could align and / or influence practice in other mainstream interfaces, such as education.

**Alignment**

That the NDIA should align with or adopt existing work, including national strategies and frameworks, and clarify interfaces with other systems of supported or substitute decision making (such as medical and financial decisions) and consent. Lots of existing work and resources about Support for Decision Making were recommended such as:

- The Australian Law Reform Commission's National Decision Making principles.
- The University of New South Wales' Good Practice in Supported Decision-making for People with Disability Report prepared for the Department of Social Services.
- The La Trobe Support for Decision Making Practice Framework.
- The Independent Mental Health Advocacy service model that promotes supported decision making and embed lived experience leadership, and co-designed and co-produced training modules.
- The Victorian Department of Human Services Supported Decision-Making guide
- Resources and capacity building work that disability organisations have, and are, producing about Support for Decision Making.
- The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and decision-support principles, specifically when addressing the Nominee Rules.

**Reflection of diversity and specific needs**

- Do more work to ensure the policy reflects the perspectives and decision making support needs of:
  - Aboriginal and Torres Strait Islander communities, especially those who are disconnected from family and cultural networks
  - Culturally and linguistically diverse communities
  - Complex Communication Needs
  - Young people in out of home care and institutional settings, particularly First Nations children and young people
  - People with psychosocial disability
  - LGBTIQA+
  - Participants with no informal supports.

- Look into targeted approaches for the above groups (e.g., the utility of peer support for particular groups).
- Recognise those who will always need support or substitute decision making.

**Language**

- Define and use the terms 'capability' and 'capacity' more clearly.
- Use the word 'decision' rather than 'choice' for the role of the participant.
- Use 'supported decision making' as the term which applies to both the process, and resources and tools.
- Do not use the term 'best interest' in policy or framework.

**Decision factors**

- Consult more deeply with people with disability, families and other supporters, and disability representative organisations on how decisions and what is needed to make decisions interacts with the NDIS Support for Decision Making policy.
- Ensure the approach also considers the decision itself (such as impact) and the broader environment in which the decision is being made (for example, opportunities and time).
- Ensure the conflict of interest policy takes into account that conflicts in service provision are not always malicious and that using a strong compliance approach with registered providers to try and eliminate all risk of conflict of interest is unlikely to be a practical or appropriate response.
- Ensure Support for Decision Making policy considers people with dual disability diagnosis.

**Safeguards**

- Provide more detail about safeguards in the policy.
- For the NDIS Quality and Safeguards Commission:
  - Take responsibility for guidance and monitoring of supported decision making processes by service providers, especially home and living providers.
  - Manage a registration process for informal and formal decision supporters (including support coordinators and plan managers).
  - Regulate potential conflict of interest situations.
  - For there to be additional checks for NDIS Service Providers who apply to be Nominees or Guardians.

- Recognise that all decision supporters and the NDIA (in addition to service providers) have responsibility to safeguard the participant against undue influence in making and implementing decisions.
- Safeguard against the risks of leaning too heavily on informal support networks.
- Safeguard against the potential undue influence of service providers (and provide guidance around how they can enable risk).
- Safeguard against the risks of family violence, including identification and the considerations that this will have on decision making capacity.
- Recognise the need of people who have no informal supports, or ageing parents, and the potential risks involved.
- Safeguards in place to ensure limited or no conflict of interest between participants and plan management service providers.

**Risk**

- Consider dignity of risk, enabling risk and the right to make 'unwise' decisions in the Decision Making Capability Framework.

**Rights and consent**

- Make sure the policy upholds the rights of people who cannot or will not consent to Support for Decision Making.
- Separate the concept of capacity from good, rational decision making.
- The policy should reiterate that it is the person's choice whether they want support with decisions or not and the best people to help with decision-making are those that the person chooses.
- Acknowledge that people have the right to make bad decisions.
- Review a participant's right to request changes to their plan without a nominee's consent.
- Review potential harm of current nominee rules to victim-survivors of family violence.
- Require a substitute decision-maker, such as a plan nominee, to act on the basis of the person's will and preferences as much as possible, rather than on the basis of perceived best interests
- Language in the policy conveys a message that a participant's access to decision-making support will be determined by the Agency. This fails to reflect the ethos of the CRPD which requires people with disability to make their own decisions, including deciding upon how their decision-support needs can best be met. The policy's

starting point must be to establish the views of the participant with respect to how best to meet their decision-support needs.

**Guardianship**

- Clearly explain the limitations of the NDIA's policy on guardianship, its relationships between different state/territory guardianship systems and how the NDIS Support for Decision Making policy will interface with those systems.

