



People with Disability and Supported Decision-Making

A guide for NDIS
providers in NSW

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▶ How this guide can help

Why is supported decision-making important to understand?

Supported decision-making (SDM) is the best practice approach to enhance the ability of people with a disability to make their own decisions. This guide is for workers, volunteers, managers and directors/ Board members of National Disability Insurance Scheme (NDIS) providers. Each section of the guide explains key aspects of supported decision-making, as well as the implications for NDIS providers. Some information is specific to NSW, but most of it is relevant in all settings across Australia.

When someone makes a decision on behalf of another person without their consent, a fundamental right is being denied. This applies to every person, including people with a disability. While the right to make our own decisions has always been there, it is a right that not everyone with a disability has enjoyed. For people who have difficulty making a particular decision, supported decision-making is an approach that demonstrates respect for people's rights to make decisions about their own lives.

▶ Significant legislative changes are occurring across Australia that will increase the obligations on a wide range of organisations, including NDIS providers, to support people with a disability to make their own decisions. This guide outlines practical information about how to implement SDM in this context.

How to use this guide

SDM is a simple idea, but can be complex to do well. Therefore, this guide includes a lot of information so that it is as comprehensive as possible – some of which will be new to some readers. So that it is easy to use, select the part/s that are most relevant to your work. It is suggested that –

- Board members should at least read all of Sections 1 and 4
- Managers should read the whole document
- Workers and volunteers should at least read Section 1 C and D, all of Section 2, and Attachments 3, 4, and 5.
- Everyone should read Attachment 8, which has three one-page summaries about the responsibilities of Board members, managers, and workers/ volunteers.

Most of the information in this guide applies broadly across Australia and can be implemented now. It clearly states when the information is specific to NSW only – which is mostly in Section 3 of this guide.

If providers are delivering services and supports in other States and Territories, check local legislative and policy provisions for authorising processes for alternative decision-making.

Sections in the guide

1. All about rights

Every person has the right to make decisions about their own lives, including people with a disability

The legal basis for this right is described in clear terms, and includes proposed changes to the law in NSW. It also describes how rights are applied to decision-making under the NDIS, and to service provision.

2. Supported decision-making

Support should be provided to a person who has difficulty making one or more decisions

This section describes a range of approaches NDIS providers can take to support people who have difficulty making some decisions. It will help you to -

- Identify when a person with disability needs support to make a decision
- Provide support to the person to make a decision
- See how supported decision-making can work in some examples.

3. When support is not enough

There are circumstances when another person can lawfully make a decision on behalf of a person with a disability

This section outlines how a lawful decision can be made when a person with a disability is unable to make that decision, including NDIS-related decisions. It includes suggestions about how providers can assist decision-makers.

4. Challenges for NDIS providers

This section pulls together the various challenges identified in throughout the guide, and provides some suggestions about strategies that NDIS providers could consider for each situation.

Attachments

At the end of this guide are several attachments. These include more detailed explanations about issues raised in this guide, and links to further information and resources.

All about rights

Every person has the right to make decisions about their own lives, including people with a disability.

A - Decision-making rights

The legal rights of all people to make decisions about their own lives is described in international documents, including the *United Nations Declaration of Human Rights*, the *United Nations Convention of Civil and Political Rights*, and the *United Nations Convention on the Rights of Persons with a Disability* (CRPD). Australia has ratified these documents, which means that it agrees to make laws that uphold these rights in all areas of Australian life.

These rights apply to every person in Australia, including people with a disability, and are based on the presumption that every person has the legal capacity to make their own decisions. However, there is a difference in meaning between a person's 'legal capacity' to make decisions and their 'decision-making ability'.

This area of difference can be complex when considering the decision-making ability of some people with a disability. Someone else's personal opinion often becomes the basis for deciding whether or not a person with a disability can make a specific decision. We have all heard someone say, or act as if they believe, that 'they have a disability so they can't make a decision'. This approach is very dangerous ground, as there is the very real risk that the rights of the person with a disability will be disrespected or breached.

To avoid this outcome, supported decision-making is internationally recognised best-practice to enable people with a disability to exercise and enjoy their rights.

B - Legal changes are underway

In Australia, legislative changes are currently being made by Commonwealth, State and Territory governments to comply with the CRPD. It will take time for these changes to occur, so for several years there may be inconsistencies between the States and Territories.

For example, the NSW Law Reform Commission has made a number of recommendations to enable organisations to comply with the implications of the CRPD for decision-making. If the LRC recommendations are accepted by the NSW government, some of the likely changes will include –

- Defining the meaning of the term 'decision-making ability'
- Emphasising the wishes and preferences of people with a disability in decision-making processes
- Requiring all agencies to actively enable and support people with a disability to make their own decisions
- Establishing new arrangements for people to directly appoint another person to support them when decisions need to be made (replacing the existing Powers of Attorney and Enduring Guardian)

- Redefining the criteria for courts and tribunals to make formal appointments of substitute decision-makers
- Establishing a new Office of the Public Advocate.

This guide assists NDIS providers to prepare for the proposed changes, and refers to the current legal provisions in NSW.

Attachment 1 lists the key organisations involved in decision-making and people with a disability. It includes contact details, and links to documents and resources.

C - What decisions are we talking about?

In one way, the answer is simple - we are talking about every decision. People with a disability have the right to make every decision about their lives, including –

- What to wear
- When and what to eat and drink
- What to do during the day, including work
- Who to spend time with, such as friends and family
- How to spend leisure time, including travel
- When to shower
- When to go to bed
- Where they live
- What services they receive (including, but not limited to, NDIS)
- Consenting to medical and dental treatment
- What healthcare they receive
- How their finances are managed
- Who and if they marry
- Legal matters, etc.

In practice, people with disability should be routinely asked about their wishes, preferences, and decisions – for all types of decisions, large and small.

However, the answer to what decisions we are talking about is also very complex. Some people with a disability may find some decisions are harder than others, particularly if the decision determines big issues in their life. Their right to decide means that they may need support to learn how to make those decisions. However sometimes, no amount of support will enable a person with a disability to make a very difficult or complex decision.

This guide includes information about how providers can support people with disability to learn to make their own decisions, and what to do if it is difficult to obtain a clear decision.

D - Risk enablement

There are always risks in life, whatever decisions we make. Everyone has the right to take risks and make mistakes, including people with a disability. Some common mistakes are buying something we later regret, getting lost on the way to somewhere unfamiliar, having too much alcohol when out with friends, or trying a new activity before realising we don't enjoy it. We might even feel a bit foolish at the time; but when we make mistakes, this may be the best time to learn how to make better decisions in the future. However, there are also times when a mistake turns out to have an unexpected benefit. For example, getting lost and finding a great new café, or making a new friend even if you don't like the activity.

This means that providers who are supporting a person with a disability to make their own decisions need to respect that person's right to take risks, even if there is the potential to make a mistake. Of course, this doesn't mean people should be actively encouraged to make mistakes, particularly if there is likely to be significantly detrimental consequences for the person. However, as part of providing support, providers can point out potential risks, and assist the person to explore how they could avoid or handle some of the predictable risks.

Attachment 4 has a link to a range of risk enablement tools and resources.

Sections 2 and 3 of this guide explore many of these issues in more detail.

How rights apply under the NDIS

Under the CRPD, the Australian government must promote the rights of all people with a disability, whether or not they are eligible for the NDIS. The NDIS framework, including the NDIS Commission, was developed to meet these international obligations, and is a rights-based approach. As such, it is transforming the way services and support occur for people with a disability.

Part 2(6) of the *NDIS (Provider Registration and Practice Standards) Rules 2018* states that “Each participant is supported by the provider to make informed choices, exercise control and maximise their independence in relation to the supports provided.” The NDIS (Quality and Safety) Commission embeds participant's rights in the Practice Standards required for registered NDIS providers.

The NDIS acknowledges that some participants may have difficulty making some decisions. It recognises other people who can lawfully make certain kinds of decisions on behalf of a person with a disability, including NDIS nominees, Guardians, and Attorneys or Financial Managers. The conditions for appointing people into these roles are described in Section 3 of this guide.

Consequently, NDIS providers are obliged to respect and uphold the rights of participants, and must comply with the requirements of the NDIS framework. More specifically, it means that providers must actively encourage and support participants to make their own decisions, and take action to eliminate the risks of participants' rights being disrespected or breached.

One of the key impacts of the NDIS for providers is that participants' rights are being more clearly defined. In addition, the proposed legislative changes across Australia will emphasise the importance of obtaining participants' wishes and preferences, and providing support to participants to make their own decisions.

Supported decision-making

Support should be provided to a person who has difficulty making one or more decisions.

A - Everyone needs to learn new skills

Providing effective decision-making support requires knowledge and skill, and may need lots of time and access to external expertise. This applies equally to some people with a disability, as well as to some staff being asked to provide that support.

