

**ndis**

National Disability Insurance Scheme

# Companion Paper: Supporting you to make your own decisions

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# Support for Decision Making

This document complements the '[Consultation Paper: Supporting you to make your own decisions](#)' that was released for public consultation on 21<sup>st</sup> June 2021. This document was developed based on input from a range of stakeholders including:

- members of the Participant Reference Group
- members of the Independent Advisory Council's Intellectual Disability Reference Group
- Advocacy Organisations
- Disability Organisations
- Peak Bodies
- Leading Academics in Supported Decision Making, and
- Department of Social Services.

Input from these stakeholders also informed the development of the proposed Support for Decision Making Framework that is available for comment in the [Consultation Paper: Supporting you to make your own decisions](#)'.

## Current State of Decision Making

There are a wide range of resources and supports to help people with disability to learn and practice making decisions. This can include both informal and formal supports and ranges from peer support to supportive networks of family and friends (such as Circles of Support and Microboards). In some circumstances, there is a need for a substitute decision maker.

We know that the current environment can often be weighted towards substitute decision making. Participants are not always provided with the chance to make the decisions they are able to or supported to improve their ability to make decisions. We want to change this so participants are supported to have more control about decisions that impact them.

The following section outlines the roles or types of support that are currently the most common.

### Decision resources and support

There are a range of supports and resources that can support a participant to make decisions or help the participant to identify and communicate their will and preference. These options do not take away the participant's authority to make their own decisions.

#### Advocacy

Independent advocacy is a disability support that has been in place for a long time. The National Disability Strategy states that 'Disability advocacy enables and supports people with disability to safeguard their rights and overcome barriers that impact on their ability to participate in the community'. Independent advocacy often involves helping people to find or understand information and options. It also helps people to communicate and pursue their preferences and goals. Individual and systemic advocacy supports are funded by Government (state and federal). The NDIA does not fund independent advocacy.

## **Circles of Support**

A Circle of Support (CoS) is a group of people who volunteer to meet with a participant on a regular ongoing basis to help with thinking, planning and acting on their personal goals. This group is usually people already involved in the person's life such as family, friends and associates. There is some tentative evidence to support the use of skilled facilitators to recruit and build intentional relationships and CoS for a person who does not have informal networks.

A CoS gives the participant the chance to develop these relationships and discuss their life goals and aspirations. It puts the person with disability at the centre and provides support for decision making by:

- listening to the person's ideas
- supporting their choices
- identifying their goals and aspirations
- planning to make things happen

## **Microboards**

A Microboard is a legal entity made up of a small group of people. 'Micro' means small and 'board' means a non-profit/non-government agency. These are usually made up of committed family and friends of a participant. These people form an incorporated association to work with the person to make sure their wishes and needs are met.

The role of a microboard role can include:

- clarifying a life vision and goals
- helping the person to have a meaningful life and make meaningful contributions
- assisting with coordinating support services
- finding and keeping employment
- facilitating friendships and community access

A Microboard can receive funds for the person (at the centre) and is a more formal way to provide support for decision making. Some forms of Microboards don't want or request money and only provide support for decision making to work towards the person's goals in life.

## **NDIA Staff and Partners**

NDIA staff, Local Area Coordinators (LACs) and Early Childhood (EC) partners understand that it is important to support participants to make decisions. Their role is to help the participant to understand the decisions that are required as part of being an NDIS participant. Their role is to also connect them to the right decision making supports at the right time.

## **Consent Forms**

The use of consent is an alternative to the use of a substitute decision maker like a nominee. The NDIA has two forms of consent:

- 'Consent for the NDIA to Share Your Information'

- ‘Consent for a Third Party to Act on Behalf of a Participant’.

The NDIA is developing an operational framework for Consent and Informed Decision Making. This will help NDIA staff and partners to make sure that participants, their informal supporters and legally appointed decision-makers understand their rights and responsibilities when making informed decisions and giving consent.

The use of consent assumes that participants have the ability to make their own decisions unless proven otherwise. We understand that a participant’s ability to make a decision can change for different types of decisions and situations.

## Capacity Building support

There are a range of supports and services that help participants to build their decision making capacity. Some of these supports can be part of the participant’s NDIS plan and others are available through other organisations.

