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Family &  
Community Services  
Ageing, Disability & Home Care

# Supported Decision Making

## A handbook for facilitators





# Contents

The basics	5
What is supported decision making?	5
Who is this handbook for?	5
Beliefs and principles	6
Laws and policies	6
United Nations Convention on the Rights of Persons with Disabilities 2006	6
Disability Inclusion Act, 2014	6
NSW Disability Standards	7
Guardianship legislation	7
Ready together	8
Living Life My Way	8
Lifestyle Planning Policy	8
Decision Making and Consent Policy and Guidelines	8
Facilitating supported decision making	9
What is supported decision making?	9
How can a facilitator help?	10
Fact sheets:	12
Fact sheet 1: Getting started	12
Fact sheet 2: Identifying supporters	13
Fact sheet 3: What do facilitators do?	15
Promoting supported decision making	15
Informing	15
Mentoring	15
Coaching	16
Facilitating supported decision making is...	16
What it is not...	16
Fact sheet 4: Decision making in action	18
Five steps to effective decision making	18
Fact sheet 5: When things go wrong	21
Lack of supporters	21
The supported decision making relationship ends	21

Misuse of the supporter's role	21
Disagreements	22
Barriers to decision making	22
When a decision maker is unable to make a decision	22
Substitute decision making	23
Managing risks in decision making	24
When decisions go wrong	25
<a href="#">Fact sheet 6: developing reflective practice</a>	<a href="#">27</a>
Roles and boundaries	27
Time management	27

# The basics

## What is supported decision making?

Everyone has the right to make decisions about their lives. This is something that we take for granted every day when we make big and small decisions about things that affect us. People with disability have the same rights as everyone else, however many people with disability have not had the same opportunities to make decisions and to develop the skills and knowledge to direct their own lives. Getting support for decision making is something we all do. If the decision is important to us we might take longer to decide. We might ask other people for ideas or information, or to help us make up our mind by talking about the options. There may be times in our lives when we need more support to make decisions, particularly when we have to make major decisions. In the context of working with people with disability, supported decision making draws on our experience of decision making and support, and applies this in ways which help the person with disability to make more decisions for themselves.

Supported decision making is a practical way for a person with a disability to make sure that they are at the centre of making their own decisions and are heard by those around them. Support is provided by someone the person trusts. This could be a family member, friend, service provider or someone else chosen by the person. Supported decision making may also help the person with a disability to build their skills in decision making and develop the confidence to decide more for themselves.

## Who is this handbook for?

A range of people may be involved in supporting a person with disability to make their own decisions and building their knowledge, skills and confidence to make decisions.

The main supported decision making roles are:

- the **decision maker** who wants support to make decisions
- the **supporter** who provides direct support to the decision maker
- the **facilitator** who works with the supporter and decision maker to build their supported decision making skills.

This handbook has been written as a guide for facilitators. The role of a supported decision making facilitator is new and evolving. Facilitators may be involved because they have an existing relationship with the decision maker as a service provider, support worker or carer. It is likely that facilitating supported decision making will be one aspect of a broad range of support or service provided to the decision maker.

## Beliefs and principles

The decisions we make, big and small, add up to the type of life we lead and the people we are. Being able to make decisions about the way we live our lives is a human right. Everybody has this right - it doesn't matter if you were born in Australia or overseas, if you are younger or older, male or female or if you have a disability. These rights are set out in laws, conventions and policies. Some people need support to make sure they can act on this right. People with disability also have the right to get the support they want to make decisions.

Supported decision making is built on some important beliefs and principles. These principles guide practice around supported decision making.

- People have the right to make decisions about things that affect their lives.
- People are presumed to have the capacity to make their own decisions and give consent when it is required.
- People have the right to be supported to make decisions about their own lives.
- People have the right to choose who will provide support for decision making, and how this support will be provided.

## Convention, laws and policies

### United Nations Convention on the Rights of Persons with Disabilities 2006

Australia adopted the UN Convention on the Rights of Persons with Disabilities in 2008 (the Convention). The Convention is an international agreement by governments all around the world to uphold the rights of people with a disability. The first general principle of the Convention is *'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'*.

The Convention also outlines the rights of people with disability to have equal access before the law, and to be provided with support when needed. Under the Convention, Australia has a responsibility to remove barriers and discriminatory practices affecting people with disability. You can find an 'easy read' version of the convention here: [www.unicef.org/publications/index\\_43893.html](http://www.unicef.org/publications/index_43893.html).