Firstly, from the point of view of a person with a disability, some people may have had very few opportunities to make their own decisions. Someone else, perhaps trying to be helpful or to speed up the process, has assumed the person cannot make a particular decision, and denied them the chance to try and to learn. For some people with a disability, this happens over and over again throughout their lives. This means that some people with a disability will not know how to go about making decisions, and may not know what help they need.

Secondly, many new support staff will have no experience providing disability services, and know very little about the rights of participants, or how to provide decision-making support. Often, they will look to the example of more experienced staff, some of whom may also have very limited experience providing support in decision-making.

It is challenging to invest in the capability of people so that effective decision-making support is routinely occurring, particularly in the context of a new service delivery framework, a changing workforce profile, and competing budget constraints. Despite this, providers have an obligation to enable people with a disability to exercise their rights to decision-making.

As a start, the systems and practices that providers should have in place include -

- Policies and procedures that describe participants' rights to make their own decisions
- Recruitment, training and supervision systems for all personnel that focus on respecting participants' rights
- Staff trained in the necessary skills to support participants to make their own decisions
- Staff access to resources and tools to support participants' own decision-making
- Staff know, for each participant, who to approach for a specific decision if the participant is unable to make it themselves
- Systems to ensure that all decisions made on behalf of participants occur lawfully.

Providers will need to explore ways of funding the time and resources that are needed to develop the skills and ability of participants and staff. For example, providers will need to give quotes to participants to use in planning processes that include time for participants to develop their decision-making skills. Providers could also consider developing partnerships with experts in supported decision-making to design tailor-made tools for one or more participants to make decisions, such as for people with limited verbal or cognitive abilities.

Section 4 of this guide describes some of these challenges and strategies in more detail.

Attachment 2 is a checklist for providers.

B - When is support needed?

Having the right to make decisions is not the same as being able to make them. For all of us, important decisions are sometimes hard to make.

To make a well-informed decision, we weigh up options, consider risks and benefits, and then put our decision into action. Sometimes, we defer a decision because it's complicated, or we need more information. Sometimes we ask friends or family for advice, or try to avoid the decision if we feel fearful about the consequences. At times, we all need extra support to make important decisions, and it is no different for people with a disability.

Each person is different, and each decision is different. This means that decision-making ability is decision-specific. If someone with a disability has difficulty making a decision in one area of their lives, it doesn't mean they'll have difficulties with every other decision. The ability to make decisions can also change over time, as a person gains life experience and practices making decisions. For example, many young people have very little experience managing their money, but can gain this skill with opportunities to learn.

“ Being unable to make a decision in one area doesn't mean a person will have difficulties with every decision ”

Nevertheless, some groups of people with disability are more likely to need support than others. It does not mean they cannot make their own decisions, but they may, at least, need help accessing and analysing information and communicating their decisions. For example –

- People who are non-verbal, or use specific communication devices or methods
- People from culturally and linguistically diverse (CALD) communities, who have different languages or cultural needs
- Aboriginal and Torres Strait Island people, who may have different cultural and language needs
- People with cognitive impairments, or fluctuating psychosocial disability, who may sometimes have difficulty understanding some concepts.

Some people need support because a particular decision is complex and hard. Some people have difficulties making decisions due to the nature of their disability, such as a cognitive impairment. However, having a cognitive impairment does not automatically mean the person cannot make decisions, even important ones. They may simply need more time and skills. Generally, decision-making can be more difficult if a person is unwell or in pain, and so it may be better to delay asking the person for a decision. Therefore, it's important to try to understand why the person is having difficulty.

Assessing decision-making ability

There are various ways that professionals assess a person's decision-making ability, such as -

- Assessment tools used by healthcare clinicians to determine the person's capacity to consent to treatment or medication
- Legal descriptors in legislation used by courts and tribunals to determine a person's ability to make lifestyle and financial decisions.

Providers should be wary using assessment tools that were not designed for community and social environments. Wherever possible, when selecting or developing assessment tools, providers should look at strengths-based approaches that identify the person's abilities, as well as areas of deficit. Whatever tool is used, the results will only relate to that point in time, and for that specific decision – and should not be done once and relied on for years to come.

Attachment 1 includes links to key organisations that have information about assessing decision-making ability.

Attachment 3 shows decision-making steps, which is one way of assessing a person's ability to make a specific decision, and indicates the kind of support they may need.

C - What does support mean?

If a person with a disability is able to make their own decisions and can do so, then support is not needed. Nevertheless, providers could offer the availability of support, if the person would like assistance sometime in the future.

If the person does need support, then it is necessary to identify what kind of support is needed. Supporting a person with a disability to make a decision is not simply presenting them with a list of options and asking them to choose. They may need targeted support that is tailored to suit them. The person may not recognise that they need support, but may show through their actions that the decision is difficult for them. There are some key questions to be considered.

Q1. How does the person communicate?

Some people with a disability can clearly talk about their wishes, preferences and decisions. Other people may use sign language, body movements, or technology to communicate. Therefore, staff need to understand each participant's own communication methods and styles.

It can take time getting to know what a person likes and dislikes, and how they express themselves in different situations. However, this work is the basic foundation to enabling participants to gain experience and skills in decision-making, and shows respect for their right to do so.

It may be that the person has not yet had access to a communication tool that can better assist them to communicate clearly with others. Or, for people who are non-verbal, perhaps staff do not know how the person is using their technology, or subtle body movements (such as eye blinks, or hand movements), to communicate.

For some people with a disability, it may be sufficient to improve how their communication occurs and ensure that it is understood.

Q2. How can I know a person is having difficulty with a decision?

Some of the indicators that a person is having difficulty making a decision include -

- Making a snap decision without considering all the options, and the advantages/ disadvantages of each option
- Being unable to choose between the available options
- Frequently changing their mind
- Making a decision or acting in ways that exposes themselves or others to significant risk of harm
- Being unable to understand what decision is needed, or what the issues are.

If staff have a good understanding of a participant's communication methods, they will be more likely to be able to identify the reason/s the person is having difficulty with the decision. Therefore, if it seems that the person does not yet have the ability to make a specific decision, support should be the first approach to build the capacity of the person to learn the necessary information and skills to make that decision for themselves.

Q3. What types of support can be provided?

When staff understand what difficulties the person is having with the decision, then the type of support will be easier to select. Support could include one or more of the following approaches –

- Providing information about the range of available options, through one-to-one discussion, access to training and skill development
- Talking with a peer who has already made a similar decision
- Describing the benefits and disadvantages of each option, assisting them to weigh up the pros and cons
- Trying out some of the options before making a decision
- Using tools to help in the decision-making process, such as charts, diagrams, DVDs.

Some people may need time to learn the information they need to make a decision, as not all decisions have to be rushed. Ideally, providers should assist participants to make all day-to-day decisions, so that they develop skills, ability, confidence and experience when important or complex decisions are needed.

Generally, learning the skills of decision-making is based on separating a decision into smaller parts, and working through each one. The more complex the decision, the more parts that decision may have. Depending on the person's ability to understand each part of a decision, they may need several types of support to work through the information so that the person can gradually come to understand and make the decision.

There is a wide variety of supported decision-making tools and resources, many of which have been developed by experts using evidence-based research. Staff should be familiar with the range of tools and resources, so that they can offer the relevant support to people with a disability.

Attachment 4 has links to various supported decision-making tools and resources.

Q4. Who can provide support?

Anyone can provide the necessary support, including workers, volunteers, family, carers, friends, advocates, or specialists.

When identifying who will provide each type of support, be aware of the potential for conflict of interest, or unconscious bias, so that the person isn't pressured into an option that suits the support person. We all need to be very mindful of our own values and attitudes. Our approach to the rights of people with a disability will show in our words and actions, whether or not we are aware of it. It may be easy to think we know what the 'best' decision should be, and try to influence the person to make that decision. The language we use around decision-making is particularly important. We cannot *give* someone the right to make a decision about their own lives – they already have this right. But by our words and actions, we can take the right away.

“ We cannot give someone the right to make a decision about their own lives – they already have this right.

But by our words and actions, we can take the right away ”

Finding someone else to make a decision should be a last resort.

Section 3 of this guide provides information on what to do when providing support is not enough to enable a person with a disability to make a decision.

Attachments 1, 3 and 4 have further resources about supported decision-making.

Attachment 5 contains Frequently Asked Questions, including what to do if providers are concerned about a particular decision that a person has made, and SDM for children and young people.