The National Disability Advocacy Program (NDAP), run by DSS, is running a Decision Support Pilot. They are targeting people interacting with the NDIS who have limited decision-making capacity and no decision-making support such as family, friends or a guardian. This pilot has been extended until 2022.

### Self-Advocacy

Self-Advocacy supports people with a disability to build their skills and confidence to speak up for themselves, understand their rights and have greater control over decisions about their life. Self-advocacy focusses on empowerment and leadership. It also includes having opportunities to connect with peers and represent themselves and others in public forums.

### Self-Advocacy Groups

Further to above, Self-Advocacy groups are also an important capacity building option. Self-advocacy groups are groups that are run by people with disability who join together to support each other to listen, hear and learn from each other. Self-advocacy groups provide opportunities for members to learn and speak up about their rights, have a say about the services they use and want, and collectively work together to make changes happen.

### Peer support and individual capacity building

Peer support can also play an important part in support for decision making. This can be individual or in groups. They are often helped by organisations run by and for people with disability (known before as Disabled People’s Organisations and Family Organisations – DPFOs). A peer support network is where people get together as equals to give each other support because they have similar experiences or circumstances in their life. There is evidence that peer support helps people feel more confident, capable and less isolated.

Many advocacy and/or disabled people’s organisations run peer support networks. These may be self-advocacy groups (see above) or other networks or groups arranged by age, gender, disability type, interest or for another reason. They can also be ‘self-help’ groups, or networks arranged by local associations. These groups might come together because of the type of disability, health condition or diagnosis. Networks, or communities of people with disability, encourage people to support each other, to be involved in the community and to grow as a person. They also help with education, information sharing, and networking on the ‘grassroots level’.

## Information, Linkages and Capacity Building

As part of the NDIS supporting all people with disability to access information and referral services, a Tier 2 was created. This was based on a recommendation from the Productivity Commission in 2011. This was funded through the Information, Linkages and Capacity Building Program (ILC). In mid-2020, the responsibility for the ILC moved from the NDIA to the Department of Social Services (DSS). This was to make sure the ILC aligned with the new National Disability Strategy and other national disability programs. The NDIA is continuing to work with DSS about the ILC. This includes how it overlaps with the Local Area Coordinator role.

As part of the ILC Investment Strategy 2019-2022, funding was given to Disabled People's Organisations and Family Organisations. This was so they could do more work in capacity building with participants and non-participants. This includes support for decision making. Opportunities exist to leverage the role of ILC funded organisations who work with people most likely to benefit from support for decision making.

## Recovery Coach

A Psychosocial Recovery Coach helps participants take more control of their lives and manage the challenges of day-to-day living. They work with participants, families, carers and other services to design, plan and put a recovery plan into practice. They also help with the coordination of NDIS and other supports.

Participants can choose from two types of recovery coaches. They can have either lived experience or learned knowledge of psychosocial disability and mental health.

## Support Coordinators

NDIS Support Coordinators support participants to develop skills to manage their supports. They help them decide how they would like to be supported and who they would like to support them. They help participants build their ability to exercise choice and control, coordinate supports and access the local community.

## Substitute Decision Making

There are instances when substitute decision makers make decisions for the person with a disability. The appointment of a substitute decision maker can be set by the NDIS or under state or territory government systems. The NDIS interacts with these complex systems that vary across states and territories.

## Nominees<sup>1</sup>

A nominee in the NDIS is a decision 'supporter' for people over 18 who are unable to make their own decisions. They should include the participant in decisions and build their decision-making capacity. They also have the authority to make decisions on the participant's behalf. Nominees must 'reasonably believe' that they have tried to understand the participant's wishes and that the decision they make will improve the participant's health and wellbeing. There has been some concern, including from the Independent Advisory Council (Council),

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<sup>1</sup> A nominee under the NDIS is a person who is appointed to act and make decisions for a participant over the age of 18 who is deemed unable to make their own decisions. Appointments of nominees will be justified only when it is not possible for participants to be assisted to make decisions for themselves. It is the duty of the Nominee to involve the participant in decision-making that affects them, including making decisions for themselves, to the extent possible

that nominees are overused and are not given enough support to perform their role in the NDIS context.

Under the NDIS (Nominees) Rules 2013 (section 3.3 and 3.14 (b)(ii)), a nominee should be appointed only when:

- participants cannot be assisted to make decisions for themselves
- it is necessary
- as a last resort
- with appropriate safeguards.