**Provision of formal decision support**

- Block fund formal decision support under the NDIS Support for Decision Making policy to be provided by independent decision supporters who are best placed in independent advocacy organisations and DROs.
- Fund and strengthen currently funded advocacy, especially if the NDIA is introducing policy which may increase the need for advocates.
- Prioritise funding and resources for LACs, NDIA planners and support coordinators.
- Invest in and encourage longevity in the service relationship between decision supporters and people with disability

**Provision of informal decision support**

- Fund peer support for young people, their families and other informal supporters.
- Make sure decision making capacity building activities are developed and funded through a focus on ILC/Tier 2, including training opportunities, supported decision making tools, and resources for non-professional decision supporters.
- Longer term funding for initiatives through ILC
- Work together with other government bodies to ensure appropriate funding of peer support and capacity building for decision supporters.
- Invest in capacity building to improve decision making support across the broader community
- Consider life coaches and access to independent mediation

**Plan funding**

- Therapeutic support to increase participant involvement in decision making
- Make sure the flexible use of plan funds.
- Fund decision support:
    - For day-to-day lifestyle, personal and financial decisions
    - In advance of significant life transitions

- o For NDIS-related planning.
- Fund the setup and management of circles of support
- Fund trials of support providers to enable participants to practice and take risks in their decision making.

**Role of decision supporters**

- Separate out responsibilities for informal and formal supports.
- Assist 'traditional' decision makers to relinquish some control, power and authority.
- Use a matrix of decision making to help guide decision supporters.
- Be aware of the role of supporters in decision-making and where the boundaries lie.
- Engage with peer networks.
- The decision supporter should provide mentoring, feedback, guidance and role modelling.
- In many instances it was preferable to allow the autistic person to engage in goal setting without their parent or carer present.
- Recognise microboards and other forms of support
- Encourage shared decision making approaches.

**Role of participants**

- Include a responsibility for participants engage a formal decision supporter where appropriate.

**Role of the NDIA**

- Clarify what is meant by reviewing progress of capacity building initiatives at plan review and how the NDIA proposes this will be done so that the disability community can provide feedback.
- Ensure appropriate levels of funding are made available so participants can afford opportunities to explore other options for support.
- Openly acknowledge the financial boundaries of Support for Decision Making.
- Clarify how decision making capacity and outcomes will be measured.
- Clarify how overall wellbeing / outcomes of NDIS transition will be measured.
- Acknowledge the gap in interactions between the NDIA and other statutory systems.
- Engage in inclusive recruitment at all levels, including in higher delegate positions, in NDIA to ensure comprehensive representation of the lived experience of people with disability as well as people who identify as LGBTIQA+, First Nations People and/or culturally and linguistically diverse (CALD).

- Representation of people with cognitive impairment must be included in any inclusive recruitment at the NDIA, including in higher delegate positions.

**Role of service providers**

- Clarify the role of Support Coordinators as they often fill the role of decision supporter.
- Recognise the role that allied health professionals have in supporting people with disability in making decisions.
- Separation of SIL and Support Coordination should be a priority for NDIA.
- Clarity and support for providers to navigate the balance between dignity of risk and duty of care.
- Consider role of unregistered providers.
- Require NDIS service providers to adhere to supported decision-making practices.
- Service providers must accurately document the instances of successful decision making by each participant.

**Evaluation**

- Policy and implementation should be measurable and quantifiable. Quantitative data should be paired with qualitative information, where appropriate, to guard against overly blunt evaluation instruments.

4. Design – Getting ideas ready for action

**Rights and consent**

- Make sure the operational framework for consent and informed decision making upholds the rights of people who cannot or will not consent to Support for Decision Making.
- Make sure when reviewing nominee appointments, the participant is spoken to directly, outside of the influence of the appointed nominee.
- Make sure that persons, including those with appointed decision-makers, are always involved in decision making using a capacity building approach.

**Provide examples**

- For how the Decision Making Capability Framework would support people with disability to make complex life decisions.
- When providing examples of options, ensure to include a 'way out' of the decision.

**Co-design**

- The Decision Making Capability Framework with people with cognitive disabilities (including intellectual disability, autism and acquired brain injury), their families and other supporters, and disability representative organisations.

- Tailored supports to enable participants who have no decisions supporters to communicate their will and preferences.

- The finalisation of the Framework, Implementation Plan and Operational Guidelines, by work closely with participants, carers, families, friends and other unpaid supports (both informal and Nominees) to ensure the policies and guidelines both align best practice, and are practically applicable and tailorable to real life.

- Consult with children and young people directly at before finalising the Decision Making Capability Framework, and on individual capacity building resources and information.

- Undertake further community consultation in the context of psychosocial disability.

- Ensure the active involvement of diverse communities, including people who experience mental health issues or identify as having a disability, First Nations people, people from culturally and linguistically diverse backgrounds, LGBTQIA+ community members, people with different socioeconomic backgrounds, young people and older people.

- The Support for Decision Making policy and implementation plan with advocacy organisations.

- The formal process to identify a participant's decision making capacity with the Australian Psychological Society.

- NDIS planning and review processes with participants, families, carers, disability advocacy and representative organisations to ensure each participant has their voice heard and decision-making rights are maximised.

- More inclusive language.

- Build time into decision making processes to enable the decision process to progress at the pace required by the disabled person.