Supported decision-making and the NDIS

Section 1C of this guide lists many of the decisions that everyone has the right to make about their own lives, including people with a disability. Under the NDIS, participants also have clearly defined rights to make specific NDIS-related decisions, including –

- Consenting to access the NDIS
- Identifying goals and needs
- Consenting to share plans
- Deciding who can contact the NDIA and providers on their behalf
- Negotiating the way services and supports are provided
- Signing service agreements
- Accessing information held by providers about themselves
- Opportunities to provide feedback and have input into providers' governance
- Making payments to providers
- Checking that supports meet their needs
- Changing support providers
- Acting to address problems, including making complaints and lodging appeals
- Deciding to leave the NDIS.

Although participants cannot determine the amount of funds allocated to them under the NDIS, they have the right to decide how to use those funds in accordance with the plan.

D - Examples of SDM in practice

Every situation is different, because every person with a disability is different. This can make it challenging for providers to select the right support when it is needed. The following examples use a three-step SDM process that providers could adopt, and shows how support could be provided to people for typical lifestyle and NDIS-related decisions.

Consenting to medication

1. What is the decision?

When a health professional prescribes a specific medication, the decision for an adult is whether or not to consent to taking it.

2. Indicators that the person may need support

- The person believes that they must do what the doctor says - this belief suggests that the person doesn't understand that there is a decision that needs to be made.
- The person accepts the recommended medication without questions - this may suggest that the person is being compliant to a person in authority, or does not understand what the medication is for, or its risks.

3. What support could be provided?

Some medications have significant effects on a person, such as psychotropic or contraceptive medications. Therefore, giving informed consent means the person will need to learn some complex information, as outlined below. Support options could include -

- Meeting/s with the prescribing health professional to hear an explanation about the condition that needs treating, what the medication will do (and whether they will feel a difference in themselves when taking it), whether it is for a short time or ongoing, if there are any side-effects or long-term risks, the risks of not taking the medication, and if there are alternative treatments.
- Discussion/s with staff about how they can provide support, such as help to get the medication from the pharmacy, reminders to take the medication, and what staff can do if the person refuses the medication.
- Access to factsheets, diagrams or videos about the condition and recommended medication
- Discussion with someone else who takes the medication.

For simpler medications, the information may be easier to learn, and the person may need less support.

Selecting a service provider

1. What is the decision?

The decision for the person with a disability is selecting a provider to deliver a specific type of support.

2. Indicators that the person may need support

- The person is unable to find all the options, or choose between the options available – this may suggest that the person doesn't understand the options, or is having difficulty weighing up the advantages and disadvantages of each one

- The person delays or refuses to make a decision – this may suggest that the person doesn't like any of the options, or doesn't understand how they will benefit from the service type
- The person asks someone else to make the decision – this may suggest the person is inexperienced making decisions, or is afraid of making the 'wrong' decision.

3. What support could be provided?

Support options could include -

- Assisting the person to clarify what outcomes they want from the service, so they can compare what each option is offering
- Identifying options available
- Visit/s to, or meetings with, each of the providers to learn about the services and see how services are delivered
- Talking with other participants who use those services
- Accessing information about each of the providers, such as brochures, websites, DVDs.
- Using tools to consider parts of the decision, such as a chart to compare the options
- Talking with a Support Coordinator (if funded), or the Local Area Coordinator, to find out more information about the options, such as the reputation of each provider, and whether there are differences between the options.

Most people with a disability will not need all of these supports to help them make an informed decision.

Raising a concern with a provider

1. What is the decision?

The decisions for the person with a disability are how to raise their concern, and what response is an acceptable resolution.

2. Indicators that the person may need support

- The person's usual behaviour changes when services are being delivered, or when they get home – this may suggest the person is unhappy with something that has happened, but doesn't know how to clarify the problem and raise their concern
- The person tells a family member or friend about their concern – this may suggest that the person doesn't know about the provider's complaint procedures, or is afraid to raise it directly with a staff member
- The person is not happy with the way the provider says it will fix the problem – this may suggest that either the person doesn't understand what the provider can and cannot do, or that the provider is unwilling to be more flexible.

3. What support could be provided?

- Provide information to the person and their supporters about the provider's complaint handling process – in accessible formats
- Link the person with someone who can assist them to identify what they feel, and what that feeling is linked to – for people who have difficulty making sense of why they feel unhappy. Tools may be useful to support the person for this part.

- Assist the person to document their concern. This may mean that staff or another support person listens to their concern and writes it for them.
- Nominate a worker to keep in contact with the person, and update them on the progress of an investigation
- Link the person with an independent advocate, legal service, or other complaint handling body
- Provide explanations to the person about what options the provider has to fix the problem. Wherever possible, there should be a range of options so that participants can choose the outcome that best suits them.

When support is not enough

There are circumstances when another person can lawfully make a decision on behalf of a person with a disability.

Sometimes, no amount of support will enable a person with a disability to make an important or complex decision.

Any time another person makes a decision for a person with a disability, their right to do so is being denied. It does not mean it should never occur, only that there should be extreme caution when taking away a person's rights. Nevertheless, there are some circumstances when a decision must be made to ensure the person's personal and social wellbeing.

Commonwealth, State and Territory governments have a range of legal mechanisms to allow someone to make specific types of decisions for another person. For example –

- Parents can make decisions for their children, until they are 18 years old
- Government Ministers can make decisions for children in statutory care
- Doctors can make decisions about life-saving treatment, or for people with psychosocial disabilities who are scheduled under mental health legislation
- Person Responsible (in NSW) recognised by health professionals to make medical and dental decisions
- Anyone can directly appoint someone else to make specific types of decisions on their behalf, such as manage their finances, or make health and lifestyle decisions. Currently in NSW, these roles are Powers of Attorney or Enduring Guardian.

A - Informal decisions for a person with a disability

In practice, many lawful decisions can be made informally for a person with a disability who cannot do so, without needing a formal decision-maker. This could be the person's family or carer, or a friend in their life with a close and continuing relationship. Ideally, informal decisions can be made when –

- The decision reflects the person's wishes and preference, where known
AND
- The person seems willing to go along with a proposed decision
AND
- There is a shared view among the significant people in the person's life about what should happen
AND
- It is not a decision that requires a formally appointed decision-maker.

Providers and their Board members, staff and volunteers cannot lawfully make important NDIS, lifestyle, health/ medical and financial decisions on behalf of participants. However, providers can support and encourage informal decision-makers to respect the rights of the person with a disability.

“ Providers and staff cannot lawfully make decisions on behalf of participants ”

B - Formal decisions for a person with a disability

There are some circumstances when a necessary decision cannot be made informally for a person with a disability who is unable to make that decision themselves, including -

- There are people in the person's life who could make the decision, but there are different views or conflict about what option is best for the person with a disability
- When the person is objecting (verbally or by their actions) to the proposed decision
- When an organisation's rules prevent someone else making informal decisions, such as banks, utility companies and government agencies
- For specific types of decisions described in legislation, such as restrictive practices, sterilization, over-riding a person's objections to medication or treatment, certain medical treatments, etc.

In these circumstances, a formal decision-maker will probably be needed. For people with a disability who cannot make a particular decision, the legal mechanisms include -

- Recognising or formally appointing a person who can make decisions on behalf of someone else. Currently in NSW, this includes the roles of Person Responsible (for medical/ dental decisions), Guardian, and Financial Manager.
- A government body with authority to make decisions directly on behalf of another person. In NSW, the NSW Civil and Administrative Tribunal (NCAT Guardianship Division), can make certain decisions relating to medical and dental consent.

Attachment 1 has links to further information about the roles of the NSW Trustee and Guardian, the NSW Office of the Public Guardian, and NCAT.

Attachment 6 has further descriptions about formal decision-making mechanisms and roles.

Attachment 7 includes two summary tables showing who can make decisions on behalf of another person, including NDIS-related decisions.

Obtaining NDIS-related decisions

The NDIS framework presumes that people with a disability can make their own decisions.

However, it recognises that some people may be unable to make some decisions, and a Nominee can be appointed by the National Disability Insurance Agency (NDIA) to make planning and/ or correspondence decisions. The NDIA states that it also recognises formal appointments made by either the person themselves, or by NCAT (in NSW).

The NSW Trustee, and NSW Office of the Public Guardian, have provided guidelines for authorised decision-makers in relation to NDIS decisions, as follows -

- If a Guardian (either public, private or enduring) is appointed with a services or advocacy function, then they can consent to the person accessing the NDIS, and advocate for NDIS services and supports. They can also appeal decisions and make complaints on the participant's behalf. In these circumstances, Guardians can assume to act in the role of NDIS Nominee. (Note that the NDIA will still require the Guardian to apply to be recognised as a Nominee.)
- If the NSW Trustee is appointed as Financial Manager, it cannot sign NDIS access forms, advocate for support plans, arrange payments, and sign service agreements.
- Private Financial Managers and Powers of Attorney, may act in some roles if they are also appointed as the participant's NDIS Nominee. However, they are not authorised to advocate in relation to services or support plans.