### Disability Inclusion Act, 2014

The *Disability Inclusion Act*, 2014 (the Act) replaces the Disability Services Act, 1993. The Act underpins the delivery of all Family and Community Services (FACS) funded and operated disability services and supports in NSW. The Act includes a set of principles that support the implementation of the Convention to ensure the rights of people with disability are upheld. These include principles directly related to supported decision making.

Principle 5 states that people with a disability have the *'same rights as other members of the community to make decisions that affect their lives (including decisions involving*

risk) to the full extent of their capacity to do so and to be supported in making those decisions if they require or want support’.

Principle 9 states:

*‘People with a disability have the right to access information in a way that is appropriate for their disability and cultural background, and enables them to make informed choices’.*

The Act also acknowledges the right of people with a disability to participate in and contribute to social and economic life, and to realise their physical, social, sexual, reproductive, emotional and intellectual capacities. FACS services funded and operated under the Act are required to uphold these principles. The Act is available at [www.legislation.nsw.gov.au](http://www.legislation.nsw.gov.au).

## NSW Disability Standards

The NSW Disability Standards called ‘Standards in Action’, outline the obligations that services have to people with a disability who receive supports that are funded and operated by the NSW government.

The standards relate to six areas of disability service delivery. The right to express choices and make decisions is reflected in all of the standards:

1. Each person receives a service that promotes and respects their legal and human rights and enables them to exercise choice like everyone else in the community.
2. Each person is encouraged and supported to contribute to social and civic life in their communities in the way they choose.
3. Each person is supported to exercise choice and control over the design and delivery of their supports and services.
4. When a person wants to make a complaint, the service provider will make sure that the person’s views are respected, that they are informed as the complaint is dealt with, and have the opportunity to be involved in the resolution process.
5. Each person is assisted to access the supports and services they need to live the life they choose.
6. Service providers are well managed and have strong and effective governance to deliver positive outcomes for the people they support.

For more information about the NSW Disability Standards please refer to the ADHC Website - [www.adhc.nsw.gov.au/sp/quality/standards\\_in\\_action](http://www.adhc.nsw.gov.au/sp/quality/standards_in_action).

## Guardianship legislation

In some circumstances, a person with a disability may need a substitute decision maker to make important lifestyle or financial decisions for them. The NSW *Guardianship Act, 1987* allows for the appointment of legally appointed decision makers (guardians for health and lifestyle matters, and financial managers for financial and property matters). Guardians and financial managers have the legal authority to make certain decisions on behalf of a person with disability. Guardians and financial



managers are usually appointed by the NSW Civil and Administrative Tribunal (Guardianship Division).

## Ready together

Ready Together follows on from Stronger Together 2 – the NSW program of disability reform that created more funding for people with disability to access support. Ready Together focuses funding to give people more flexibility, more choice and more control. It is implemented through the Living Life My Way framework, and prepares NSW for transition to the National Disability Insurance Scheme (NDIS). More information is available at: [www.adhc.nsw.gov.au/about\\_us/strategies/ready\\_together](http://www.adhc.nsw.gov.au/about_us/strategies/ready_together)

## Living Life My Way

Living Life My Way is a part of Ready Together, and creates individualised funding for people with disability so they can receive more tailored supports to meet their needs. This program is part of the transition of supports to the NDIS. More information can be found at: [www.adhc.nsw.gov.au/about\\_us/strategies/life\\_my\\_way](http://www.adhc.nsw.gov.au/about_us/strategies/life_my_way).

## Lifestyle Planning Policy

The ADHC Lifestyle Policy and Practice Manual includes the Lifestyle Planning Policy, Guidelines and resources that provide a range of person-centred thinking and planning tools that are central to supported decision making. You can find them online here: [www.adhc.nsw.gov.au/publications/policies/policies\\_a-z/?result\\_237652\\_result\\_page=L](http://www.adhc.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=L)

## Decision Making and Consent Policy and Guidelines

The ADHC Decision Making and Consent Policy and the Decision Making and Consent Guidelines provide detailed information and guidance about supporting people with disability to make decisions and to provide consent regarding a range of issues affecting them. You can find the policy and guidelines on line at: [www.adhc.nsw.gov.au](http://www.adhc.nsw.gov.au).

### Key points

1. The law says that people with disability have the same rights as everyone else to make decisions that affect their lives.
2. Legislation and policy supports the rights of people with disability to access support to make decisions and to have choice and control over their lives.