### **Child Representatives**

In the NDIS, a person under the age of 18 is supported by a child representative for preparing and using their NDIS plan. Usually, a child's representative will be their parents or the people who have parental responsibility for the child. When the State or Territory has parental responsibility for a child, another person can be nominated to be the child's representative.

The child's representative has duties to the child under the NDIS Act (Section 76) that guide how they make decisions and plans for the child. These duties include finding out the wishes of the child and acting in the best interest of the child. It is also expected that the child will be given chances to build their decision making capacity.

### **Guardians and Trustees**

Guardians and Trustees are legally appointed to make decisions on behalf of a person about things like:

- personal and lifestyle matters
- health
- finances
- property

This is often called 'substitute decision making.' Legislation about this varies between states and territories in Australia. Usually, substitute decision makers only make decisions that relate to the parts of a person's life that need a significant decision. The orders to appointment a Guardian or Trustee are usually for a period of time and about a certain type of decision.

## **Issues we have heard**

### **People with disability experience chronic disempowerment**

People's experiences have an effect on whether we can ask for what we want, if we trust other people and if we feel safe to stand up for ourselves. Being unseen, unheard and entrenched in disadvantage is 'chronic disempowerment'<sup>2</sup>

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<sup>2</sup> NDIS\_FS03\_GA\_201607.pdf (disabilityloop.org.au).

People with disabilities are more likely to experience abuse and neglect. They are also more likely to:

- live in poverty
- have poor-quality or insecure housing
- have low levels of workforce participation and education
- be socially excluded or marginalised
- face violence and discrimination
- have difficulty getting appropriate health care<sup>3</sup>

The NDIS, along with other systems that support people who have experienced chronic disempowerment, needs to think about how to support people in this situation and make adjustments to assist them. Understanding why people with disability make or refuse certain choices will help us understand how to increase the opportunity for them to have more choice and control.

Chronic disempowerment means that people with disability might find it very difficult to know, or speak up about, what they want or feel. For example, if a person from a government agency asks or suggests something, a person with disability may agree with whatever is suggested, especially if they are worried they will lose supports otherwise.

Sometimes people with disability do not want to talk about the sad, disempowering and difficult aspects of their lives and will choose not to say what they want or feel.

## **Formal Decision Making Supports are not consistent**

The way Guardians and Trustees work with the NDIA is not consistent. This is because each state and territory has different laws and rules. NDIA data shows that there are also differences between locations and disability groups in the way guardians are used. These differences are having an effect on people with disability.

A court or tribunal legally appoints Guardians and Trustees but NDIS delegates appoint nominees. We can see that there are differences in the way the policy is being applied by NDIA staff. Nominees are being appointed when they might not be necessary and without exploring other options.

## **There is a lack of emphasis on building decision making capacity**

There is a long history of people with disabilities not being supported or enabled to make decisions for themselves. This reinforces the idea that because a person doesn't make decisions, they don't know how to or don't want to make decisions. This is why we have relied on substitute decision makers rather than exploring a person's potential to make their own decisions.

Decision making is not a formal subject at school and there is little emphasis on it for children and young adults with cognitive impairment. As a result, there is a general lack of

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<sup>3</sup> WHO & World Bank (2011). World Report on Disability Summary.

capacity building support available to encourage people with a cognitive impairment to be involved in making decisions about things that affect them.

There is not much readily available information and support for parents, carers and professionals to work with people to support and build their decision making capacity. Because of this, people with cognitive impairment are often left out of decisions about their lives. They are usually dependent on other people to make decisions for them. These decisions are made formally or informally and are in the person's 'best interest'. This does not necessarily mean their will and preference has been considered. Nor does it mean that they have been given a chance to express what they want or to look at the options.

## **Life transitions are not well supported**

We want to improve decision making around major life changes. These transitions are not well supported and resources are not always available to help.

These changes could be:

- leaving school
- moving into employment or further education
- moving out of home

The lack of support means that people fall into old patterns – e.g. from specialist schools to adult day programs, from the family home to group homes.

At the moment, children turning 18 are not well supported to move from having a child representative to independently engaging with the NDIA. This means that many parents continue to act as representatives, sometimes without the consent of the participant.