C - How providers can assist decision-makers

When providers are looking for another person to make any decision on behalf of a participant, it is essential to check if that person has the specific authority to make the decision that is needed.

When a decision needs to be obtained on behalf of a participant, there are various ways that providers can assist the decision-maker to make good decisions, including providing information that the decision-maker will need to take into account, such as –

- The available options to be considered, and the necessary decision, the recommended option and why it is preferred
- Details about the efforts made to assist the person to make the decision themselves, and their wishes and preferences, where known
- The timeframe for the decision, when the decision needs to be made so that it can be implemented effectively
- The likely impact of that decision for the participant, where known
- Assessments and professional reports that are relevant to that decision, where available, and where there is consent to share these.

Some alternative decision-makers are very experienced at making complex decisions, such as public Guardians. However, many private Guardians may have limited experience in making complex decisions, and may need time to become informed about the options.

Even when an alternative decision maker is appointed to make specific decisions, they cannot make decisions if the person with a disability is able to do so. Here are some examples using the previously outlined three-step SDM process, to promote supported decision making when there is an alternative decision-maker.

Accommodation decision

1. What is the decision?

A participant wants to leave the family home and live with people their own age. The person's mother has been appointed as their Guardian with the function of decision-making for accommodation.

2. Indicators that the person may need support

- There is a Guardian in place. The person may have self-appointed the Guardian if they recognised they would need help, or a Tribunal may have appointed the Guardian because a decision needed to be made, and the person was unable to make it at that time.
- The person may delay taking steps to find or select accommodation options
- The person says they are unhappy at home, or may have been running away from home.

3. What support could be provided?

The participant, their mother/ Guardian, and other supporters (including NDIS providers) could discuss the various decisions that are involved, including location options, potential costs, preferred number of co-residents, researching vacancies that are available, etc. The participant should be encouraged to make as many decisions as they can, and other people can assist where needed.

For example –

- The participant may describe the kind of home they would like, such as close to their workplace, friends and activities. If they have a fixed budget, this would determine how much they can afford on rent, utilities, food and travel, etc.
- The provider may assist the participant to research vacancies, and visit some options. Ideally, the options should reflect the participant's wishes.
- The Guardian should listen to the participant's preferred option, and either confirm that as the decision, or decide on a different option. If it is a different option, the Guardian should explain their reasons to the participant.

Restrictive practices

1. What is the decision?

The decision is whether a restrictive practice is needed because providers are concerned that a participant's behaviour has the potential to cause harm to themselves or others.

2. Indicators that the person may need support?

- The person is unable to manage some aspects of their own behaviour
- Workers have tried to explain their concerns when the person is calm, but the person is unable to follow their suggestions for self-management
- There are known trigger situations, and trying to calm the person verbally is ineffective
- Positive interactions and preventative strategies (such as avoiding triggers) are insufficient to cease the behaviour/s of concern.

If all support options have been tried and are unsuccessful to prevent harm, there may be a need for the use of restrictive practices on a temporary basis.

Attachment 5 on *Frequently Asked Questions* includes the issue of whether or not a person can consent to restricted practices being used on themselves.

3. What support could be provided?

For NDIS registered providers, there are formal processes required for the development, authorisation and consent, use, and reporting of restrictive practices. It should only occur in the context of a behaviour support plan, and include positive strategies to reduce and eliminate the use of the restrictive practices. In NSW, authorisation is either provided by a Guardian appointed by NCAT (which must include the specific function of consenting to restrictive practices), or via authorisation panels that comply with the requirements of Family and Community Services.

Providers should engage a NDIS registered behaviour support practitioner to develop the plan, seek and obtain consent/ authorisation, ensure staff are trained in its implementation, monitor implementation and meet reporting requirements. Providers should also communicate closely with the person providing consent, such as the Guardian, to explain the impact for the participant.

For participants, restrictive practices are usually occurring against their will. It may be frightening, humiliating and traumatic, and they may not understand why it is happening. Its use may also affect the trust between the participant and staff. The plan should take all these factors into account, and provide guidance to staff about how to talk with the participant about its use before, during and after incidents.

Sometimes restrictive practices are being used on a person with a disability that are either contrary to, or in the absence of, a behaviour support plan. Or it may be occurring in another setting, such as the family home, or with another provider. In these circumstances, the use of restrictive practices may be considered to be an assault. Providers should discuss their concerns with the parents/ carers or providers, and provide information about alternative behaviour support options and requirements.

Attachment 1 has links to further information and support for alternative decision-makers, and links to the NDIS Commission's requirements for restrictive practices.

Challenges for NDIS providers

The obligation to provide support to all people with a disability to make their own decisions, wherever possible, raises challenges for NDIS providers. Some issues have been referred to in previous parts of this guide. This section pulls together the key challenges, and suggests some practical strategies that NDIS providers can consider if any of those issues are relevant to their work.

Level of understanding within the organisation about participants' rights to make their own decisions

As legal clarity about participants' rights is currently being developed in Australia, it would be expected that many workers, managers and Board members may not yet have an up-to-date understanding about these rights. Some strategies to building this knowledge include –

- Allocate responsibility to a manager to collect and distribute information (including this guide) about participants' rights to all workers, volunteers, managers and Board members
- Support staff to learn about participants' rights
- Invite specialists to speak at staff and Board meetings.

Effectiveness of organisational culture and systems to promote participants' rights

If the organisation has clear systems to promote participants' rights, which are supported by senior staff, then new and existing staff are more likely to comply with the requirements. Strategies to build culture and systems in this area include –

- Analyse existing organisational policies and procedures, and identify how systems to promote participants' rights can be improved, and take corrective action as needed
- Engage peer support personnel to work alongside participants when key decisions need to be made
- Develop an organisational-wide practice of routinely asking participants about all decisions that affect them, large and small
- Record the wishes and preferences of participants about key aspects of their life.

Capability of personnel to implement supported decision-making

Across the organisation, some staff may be more capable in supporting participants' decision-making than others. Sometimes, it may be long-term staff who have beliefs about their 'protective' role that limit opportunities for people with disability to make decisions. Some strategies to build staff capability include –

- Identify personnel who have effective skills and provide opportunities for them to lift the capability of other staff, such through buddy or mentor schemes
- Invite specialists to speak at staff meetings, or conduct in-house workshops
- Recognise staff who are supporting participants to make their own decisions
- Learn from experiences when participants were not given adequate support; to explore better approaches.

Accessing resources to train and equip staff with the skills and tools they need

There will be costs for providers to enable staff to participate in learning and development, and to obtain best practice tools and resources for supported decision-making. Some strategies for finding these funds include –

- Partner with other providers to share the costs of hosting training events, or purchasing tools/resources
- Access tools and resources that are freely available, checking first that they were developed using best practice research and apply in the Australian context. Attachment 4 of this guide has links to some free tools and resources.
- Identify the costs associated with skill development and purchasing tools and ensuring that these are factored into any unit costing, and for NDIS quoting purposes.

Resources available in participants' plans to allow time to develop their decision-making abilities

Participants will also need time and possibly other support categories, included in their NDIS plans to access support so that they can develop their decision-making abilities. While providers cannot determine what is funded in participants' plans, nor determine what participants choose to purchase, there are some strategies to increase the potential for this to occur –

- Develop formulae for the costs associated with the time each participant needs to develop their decision-making ability – this may be needed for each service type included in the plan. For example, quotes for participants could include estimates of the time (and cost) for each of the key decisions likely to occur during the next plan, based on the person's current abilities and experience.
- Provide quotes to participants for NDIS planning meetings about the costs of developing tailor-made communication strategies, and/ or purchasing decision-making tools.

Managing external barriers

There are several barriers to providers being able to provide decision-making support that are beyond their control. Some examples and strategies for these situations are –

- ***When family or carers insist on a particular decision or outcome, and resist supported decision-making.*** If the provider believes the person with a disability is able, with support, to make the decision, then the family/ carer may need further education or information about providers' obligations to support participants to make their own decisions wherever possible. Providers may also need to clarify the rights of participants, and that there are legal processes to be followed if a substitute decision-maker is needed.
Attachment 4 includes resources developed specifically for families/ carers to learn about SDM.
- ***When the provider becomes aware that another mainstream or community organisation does not allow a person with a disability to make their own decision.*** The provider could share information with the organisation that it also has obligations to support decision-making. They might also advise the LAC or Support Coordinator, or make a referral to an advocacy agency, to follow up the issue.
- ***When NDIS plans do not include any resources to enable supported decision-making activities to occur.*** It may take time for the NDIA to consider quotes and proposals for the costs associated with supported decision-making to be reasonable and necessary. Nevertheless, providers should continue to provide the necessary evidence to participants, and could consider

supporting participants in making complaints or appeals, if those items are refused, or if there is likely to be a detrimental impact for the effective implementation of the participants' plans and the achievement of outcomes.