# Facilitating supported decision making

## What is supported decision making?

Supported decision making happens when a person with disability chooses a trusted person or people to help them make decisions. Most of us will seek support for decision making at some point in our lives. In this guide, we are focusing on the needs of people with disability who want or need support to make decisions. This may be because of an intellectual disability, brain injury, mental illness or other disability that affects a person's decision making capacity. It could also be because people with a disability haven't been given the opportunity to make their own decisions or learn from their mistakes. For these reasons, some people haven't been able to gain experience in decision making. Supported decision making is a way of giving the person with disability the opportunity to learn more about decision making and to gain more choice and control in their lives.

Supported decision making always involves:

- the **decision maker** who wants support to make decisions; and
- the **supporter** who provides direct support to the decision maker.

Supported decision making may also involve:

- a **facilitator** who works with the supporter and decision maker to build their supported decision making skills.

Supported decision making starts with the decision maker. The decision maker will choose supporters because they want their help to make a decision. Supporters are people who the decision maker trusts and usually they already know the decision maker. However, some supporters may be new to the decision maker. Supporters can come from all walks of life.

A decision maker may choose someone to support them in only one decision or in many decisions about their life. They may choose one supporter or have a group of supporters.

The role of a supporter is to make sure the decision maker is able to exercise their right to make decisions that affect their lives. This may involve supporting the decision maker to find information, identify options, weigh up options, communicate a decision, understand elements of the decision or anything else the decision maker needs.

The **Handbook for Supporters** in this package has more information about the roles of the decision maker and the supporter.

Supported decision making will often mean that a new relationship is created between the decision maker and the supporter. It may involve re-thinking an existing relationship, learning new skills or approaching decisions in a different way.

Sometimes, it is helpful for the supporter and the decision maker to have someone else involved in facilitating this process. A facilitator is not always needed in supported decision making, but at times it can help to keep things on track.

## How can a facilitator help?

A facilitator helps decision makers and supporters work together. Facilitators are outside the decision making relationship, and do not have decision making authority. A facilitator applies the concepts, legislation and policy underlying supported decision making to assist the decision maker and the supporter. Facilitators take a person centred approach when working with decision makers and their supporters. Being a facilitator does not mean doing something for somebody; rather it is mentoring or coaching them so they can increase their skills and confidence to do things for themselves.

Facilitating supported decision making can include:


- Explaining supported decision making to decision makers and supporters and providing training or mentoring as needed.
- Modelling behaviour to supporters and others involved in the supported decision making process. For example, demonstrating active listening or using person centred thinking tools to clarify what is important to/for the person.
- Helping decision makers and supporters get access to practical supports like communication aids, meeting places and other resources that will help with the decision making process.
- Helping supporters maintain a clear distinction between other roles they may have, such as support worker, carer, friend or advocate.
- Ensuring the supporter is not unintentionally making substitute decisions for the person or exerting undue influence on the decisions the person makes.
- Motivating the supporter and decision maker to engage in and commit to the process.
- Ensuring the decision maker's communication needs are being met or are optimised.
- Helping the supporter work through 'ethical dilemmas'. This could include balancing the supporter's duty of care to the decision maker with the decision maker's right to make decisions that are risky, or help to resolve actual or perceived conflicts of interest.

The role of a facilitator will be challenging at times. In practice the decision maker may find it difficult to choose a supporter, may choose a supporter who is not trustworthy, or may find it difficult to grasp and make an informed decision. A skilled facilitator will be alert to these potential issues and help to find a resolution.

As a facilitator, you need to be very aware of your role, and to make sure you are not taking over as a supporter or imposing your values and beliefs on the supporter or the decision maker. This guide includes a series of fact sheets which explore some of the issues facing facilitators in supported decision making.

**Things to remember** 

- 1. Make sure the decision maker and supporter know of, and have agreed to, your role as a facilitator.
- 2. You don't need to have all the answers!

**Something to think about** 

What is your relationship with the decision maker? How might this change if you take on a role in facilitating supported decision making?

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What strategies could you use to make sure you stay within the boundaries of your role as facilitator?

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## Fact sheet 1: Getting started

As a facilitator, your role will be to guide people through the supported decision making process and help to remove some of the practical barriers to decision making that might come up. For example the decision maker might need an aid, access to technology or specialist support to help them with communication.