When a young person is moving from voluntary or statutory out of home care, it is unlikely that they will have an extensive support network to support their decision making. Young people should be given the chance and support to build their confidence and skill in making decisions well before these changes are going to happen.

As a person ages it is important to think about whether their cognitive functioning will decline. In this situation, a smooth and planned transition to formal decision making arrangements needs to happen.

## **Some participants have no informal supports to help them to make decisions**

We know that some people with a disability do not have people in their lives to help them work with the NDIS or to help them to develop and use their NDIS plan. We need to make more effort to make sure tailored supports are there to help with decision making. We want all participants to have a voice when communicating with the NDIS and service providers.

## **Advice from NDIA Staff and Partners is not consistent**

We know that NDIA staff and partners have different levels of understanding about support for decision making practices and how best to support participants with decision making. We know that we have relied too heavily on nominee appointments.

NDIA data from 30 September 2020 shows that about 30 percent of participants have a nominee appointed. This increases significantly for people with cognitive impairment. The data also shows differences between location and disability types.

In the Northern Territory, nominees are used by 31% of participants with acquired brain injury, autism spectrum disorder, cerebral palsy, Down syndrome and intellectual disability. In Western Australia, it is 50% for the same group. Participants with Down syndrome are most likely to have a nominee (69%), while 43% of participants with intellectual disability have a nominee.<sup>4</sup> This information shows that there are likely to be inconsistencies in the way nominees are appointed by the Agency.

We also have limited resources available to staff and partners that specifically address support for decision making. This means that interpretation of related policy and guidance is inconsistent. This is an opportunity to improve capability, resources and guidance.

## Potential for Provider Conflict of Interest

There can be a conflict of interest between a service provider's interests and the participant's preferences. This can lead to participants being left out of decisions about their lives or from having their wants and needs considered. Some examples of this have come from participants living in supported accommodation where participants are not included in decisions that could interrupt the house routines. For example, decisions around weekly menus, meal and activity schedules.

It is not only providers that can have perceived or actually conflict of interest. Support workers or anyone that have a vested interest in the outcome of participant decisions can also have a conflict of interest. There are also examples of house managers attending planning meetings without the participant. They make decisions on the goals and supports the participant needs without them.

The NDIS Quality and Safeguard Commission (the Commission) can take action where there is an identified conflict of interest with a provider.

## Potential for undue influence

NDIS providers are regulated by the Commission and have requirements to prevent real and perceived conflicts of interest. However, there is no system to identify or take action around potential conflicts of interest with nominees, families or other informal supporters.

Nominees, families and other informal supporters play very important roles in supporting participants in decision making. It is critical that they have a good understanding of the potential to influence decisions that are convenient for them without fully considering or exploring the decision. For example, a participant may articulate a desire to move out of the family home. Their decision supporter may gently persuade the participant that they do not really want to do this until the participant actually agrees that they don't.

More significant examples of undue influence can include:

- isolation from friends and family against their will.

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<sup>4</sup> Data based on primary disability recorded in the NDIS business system

- removal of items of value to the person if they challenge decisions.
- removal of things that help the person to feel safe.
- threats to personal safety.

When it is this serious it is called coercion.

## Consultation Paper – Supporting you to make your own decisions

The proposed Support for Decision Making framework detailed in the 'Consultation Paper: Supporting you to make your own decisions' can be found on our ['Have your Say'](#) webpage once finalised, will form the basis for the NDIA to meet our obligation to provide opportunity for all participants to have the supports to make their own decisions about things that impact them and to exercise real choice and control.

# Glossary

Term	Definition
Advocate	<p>Someone who supports or represents a person (with their consent). Generally, the person being represented is someone who is considered at risk. Advocates promote and safeguard the rights and interest of the people they support.</p>
Capacity Building	<p>Capacity building supports include a range of things to build a participant's independence skills. With capacity building, participants will be more involved in their local community. It could include:</p> <ul style="list-style-type: none"><li>• funding to help a participant find a job or study opportunities,</li><li>• apply for suitable accommodation, or</li><li>• learn a range of organisation and self-management skills.</li></ul> <p>For example, a '<i>Core Support</i>' might delivery of meals on a weekly basis. A Capacity Building support would be build the skills of the participant to prepare healthy meals on their own.</p>
Choice	<p>Choices are the opportunities or options in front of a person. A decision is the final selection. Choice reflects the person's capability while decision reflects the final result. Choices are presented to you while you alone make the decision.</p>
Choice and Control	<p>Increased choice and control for participants is a core principle of the NDIS. Around 60 percent of adult NDIS participants have a disability that impacts their cognitive function. This means they might need more support to be more in control of decisions that impact them.</p> <p>Every participant has the right to make their own decisions about what is important to them. They have a right to decide how they would like to receive their supports and from whom.</p> <p>We know that support for decision making is very important in making sure participants have choice and control.</p>
Circle of Support	<p>A circle of support is an informal network. It is made up of a group of people who meet with a participant regularly. They help them with the thinking, planning and implementation of their personal goals. It is not a legal entity.</p> <p>The circle is formed around the participant. It provides them with support for decision making by listening to the person's ideas. It will help them</p>