Assessing when a participant is unable to make a specific decision

This guide includes information about assessing participants' abilities to make their own decisions. However, there will always be challenges for providers in identifying the point at which a decision cannot be made, despite sufficient attempts to provide support. The challenge could be due to one or more of the following issues –

- The participant has insufficient experience, ability, or willingness
- Staff have exhausted their capability to provide new or different support
- It may be an urgent situation where there is not enough time to provide the necessary support.

Each situation and solution is different, and will be a learning opportunity for providers, participants, family and carers. Overall, there are benefits for NDIS providers in retaining links with other providers to share their experiences of supported decision-making, and tips for handling new challenges as they arise.

When there is no-one to make a necessary decision

It can be challenging when a provider can find no-one else in the participant's life to be an alternative decision-maker, especially if a decision is necessary. This occurs when the person has no family or friends, and no-one is appointed to make significant decisions.

For example, the participant may be willing to sign a Service Agreement, but has insufficient understanding to enter into a contract. If a Service Agreement is unsigned, or the person does not have capacity to sign it, the agreement is invalid. In this situation, the options available to the provider are to seek to have a Plan Nominee appointed by NDIA, or apply for a Guardianship Order with a Services' Function. If neither occurs, the provider should record its efforts to arrange for the Service Agreement to be signed by someone able to do so, and seek legal advice.

Providers need to be aware of the significant risks they are taking if they do not seek and obtain lawful decisions.

ATTACHMENT 1

Key organisations

This table shows the key organisations that have a role in decision-making and people with disability. It includes contact details, and links to key documents.

Links to Resources Provided by Key Organisations
National Disability Insurance Agency
<p>NDIA website - https://www.ndis.gov.au/ Phone: 1800 800 110 (business hours)</p> <ul style="list-style-type: none">• Information about nominees - https://www.ndis.gov.au/understanding/families-and-carers/guardians-and-nominees-explained• Information about making a complaint and form - https://www.ndis.gov.au/contact/feedback-and-complaints• Then send completed complaint form to - feedback@ndis.gov.au
NDIS Commission
<p>NDIS Commission website - https://www.ndiscommission.gov.au/ Phone: 1800 035 544 (business hours)</p> <ul style="list-style-type: none">• NDIS Commission legislation, rules and policies - https://www.ndiscommission.gov.au/about/legislation-rules-policies• Information about reportable incidents and links to reporting forms - https://www.ndiscommission.gov.au/providers/reportable-incidents• Then send completed form/s to - reportableincidents@ndiscommission.gov.au• NDIS Commission Practice Standards - https://www.ndiscommission.gov.au/document/986• Draft Reportable incident guide - https://www.ndiscommission.gov.au/document/596• Incident management guide - https://www.ndiscommission.gov.au/document/1086
NSW Law Reform Commission
<p>NSW Law Reform Commission website - https://www.lawreform.justice.nsw.gov.au/ Phone: 02 8688 7777 (business hours)</p> <ul style="list-style-type: none">• Review of the NSW Guardianship Act Report – various documents - https://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc_current_projects/Guardianship/Guardianship.aspx

Links to Resources Provided by Key Organisations

NSW Civil and Administrative Tribunal (Guardianship Division)

NCAT website - <https://www.ncat.nsw.gov.au/>

Phone: (02) 9556 7600 or **1300 006 228** - **press 2** for Guardianship Division

After hours (only for emergency decisions/ appointments): The number is provided when the call is outside business hours.

- **Factsheets – including Person Responsible, Restrictive Practices –** https://www.ncat.nsw.gov.au/Pages/guardianship/publications_resources/gd_fact_sheets.aspx
- **Application forms – including Guardianship, and Financial Management -** https://www.ncat.nsw.gov.au/Pages/guardianship/gd_forms.aspx

NSW Trustee and Guardian (financial matters)

NSWTAG website - <https://www.tag.nsw.gov.au/> Phone: 1300 364 103

- **Information about Powers of Attorney and links to forms -** <https://www.tag.nsw.gov.au/powers-of-attorney-landing.html>
- **Information about the role of private Financial Manager and links to handbooks -** <https://www.tag.nsw.gov.au/private-managers.html>

NSW Office of the Public Guardian (guardianship matters)

NSWOPG website - <https://www.publicguardian.justice.nsw.gov.au/>

Phone (for general enquiries): (02) 8688 6070 or 1800 451 510

Phone (when the Public Guardian is already appointed): (02) 8688 2650 or 1800 451 510

After hours (only for emergency guardianship decisions if the Public Guardian is already appointed): (02) 8688 2650

- **Resources for supported decision-making -** <https://www.publicguardian.justice.nsw.gov.au/Pages/Supported-Decision-Making.aspx>
- **Information about Enduring Guardians and links to forms -** https://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_planning/pg_enduring.aspx
- **Guide for enduring and private guardians -** https://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_publications/pg_serviceprovider/private_or_enduring_guardians_publications.aspx
- **Information about the Public Guardian's Support Unit for Private Guardians and Persons Responsible -** https://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_pgsupportu/pg_pgsupportu.aspx
- **Role of the Public Guardian and NDIS decisions -** https://www.publicguardian.justice.nsw.gov.au/Pages/publicguardian/pg_NDIS/Public-Guardian--NDIS.aspx
- **Information for private and enduring guardians and NDIS decisions -** https://www.publicguardian.justice.nsw.gov.au/Documents/NDIS/Factsheet_EG_and_PGSU__July2016.pdf

Links to Resources Provided by Key Organisations

NSW Ombudsman

Ombudsman website - <https://www.ombo.nsw.gov.au/>

Phone: (02) 9286 1000 or 1800 451 524

- **Several factsheets about reportable conduct of an employee relating to child protection** - <https://www.ombo.nsw.gov.au/news-and-publications/publications/factsheets/child-protection/child-protection-notifying-and-identifying-reportable-conduct>

NSW Family and Community Services

FACS website - <https://www.facs.nsw.gov.au/> Phone: (02) 9377 6000 (general enquiries)

- **Links to policies and information about authorisation panels – for restrictive practices** - <https://www.facs.nsw.gov.au/providers/deliver-disability-services/restrictive-practices-authorisation-portal>

ATTACHMENT 2

Checklist for NDIS providers

This checklist is a summary of the key points raised in this guide. It can be used to ensure the organisation's systems encourage and enable participants to make their own decisions, wherever possible.

Documents and processes

- ✓ Policies and procedures promote participants' rights to make their own decisions wherever possible, and systems to ensure that all decisions made on behalf of participants occur lawfully
- ✓ The ability of the participant to make each specific decision is assessed
- ✓ The support needs of the participant are identified
- ✓ People who can provide support to participants are identified
- ✓ Skill development of participants
- ✓ Participants have effective communication methods that are well understood by people who are supporting them
- ✓ Participants are routinely asked to make decisions about all aspects of their lives, and build their experience

Skill development of staff

- ✓ Staff are trained in the necessary skills to seek participants' wishes and preferences, and in providing and/ or arranging support to assist participants to make their own decisions
- ✓ Staff have access to, and have experience in using, a range of resources and tools to support participants make their own decisions

Finding an alternative decision-maker

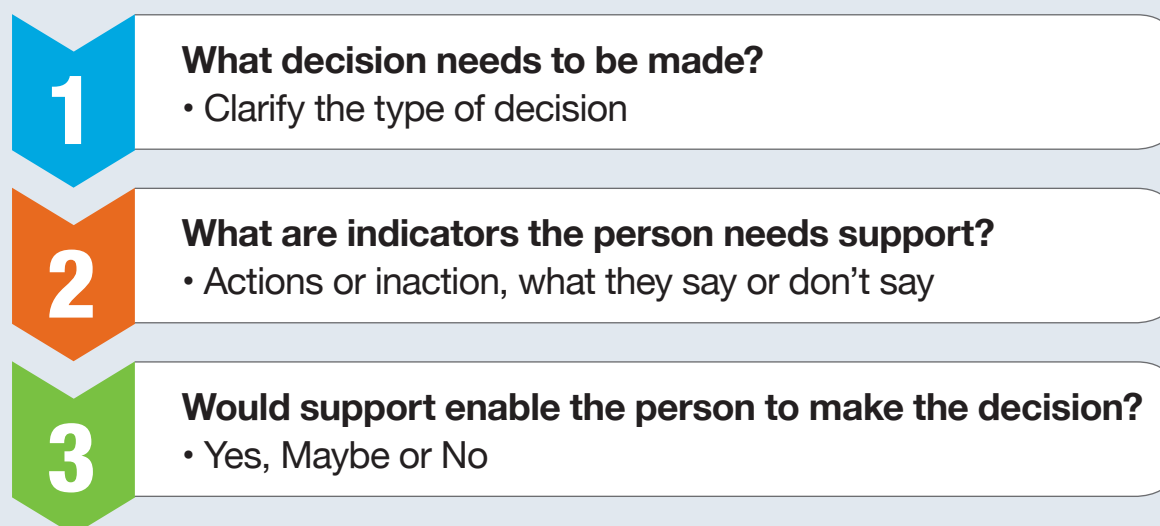
- ✓ Staff know, for each participant, who to approach for a specific decision if the participant is unable to make it themselves
- ✓ Key staff are identified who have the provider's authority to make an application for the appointment of a formally appointed decision-maker

Resourcing the costs of supported decision-making

- ✓ Develop a formula for the costs associated with supported decision-making and include it in quotes for participants, which they can use when discussing support plans with NDIA.
- ✓ Engage with universities or experts to collaborate on projects to develop specialised decision-making tools for specific participants.