**Workforce development**

- Have systems and processes that can demonstrate that staff understand and demonstrate disability awareness, rights of people with disability, the concept of 'dignity of risk', and listening skills. This might be done through increased training.

- Work with people with cognitive disabilities to co-design and present/implement supported decision making training for NDIS Planners and Local Area Coordinators (LACs).
- Adolescent/Adult Goal Setting Tool and associated professional training could support NDIS planners in facilitating genuine self-determination of neuro-divergent people including those on the autism spectrum.
- Establish /improve qualifications required of service providers.
- Work with DROs to set up formal decision support services.

**Early childhood capacity building**

- Provide capacity building supports for decision making and aided language stimulation to children and their families from early childhood.

**Safeguards**

- Introduce appropriate safeguards for young people as they transition between decision-making frameworks at the onset of adulthood.
- Clear guidelines for care-teams, circles of support and microboards.

**Decision supporter's needs**

- Advocacy training for decision supporters.
- Guides about how to be an effective decision supporter.

**Nominees**

- Analyse the factors that led to the current state of the NDIS nominee process.
- Nominee appointments should go through a considered approach before occurring.
- Stop the involuntary appointment of Nominees.
- Regular reviews of nominee appointments.
- Easy to access avenues for complaint or redress for participants in relation to their nominees.
- Dedicated 'hotline' for nominees and participants to call regarding complex decisions.

**Identify need for Support for Decision Making**

- Provide participants with access to an independent source who can assess whether they have the support they need.
- Make sure safeguards in place to manage variability in determining a person's decision making capability.

- Make sure the process for determining a person's decision making capability is a transparent process and provide information around the evidence that will be used.
- When using business intelligence to determine need, ensure safeguards are in place against pitfalls of automated systems.

**NDIA system**

- Add the ability to capture multiple decision supporters.

**Operations**

- Have consistent contacts or key workers for participants to assist in building relationships with NDIA staff. This has been raised by a number of ACCOs.
- Recognise that some people require the NDIA to provide a case management style of service delivery.

5. Implementation – Making it happen

**Capacity building for support for decision making**

- Resource the disability community to support people with disability and their decision supporters to understand effective Support for Decision Making and build this practice.
- Upskill support coordinators to actively engage with a youth justice cohort.

**Co-design**

- Develop the implementation plan with the disability community through a co-design process.

**Communication and Engagement**

- Establish communication pathways to facilitate communication across systems (including health/justice/mental health/guardianship) to ensure that all factors encompassing the client and the decision at hand, are taken into consideration.
- Use check-ins (both over the phone and in person) to ensure people are getting Support for Decision Making.
- Use plan and clear language in the implementation plan.
- Tailored and targeted approaches (including communication formats) for people with different disabilities or cultural backgrounds in the implementation plan.

**Engaging with Support for Decision Making supports in local communities**

- Refer participants to independent advocacy organisations when there is a need for formal, independent Support for Decision Making.
- Make sure LACs and Planners are informed of the supported decision making capacity building activities available in their area. Perhaps a directory of supports could be developed that all NDIS Partners in Community can access.
- Develop a directory of decision making supports in local communities for all NDIS Partners in the Community to use.
- Train people in the community to facilitate and support decision making so they can provide guidance and direction over family involvement to ensure the best interests of the PWD and that NDIS best practice principles are maintained.

**Enabling risk**

- Provide guidance to service providers on how they can enable risk.
- That using a reduction of nominee appointments is not a good measure of success and how we measure our progress here should focus on having a stronger process for how we appoint, support and review nominees.

**Evaluation**

- Build a robust evaluation process into the implementation plan to ensure success of the chosen path.

**Information and guidance**

- Develop guidance for decision supporters based on the lived experience advice of people with disability, families, advocates and representative organisations.
- Provide accessible information for decision makers that focuses on the strengths and skills people already have to make their own decisions, the supports that a person has or needs in their life, and how the NDIS can support people to build skills.
- Centre information designed for decision supporters around the person with disability they are supporting.
- Explain different ways for making and supporting decisions so that people can choose a way that is right for them.
- Provide consistent, up-to-date, accessible guidance about how the NDIS works.
- Any communication should be in Easy Read English and be available to be translated into multiple languages, including Braille. The person with disability should have the option to choose their preferred form of communication and have their accessibility needs taken into account.

- Use the La Trobe support for Decision-making practice framework to support implementation.
- Include guidance around restrictive practices and Support for Decision Making.
- Develop education and resources for NDIS staff and partners, support coordinators, plan managers, support workers, providers and nominees which includes:
    o understanding the fundamental human rights principles that underpin supported decision making
    o supporting the development of reflective ability around the decision-making process
    o facilitating appropriate documentation of supported decision-making processes used
    o understanding and identifying biases and undue influences, and
    o articulating the benefits of supported decision making.

**Workforce development**

- Include a focus on staff development and training, and a strong change management component in the implementation plan.