Facilitators also have a role in coaching or mentoring supporters and decision makers. Supporting someone to make decisions for the first time can be daunting. Even if the supporter has a long standing relationship with the decision maker, supported decision making can mean a change in the way they have been doing things or even a change in their relationship. Facilitators can offer guidance on how to navigate any tricky issues that come up.

Supported decision making relies on understanding the decision maker's preferences, goals and aspirations. There are a number of person centred thinking tools that can help supporters and decision makers get ready to make decisions. These include the *One page profile*, *Important To and Important For*, *Communication profile*, and *Decision making profile*.

Lifestyle Plans can also create a 'bigger picture' understanding of the decision maker's plans and goals, which can start the supporter and the decision maker thinking about the types of decisions they wish to make. Lifestyle plans can take a number of forms, from a series of documents to a whiteboard or poster. Lifestyle plans are completed by the decision maker, with support if needed, and input from those who are important to them. Where a person needs a lot of support with communication and decision making, facilitators may need to assist supporters to explore creative ways to make sure the person has a real say in planning processes.

You can find out more about these in the 'Useful tools and resources' section at the end of this handbook.

### Things to remember



1. Effective decision making is key to making decisions.
2. The decision maker owns their goals and aspirations and drives decision making.
3. Encourage the decision maker to keep other people in their life involved- the broader the person's network the more support they will have.
4. We all change over time, so Lifestyle plans and other tools that are used in supported decision making need to be updated regularly.

## Fact sheet 2: Identifying supporters

To facilitate supported decision making, you first need to identify who the decision maker wants to support them. For some people this will be easy, as the decision maker will be able to tell you about family members, friends or other people in their lives that they trust to support them. Other people may have a network of friends or family but will be unsure how to choose a supporter for their decision making. Some people may not have any close and ongoing relationships in their lives. As a facilitator, your role may be simply to provide existing supporters with information about supported decision making. In other situations, you may need to work intensively with a decision maker over time to develop closer links with others that can lead to a supported decision making relationship.

In NSW there is no formal process for appointing supporters, and no forms to fill in. Some people may make up a written agreement to clarify the roles and tasks of the supporter and the decision maker. An example of a supported decision making agreement can be found in the Office of the Public Advocate's Supported Decision Making Practice Manual v1.4 at [www.opa.sa.gov.au/resources/supported\\_decision\\_making](http://www.opa.sa.gov.au/resources/supported_decision_making). Facilitators need to clarify the role of a supporter with the decision maker, and ensure that the decision maker is happy for the supporter to talk about them and share information.

Taking on a role as a supporter for decision making is different from other roles the supporter may have in the person's life. Supported decision making is not about providing direct care, or advocacy, or making decisions for the person with disability. As a facilitator, you may need to work with the decision maker and the supporter to clarify this role. The Handbook for Supporters and the decision maker's handbook called 'My life, my decision' in this package provides more information on developing the supported decision making relationship.

For people who are not sure how to choose a supporter from their existing networks, you may be able to provide information about supported decision making, discuss some of the qualities of a supporter and assist the person to think about who could best meet their decision making needs at the time.

The decision maker and supporter may have known each other for a long time, and have strongly established roles within their relationship, such as parent and child, which may affect the decision making process. It can take time to learn new ways of thinking about and approaching decisions, for everyone involved. As a facilitator, you could assist the decision maker and the supporter to reflect on their roles and to clarify the supported decision making relationship.

The decision maker may choose someone they trust who doesn't feel they have the skills or confidence to undertake supported decision making. As a facilitator you may offer to coach or mentor the supporter so they can develop these skills.

If you are working with someone who has very few close relationships in their lives you can consider the following strategies to help identify supporters:

1. Work with the person to explore whether it is possible to reunite with family members, or develop closer relationships with people they know in the community or at work.
2. Give the person information about social groups, advocacy organisations or support networks which may lead to the development of stronger relationships.
3. Find out if there are any volunteer or paid decision making supporters available who could develop a relationship with the person.

**Things to remember**



1. Always confirm the role of supporters with the decision maker.
2. Supporters and decision makers may need information, coaching or mentoring about supported decision making and their roles.

**Toby's story**

Toby is a 45 year old man who lives independently in a flat. He has 'drop in' support from a disability service and goes to work four days a week. Toby's parents have died and he has very limited contact with his sister who lives interstate. He has a couple of cousins who live in a neighbouring town but he hasn't seen them for some years.