Decision-making steps

This approach is one way of clarifying which decisions a participant can or cannot make themselves, whether support is needed, and if another person should make that decision. It is the approach used in several examples in this guide. This diagram shows the decision-making steps that could be used to determine whether or not a participant can make a specific decision.



1. What decision needs to be made?

The decision needed should be clarified.

- Is it complex or straightforward?
- What part of the person's life is affected by the decision – lifestyle, health, finances, etc?
- What are the risks and benefits associated with the possible options?
- What is likely to happen if a decision isn't made?

2. What are the indicators the person needs support?

The person may show by their words or actions that a decision is difficult, which could indicate they need support. For example –

- Refuses to discuss aspects of the decision
- Makes a hasty decision without considering the options and likely consequences
- Asks or defers to other people to make the decision for them
- Seems unable to understand the decision that needs to be made.

Providers should also consider other factors that may be affecting the person's difficulty with the decision, such as language and cultural issues, personal values and attitudes, and whether they have strongly held beliefs about aspects of the decision to be made.

3. Would support enable the person to make the decision?

The participant's potential to make the decision should be assessed, including whether support and information is likely to enhance the skills of the person's own decision-making ability. The answer to this question will determine what action the provider could then take –

Yes

Provide support and information to the person, so that they are better able to weigh up the key facts and issues and make the decision themselves. Note that a person may be able to make the decision themselves, but need support to implement that decision.

Maybe

Provide support and information to the person, and test their ability to weigh up the facts and issues. If the person's preferred decision involves a high level of risk, then the person may not have the ability to make this specific decision. However, if the person expresses a preference that is one of several suitable options, then the provider should accept the person's view as the decision, and provide support to act on the decision.

No

If the person is assessed as being unable to make the decision, the provider should ensure there is evidence to support this view. Evidence could include medical or health professional reports, and/ or the results of decision-making assessments. The provider should then obtain the decision from the relevant authorised decision-maker, or seek the appointment of someone to this role, so that a lawful decision can be made. Note that only certain types of decisions require a formally appointed decision-maker, as many decisions can be made informally by someone close to the person, such as a family member or friend. However, important decisions, such as those covered by legislation, must be made by a person with authority to do so.

Supported decision-making tools and resources

▶ NSW Public Guardian

Various supported decision-making resources for people with a disability

<https://www.publicguardian.justice.nsw.gov.au/Pages/Supported-Decision-Making.aspx>

▶ Scope Australia

Supported decision-making resources (print and film) developed for providers, families and carers, and legal professionals (register to access the tools)

<https://www.scopeaust.org.au/research-project/decision-making-support-building-capacity-within-victoria/>

▶ ADACAS Advocacy

Web-based decision-making tool in plain English for people with a disability (needs a log in)

<https://support-my-decision.org.au>

▶ Office of the Public Advocate Victoria

Research and projects, including the OVAL project for NDIS-related decision-making

<https://www.publicadvocate.vic.gov.au/advocacy-research/supported-decision-making>

▶ Western Australia's Individualised Services

Planning booklet and cards to support people in planning

http://waindividualisedservices.org.au/wp-content/uploads/2017/11/Preparing-to-Plan_Tagged-1.pdf

Supported decision-making resources

<http://waindividualisedservices.org.au/wp-content/uploads/2014/11/Supported-Decision-Making-Project-Resources-Supporting-Decision-Making.pdf>

▶ RMIT/ Inclusion Melbourne

Booklet for people with a disability about making choices

http://www.inclusion.melbourne/wp-content/uploads/2013/06/Its_My_Choice_Vol1_web.pdf

▶ Family Planning NSW

Supported decision making and reproductive and sexual health

<https://www.fpnsw.org.au/factsheets/health-professionals/resources/supporting-decision-making-reproductive-and-sexual-health>

▶ La Trobe University

Risk enablement tools and resources

<http://www.enablingriskresource.com.au>

Frequently asked Questions

This section lists some commonly asked questions that arise for providers, and suggestions about how to obtain a lawful decision.

What if a participant is making poor or harmful decisions?

Sometimes, a participant makes a decision that has, or is likely to have, detrimental consequences for themselves or others, and which raises concerns for the people supporting them. They could be expressing this decision verbally or through their actions. Providers need to weigh up the person's rights to take risks and make their own decisions, comparing it to the foreseeable harm that may occur and the provider's duty of care obligations.

It may be that the person has not fully considered the disadvantages of the options, or they may think the short-term benefits outweigh the long term problems. For example, they may be refusing food, running away, or exposing themselves or others to harm. Other risks include using public transport without an Opal Card, signing up to new mobile or electricity plans, or over-spending their budget. If possible, more support could be provided to the participant, such as helping them understand, avoid and manage the risks and potential consequences.

Another example is where workers believe the person needs restrictions on their food and drink to maintain a healthy weight, but the person asks for soft drinks and treats. The local doctor may have recommended a diet and exercise regime. Workers have a duty of care to participants to promote their wellbeing, but do not have authority to refuse these requests based on their own or others' opinions. They could only do so if an approved restrictive practice is in place.

If support is not effective or possible, and there are serious risks for the person, an authorised decision-maker may be needed, particularly if a restrictive practice is being considered to keep the person or others safe. However, an authorised decision-maker is simply a decision-maker and not a carer/ worker, and may be unable to prevent a person from continuing to make some poor decisions.

What if a decision is needed urgently?

Sometimes, decisions need to be made quickly to address a crisis, or there may be insufficient time to support the person to make the decision themselves.

Life-threatening circumstances

If a person's life is at risk and they are unable to make a decision, including if they are unconscious, then no decision-maker or consent is needed. Doctors and health professionals have the authority to do whatever is necessary to save the person's life. This ensures that any person, whether or not they have a disability, can access life-saving treatment when needed.

If the situation is not a crisis, but there is insufficient time to provide the necessary support to enable the person to make their own health or medical decision, then a Person Responsible should be identified. The legislation in NSW describes the hierarchy of people who could be a Person Responsible – it could be a spouse/ partner, carer (unpaid), relative, or friend – as long as they have a close and continuing relationship with the person with a disability. If there is no Person Responsible, the medical team can make an urgent application for NCAT to make that decision.

If the treating team believe that further treatment is futile, then they must seek consent to withdraw treatment. The person being asked to make an end of life decision should ensure that the recommendation is based on clinical reasons, and not on assumptions about the potential for a diminished quality of life. If the person with a disability cannot make this decision, then doctors can ask the Person Responsible, or Guardian (if they have healthcare and medical/ dental authority). If no-one has the necessary authority, the treating team can make an application for NCAT to make that decision.

Responding to an incident

Incidents do occur, despite providers' best efforts to prevent them. Incidents could include injury (to self or others), absconding, abuse (physical, sexual, or financial abuse), and assault.

(a) During and immediately following the incident

Decisions will need to be made quickly to protect the participant and others from further harm, alert emergency services, attend to injuries (which could be physical and psychological), manage industrial and work health and safety issues, and protect property. Every circumstance is different, and the potential decisions will vary.

Providers have a duty of care to everyone affected by the incident, and can lawfully make temporary decisions to ensure people's safety.

NCAT (Guardianship Division) has an after-hours service when urgent decisions are needed. This could include restricting a participant's access to another person/ item, moving a participant to another location, protecting a participant's assets, etc.

(b) After the incident

The provider will also need to manage the longer-term impact of the incident, and develop a plan to prevent it recurring. The plan may identify specific decisions affecting a participant, such as permanently relocating to another place, or the use of restrictive practices. For some of these decisions, an authorised decision-maker will be needed.

(c) Reporting obligations

NDIS providers are required to report any 'reportable incident' to the NDIS Commission within 24 hours, and any unauthorised use of restrictive practices within 5 days, as well as details of the incident response.