Term	Definition
	identify their goals and support their choice. It also helps with planning to make things happen.
Consent	Consent is when a person gives permission for something to happen. Consent is given explicitly, either verbally or in writing. This could include a handwritten signature, a verbal statement, or use of an electronic medium or voice signature to demonstrate agreement.
Decision	A decision defines the action a person will take (taking no action may also be a decision). Decision implies there has been a selection from more than one option.
Decision Making	Decision making is the thought process of selecting a choice from the available options. When trying to make decisions, a person must weigh the positives and negatives of each option, and consider the alternatives. A person needs to think about what might happen in the future if they choose each option. Then they can decide which option is best for them.
Decision Supporter	<p>A decision supporter is a person who:</p> <ul style="list-style-type: none"> <li>• helps a participant to practice making decisions</li> <li>• helps them improve their skills, and</li> <li>• builds their capacity to make decisions for themselves.</li> </ul> <p>For example family, peer networks, advocates, support workers, LACs and planners.</p>
Guardian	<p>A guardian is person who has the authority under the law to manage all or some of a participant's affairs. This can include:</p> <ul style="list-style-type: none"> <li>• legal affairs,</li> <li>• non-legal affairs,</li> <li>• healthcare and medical decisions, and</li> <li>• lifestyle decisions.</li> </ul>
Informal Support	<p>Informal supports are the different types of help people freely give to each other in daily life. This could include the support a person receives from:</p> <ul style="list-style-type: none"> <li>• their parents or siblings,</li> <li>• extended family members,</li> </ul>

Term	Definition
	<ul style="list-style-type: none"> <li>• friends or acquaintances,</li> <li>• colleagues,</li> <li>• neighbours or other people in their community</li> </ul>
Microboard	<p>A microboard is a legal entity made up of a small group of people. They are usual committed family and friends of a person who experiences challenges in life. These people form an incorporated association for the benefit of that person and work with them to make sure their wishes and needs are met.</p> <p>Depending on a person's particular needs, a microboard's role can include:</p> <ul style="list-style-type: none"> <li>• assisting with coordinating support services,</li> <li>• finding and keeping employment,</li> <li>• facilitating friendships, and</li> <li>• community access.</li> </ul>
Nominee	<p>Under the NDIS, a nominee is a person who has authority to act on behalf on the participant. They can make decisions about NDIS matters and supports.</p> <p>Nominees should only be appointed when the participant has very little capacity to make decisions, even with support.</p> <p>Nominees have a duty to involve the participant in decisions that impact them. They also have a duty to build the participant's decision making capacity.</p>
Peer Support Networks	<p>A peer support network is a group of people who come together as equals. They connect with each other and provide support to each other because of similar experiences or circumstances in their life. Groups can also be involved in advocacy work.</p> <p>There is evidence that peer support can help people feel more confident, knowledgeable, capable, and less isolated.</p>
Substitute Decision Making	<p>Substitute decision making is where someone has authority to make decisions of behalf of an adult participant. Both Nominees and Guardians are an example of this.</p>
Support for Decision Making	<p>Support for decision making refers to a range of:</p>

Term	Definition
	<ul style="list-style-type: none"> <li>• informal and formal,</li> <li>• paid or unpaid supports, or</li> <li>• resources,</li> </ul> <p>that are available to a person to help them to make a decision.</p>
Supported Decision Making	Supported decision making is the process where a person is supported to make a decision.
Will and preference	Will describes a person's aspirations based on values and beliefs and preference is more immediate wants and desires.