If the incident relates to the conduct of an employee and involves a child up to and including 17 years of age, it should also be reported to the NSW Ombudsman.

Attachment 1 provides contact details and reporting forms for key organisations.

What if a participant disagrees with the alternative decision-maker's decision?

Generally, there are two possibilities –

When only the participant disagrees

Sometimes, a person with a disability will disagree with a decision that is lawfully made by an alternative decision-maker. It may be that everyone around the person believes the decision is in their best interests. For example, the decision may be consent for a specific medication, or that the person moves to a different home. It can be challenging for family and providers if the person is actively resisting the implications of the decision.

The alternative decision-maker has the right to make that decision, but the person with a disability also has the right to have their concerns and objections heard. It may be that they don't fully understand why the decision was made, such as the health risks of not taking the medication, or the benefits of moving house. In this case, the decision-maker should spend time to explain why they made the decision. It may be that the person's concerns raise issues that hadn't been considered, and the decision-maker may make a different decision that is more acceptable to the person.

However, if the person is objecting to the practical implementation of a necessary decision, the alternative decision-maker does not automatically have authority to force the person to comply. In NSW, applications can be made to NCAT for specific authorisation to either over-ride a person's objections to medical treatment, or to authorise ambulance or police to take, keep or remove a person to or from their location.

When the parents/ carers disagree with SDM

Participants may have goals to expand the range of their experiences and skills, and providers may be able to provide the necessary support. However the person's parents/ carers may disagree, or want to change or refuse the goals. It can be difficult for some parents/ carers to understand the potential of their son/ daughter, and see how the person could become more independent.

Providers may need to provide information to parents/ carers that participants have the right to make their own decisions as adults. You should explain that providers have obligations to support the person's decision, except where the person is at immediate risk, or where a lawfully appointed decision-maker is in place for that type of decision.

What if the alternative decision-maker is making poor or harmful decisions?

Sometimes a person who is lawfully able to make decisions on behalf of a participant does not make decisions that are in the best interests of the participant. A poor decision can be expressed by an active choice, or by a failure to make a timely decision. It may be that they have not fully considered the likely impact of the decision for the participant, or do not understand the complexities of a specific decision. They may not adequately know the participant's wishes and preferences about the available options.

A poor or harmful decision is not simply a decision that you don't agree with. The provider needs to be able to demonstrate why the decision is detrimental to the participant. Where possible, the provider should make efforts to assist the decision-maker to understand the risks and benefits of their decision, by providing more information or putting them in contact with specialists. These discussions may be difficult, particularly if the decision-maker believes he/she is doing their best for the participant.

However, if there is significant cause for concern, such as where decisions are resulting in abuse or neglect, a different alternative decision-maker may be needed to protect the participant's needs and interests. In NSW, this is likely to mean applying to NCAT to appoint a different decision-maker.

Can participants consent to restrictive practices?

People with a disability have the right to make every decision about their own lives. However, all restrictive practices, by definition, limit a person's freedom and rights.

Theoretically, a person with a disability has the right to consent to the use of restrictive practices. It is certainly possible that a person could agree, in advance, to other people limiting their access to something that may be harmful to them, or taking medication to calm them down. This approach should be explored to see if it is workable in practice.

However, usually when a need for a restrictive practice is identified, it implies that the person is unable to manage an aspect of their behaviour themselves, and that someone else is required to give consent. For this reason, the NDIS Commission requires authorisation for all restrictive practices in the context of a Behaviour Support Plan. It also requires that restrictive practices are used as a last resort, and the plan describes how they will be reduced and eliminated.

What about SDM for children and young people?

All children and young people need to learn how to make their own decisions as part of their development and preparation for adulthood, and should be encouraged and supported to do so. However, until they turn 18 years of age, their Guardian will be either their parents or the relevant government Minister (if in statutory care). This means that sometimes, children and young people, including those with disability, will not have the final say in important decisions about their lives.

Providers should support children and young people to make as many decisions as possible, in collaboration with their parents, and/ or the staff representing the Minister. The support will need to be age appropriate, and tailored to the participant's skills and experience. Providers may also need to provide information to parents and others about the child's or young person's potential to develop decision-making skills, and the strategies being used to promote these abilities.

Decision-making mechanisms

The following information provides more details about the kinds of alternative decision-making roles, and what types of decisions each can make on behalf of a person with disability. Some mechanisms are Australia-wide, and others relate only to NSW.

Self-appointed decision-makers

Anyone can appoint someone else to make important decisions on their behalf, in case they become unable to make such decisions in the future. In NSW, this is via an Enduring Guardian and/ or Power of Attorney document. The solicitor preparing the document/s must be sure that the person understands the effect of the document/s.

Some people with a disability may also have sufficient understanding to make these documents. In these circumstances, the solicitor may request a medical or neuropsychology report about the person's ability to make these documents.

This means that if a person with disability is unable to make a specific decision, and they have previously appointed an Enduring Guardian and/ or Power of Attorney when able to do so, providers can ask the appointed Guardian or Attorney to make the necessary decision. This decision must be within the authority of the Enduring Guardian and Attorney. An Enduring Guardian can only make certain lifestyle decisions; an Attorney can only make financial and certain legal decisions.

Each State and Territory has similar roles.

Person Responsible

In NSW, if a person is unable to make a specific medical or dental decision, most of these decisions can be made by a Person Responsible. This role replaces the previous process of healthcare practitioners asking the 'Next of Kin'.

The *NSW Guardianship Act 1987* describes a hierarchy of people that can make these decisions –

- **Guardian** – appointed Guardian or Enduring Guardian, if given the right to consent to healthcare, and medical/ dental treatment
- **Spouse or partner** – if there is no guardian, and there is a close and continuing relationship
- **Carer** – if there is no spouse/ partner, an unpaid carer who arranges or provides regular support
- **Relative or friend** – if there is no carer, a relative/ friend with a close and continuing relationship.

The Person Responsible has the right to know about the proposed treatment, the risks and benefits, and to say 'Yes' or 'No' to the proposed treatment. The practitioner must seek the consent of the Person Responsible before proceeding with the treatment.

However, there are some exceptions. In NSW, only NCAT can either directly consent, or give authority to another person to consent. These include –

- The person is objecting to the treatment
- Medication affecting the central nervous system
- Androgen-reducing medication to control behaviour
- Termination of pregnancy
- Treatments likely to result in infertility
- New and trial treatments.

NDIS-related decision-makers

The NDIA can appoint a Nominee for a NDIS participant. There are two types of Nominees, and a person may be appointed to either or both roles. In all cases, Nominees cannot make decisions that the participant is able to make themselves, and must comply with NDIA requests for information.

The roles are as follows –

- **Plan Nominee** – can prepare, review and replace the participant’s plan, and manage the funding for the plan. The NDIA can limit the role as needed.
- **Correspondence Nominee** – can conduct NDIS related correspondence on behalf of the participant.

The NDIA will appoint a Nominee if requested by a participant, and when all other decision-making options are exhausted. The appointment, suspension, and cancellation of a Nominee are ‘reviewable decisions’.

The NDIA also states that it recognises other appointed decision-makers, such as Guardians and Attorneys/ Financial Managers. In NSW, these people can only make NDIS decisions that relate to their appointment. However, in practice, the NDIA requires formally appointed decision-makers to apply to be appointed as Nominees.

Centrelink-related decision-makers

Under the Commonwealth Department of Social Services’ guide to social security, a person can propose another person to be a Centrelink Nominee. Centrelink then formally appoints the Nominee if they are satisfied the person understands and can perform the role of contacting Centrelink on the person’s behalf. Centrelink can also identify and appoint a Nominee if it has evidence that the person receiving a benefit/ allowance is incapable of appointing a Nominee.

Being a Centrelink Nominee does not mean that person is entitled to be a participant’s NDIA Nominee.

Court-appointed decision-makers

In NSW, several courts can appoint either a private person or the NSW Trustee and Public Guardian to make decisions on behalf of another person, if the person with disability is unable to make certain decisions themselves, as follows –

- **NSW Supreme Court** – can appoint a Financial Manager
- **NSW Mental Health Review Tribunal** – can appoint a Financial Manager
- **NSW Civil and Administrative Tribunal (Guardianship Division)** – can appoint a Guardian and/ or Financial Manager. NCAT can also revoke or replace Enduring Guardians and Attorneys, and make one-off decisions about medical and dental treatment.

Financial Management orders - can be time-limited or ongoing, and relate to financial and legal decisions. Some exclusions can apply if the person is capable of managing some aspects of their finances. For example, they can manage their income, but not other investments or assets.

Guardianship orders - are all time-limited, and specify the types of decisions that are authorised. The usual types of decisions are accommodation, healthcare, medical and dental consent, and services. Other decision-making functions can be made if needed, such as authorising police/ ambulance to take, keep or return a person to a place of accommodation, over-ride a person's objections to medical treatment, authorise certain restrictive practices (in the context of a positive behaviour support plan), limiting the person's access to other people, passport restrictions, etc.

Attachment 7 has summary tables about who can make NDIS-related decisions, and decisions in NSW.

ATTACHMENT 7

Who can make which decisions?

a. Formally appointed decision-makers in NSW

Lawful Decision Makers	Who Authorises	Types of decisions					Comments
		Accommodation	Services	Health/Medical/Dental	Restrictive Practices	Financial/legal	
Minister for FACS	Family Court	Yes	Yes	Yes	Yes	Yes	Only applies to children 0-17 years in statutory care
Enduring Guardian	Person (Adult)	Yes	Yes	Yes	No	No	EG document must be prepared by solicitor
Power of Attorney	Person (Adult)	No	No	No	No	Yes	PoA document must be prepared by solicitor
Guardian	NCAT	Yes	Yes	Yes	Yes	No	Only if specifically appointed for each type of decision. Guardians can be appointed for some legal matters. These are time-limited appointments.
Financial Manager	NCAT/ Supreme Court/MHRT	No	No	No	No	Yes	Note that some exclusions may also apply
Person Responsible	NCAT legislation	No	No	Yes	No	No	Hierarchy listed in legislation

b. Who can make NDIS decisions?

NDIS Decision	Authorised decision-maker/s	Comments
Accessing the NDIS	<ul style="list-style-type: none"> • Family member, carer or friend • Guardian (enduring, private, or public) 	If a Guardian is appointed, they must have authority to make decisions about services
Identifying goals and objectives	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS plan nominee • Guardian (enduring, private, or public) 	If a Guardian is appointed, they must have authority to make decisions about services
Developing the NDIS plan	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS plan nominee • Guardian (enduring, private, or public) 	If a Guardian is appointed, they must have authority to make decisions about services
Selecting and changing service providers	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS plan nominee • Guardian (enduring, private, or public) 	If a Guardian is appointed, they must have authority to make decisions about services
Signing Service Agreements	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS plan nominee • Enduring or private Guardian • Attorney 	<p>A service agreement is a legal contract between the provider and participant. The NDIS legislation states that “Each participant has a clear understanding of the supports they have chosen and how the supports will be provided.”</p> <p>If an Enduring or private Guardian is appointed, they must have authority to make decisions about services.</p> <p>If the Public Guardian is appointed to make decisions about services, it will not sign service agreements. Note that if the NSW Trustee is appointed as Financial Manager, it also will not sign service agreements.</p> <p>If the provision of services is agreed, but no-one is willing or able to sign the service agreement, the provider should keep records of the verbal agreement, and its efforts to obtain a signature. However, the provider has no legal protections with an unsigned Service Agreement.</p>

NDIS Decision	Authorised decision-maker/s	Comments
<p>Making payments to providers</p>	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS nominee (plan or correspondence) • Attorney or private Financial Manager 	<p>If the NSW Trustee and Guardian is appointed as Financial Manager, it does not manage NDIS payments.</p> <p>If no-one is available, NDIS payments can be made by a Plan Manager (if allocated in the plan), or directly by NDIA.</p>
<p>Making a complaint/ requesting a review</p>	<ul style="list-style-type: none"> • Family member, carer or friend • NDIS nominee (plan and/ or correspondence) • Guardian (enduring, or private) - if they have authority to make decisions about services • Attorney or Financial Manager – if the concern is about finances 	<p>A review could be for a plan review, or a requested review of a 'reviewable decision'.</p>

SDM Summary for Board Members

What does Supported Decision-Making mean?

People with disability have the right to make their own decisions about every aspect of their lives. If they have difficulty making one or more decisions, SDM is the best practice approach for respecting these rights. The NDIS framework and legislation is based on these rights, and NDIS providers are required to enhance the decision-making ability of participants.

Many people with disability have had limited opportunities to make their own decisions, but with support, these skills can be developed – including people with cognitive impairments or complex needs. Organisations will need to actively build their own capability so that everyone is equipped to provide the necessary support.

Organisations also need to be able to identify when a participant is unable to make a specific decision, despite support, and know how to find or obtain an alternative decision-maker. Organisations that do not do so, are taking significant risks of breaching participants' human and legal rights.

What is your responsibility?

As a Board member, your responsibilities are to –

- Promote an organisational culture that maximises the opportunities for people with a disability to make their own decisions
- Allocate funds to enable staff to access training and resources to develop their skills in providing decision-making support to people with disability
- Obtain reports and monitor SDM as an outcome measure for organisational performance.

Under what conditions can some-one else make decisions for people with disability?

Other people can make decisions for participants when –

- The participant has formally appointed someone to do so, or
- The decision-maker is recognised as a Person Responsible – only for medical/dental decisions, or
- A Tribunal has appointed someone to do so, or
- A panel for restrictive practices authorises someone to do so – only for restrictive practices' decisions.

NDIS providers' Board members, managers, workers and volunteers do not have authority to make decisions on behalf of people with disability.

Want more information?

Refer to NDS' guide - *People with Disability and Supported Decision-Making*, which also has links to other resources.

SDM Summary for Managers

What does Supported Decision-Making mean?

People with disability have the right to make their own decisions about every aspect of their lives. If they have difficulty making one or more decisions, SDM is the best practice approach for respecting these rights. The NDIS framework and legislation is based on these rights, and NDIS providers are required to enhance the decision-making ability of participants.

Many people with disability have had limited opportunities to make their own decisions, but with support, these skills can be developed – including people with cognitive impairments or complex needs. Organisations will need to actively build their own capability so that everyone is equipped to provide the necessary support.

Organisations also need to be able to identify when a participant is unable to make a specific decision, despite support, and know how to find or obtain an alternative decision-maker. Organisations that do not do so, are taking significant risks of breaching participants' human and legal rights.

What is my responsibility?

As a Manager, your responsibilities are to –

- ✓ Ensure policies and procedures include guidelines for staff about how to support participants to make their own decisions, and when to find an alternative decision-maker
- ✓ Stay up-to-date with changing legislative requirements
- ✓ Enable staff to access training and resources to improve their capabilities to support participants make decisions, and include SDM as a topic to discuss in team meetings
- ✓ Recognise staff who are effectively supporting participants to make decisions
- ✓ Monitor SDM as an outcome measure for organisational performance, and develop routine reports.

Under what conditions can some-one else make decisions for people with disability?

Other people can make decisions for participants when –

- The participant has formally appointed someone to do so, or
- The decision-maker is recognised as a Person Responsible – only for medical/dental decisions, or
- A Tribunal has appointed someone to do so, or
- A panel for restrictive practices authorises someone to do so – only for restrictive practices' decisions.

NDIS providers' Board members, managers, workers and volunteers do not have authority to make decisions on behalf of people with disability.

Want more information?

Refer to NDS' guide - *People with Disability and Supported Decision-Making*, which also has links to other resources.

SDM Summary for Workers and Volunteers

What does Supported Decision-making mean?

People with disability have the right to make their own decisions about every aspect of their lives. If they have difficulty making one or more decisions, SDM is the best practice approach for respecting these rights. The NDIS framework and legislation is based on these rights, and NDIS providers are required to enhance the decision-making ability of participants.

Many people with disability have had limited opportunities to make their own decisions, but with support, these skills can be developed – including people with cognitive impairments or complex needs. Organisations will need to actively build their own capability so that everyone is equipped to provide the necessary support.

Organisations also need to be able to identify when a participant is unable to make a specific decision, despite support, and know how to find or obtain an alternative decision-maker. Organisations that do not do so, are taking significant risks of breaching participants' human and legal rights.

What is my responsibility?

As a worker/ volunteer, your responsibilities are to –

- ✓ Ask participants about their decisions, for every aspect of their lives.
- ✓ Provide support to participants to implement their decisions, if needed
- ✓ Learn about SDM and provide support to participants if they are having difficulties making a decision
- ✓ Be willing to speak up if your co-workers are not respecting participants' rights to make their own decisions.
- ✓ Identify when a participant is unable to make a specific decision, and know how to find an alternative decision-maker. The organisation's policies and procedures should describe the actions you should take.

Under what conditions can some-one else make decisions for people with disability?

Other people can make decisions for participants when –

- The participant has formally appointed someone to do so, or
- The decision-maker is recognised as a Person Responsible – only for medical/dental decisions, or
- A Tribunal has appointed someone to do so, or
- A panel for restrictive practices authorises someone to do so – only for restrictive practices' decisions.

NDIS providers' Board members, managers, workers and volunteers do not have authority to make decisions on behalf of people with disability.

Want more information?

Refer to NDS' guide - *People with Disability and Supported Decision-Making*, which also has links to other resources.