How could you assist Toby to identify decision making supporters?

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Where might Toby find supporters?

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## Fact sheet 3: What do facilitators do?

Facilitators can build and encourage supported decision making relationships by working with the supporter or the decision maker. Because each relationship is unique, there are no hard and fast rules to go by.

Your first step may be to assist a decision maker to find supporters. For more information about identifying supporters see Fact Sheet 2: Identifying the supporters. Initially, both the decision maker and the supporter may need information about supported decision making – what it is and how it works. Once a supported decision making relationship has been established, you will generally be working more with supporters. You are not directly involved in the decision making process, and the supporters have been chosen by the decision maker to take on this role. Your aim is to build their knowledge and skills so that the decision maker and the supporter eventually no longer need you.

As a facilitator, you might be in regular contact with the supporter and the decision maker, at least initially until they develop more confidence. Or, you may only be approached by the supporter from time to time when they have a problem or question. A facilitator may be involved in some of all of the activities listed below.

### **Promoting supported decision making**

One of your roles is to promote supported decision making in the community. Even though we all give and receive support for decision making in our everyday lives, most people are unfamiliar with the idea of supported decision making for people with disability. You can promote supported decision making by talking to people you meet in your role as a support worker or service provider; developing brochures or flyers; or holding information sessions for the general public. It is helpful for everyone around the decision maker to understand what supported decision making is and how it can assist the person to have more choice and control in their lives. This includes services and supports, family, friends and carers of the person with disability.

### **Informing**

Facilitators can provide information to decision makers, their supporters and broader networks about supported decision making. Information can be delivered in workshops, seminars, small groups or one to one training. The resources and tools in this kit can be used to develop educational material for supported decision making.

### **Mentoring**

When you have established relationships with decision makers and supporters, you may be involved in mentoring the supporter in their role. As a facilitator, your aim is to develop the relationship between the supporter and the decision maker, and enhance their skills so that they can work independently. Your focus is mostly on the supporter, as they are the person chosen by the decision maker to assist them. If you work



too closely with the decision maker, you may end up falling into the role of another supporter. Maintaining boundaries is an important part of a facilitator's role.

The definition of a mentor varies, and can take different forms in different settings. A mentor is generally seen as an experienced and trusted guide. A mentor is not expected to know everything and resolve all of the problems raised by supporters or decision makers. Rather, a mentor will listen to the supporter, help them to think about their role and to work out how to approach decision making. As a mentor you can provide information or ideas to the supporter however you are not there to direct or instruct the supporter. It is up to the supporter to decide how they can best work with the decision maker.

As a mentor, you will also be modelling skills that the supporter can use in their relationship with the decision maker, such as active listening and taking a person-centred approach.

### Coaching

There may be specific skills or knowledge that the supporter needs. As a facilitator, you may be involved in coaching the supporter to achieve a skill or goal that they have identified they need. For example, a supporter may ask for assistance to use a person-centred tool such as the Important to and Important for tool in the Lifestyle Planning kit.

### Facilitating supported decision making is...

- working with the decision makers to identify supporters and link them up
- helping supporters to keep on track
- being a point of contact to assist supporters with questions or problems
- building the skills of supporters so they are able to independently provide support to decision makers.

### What it is not...

- telling the supporter what to do
- getting directly involved in the decision making process
- choosing supporters for the person
- knowing all the answers and solving all the problems
- a long term relationship – you have been a successful facilitator when the supporter and the decision maker no longer need your help!

### Things to remember



1. There is not a 'one size fits all' model of supported decision making.
2. When in doubt, go back to the decision maker: what do they want or need?

Something to think about



What skills and experience do you have that will help you in your role as a facilitator of a supported decision making relationship?

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What extra training or information could you use?

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How will you obtain this?

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## Fact sheet 4: Decision making in action

Everyone approaches decision making differently. Our decision making style is influenced by things like cultural background, life experience, age, gender and health and wellbeing. The way we make decisions is also affected by the options available, any barriers to decision making, and time.

Decision making can be thought of as a series of steps. Some people will follow these steps in a linear way when making a decision, while others will skip steps, jump between steps or use a different process altogether. Despite these differences, decisions can be more easily understood if we break them down into steps.

As a facilitator, it may be helpful to think about the various tasks involved in each decision making step. This can assist you to think about where the supporter and the decision maker are at, and to help them move through a process if they are unsure how to approach decision making. The Handbook for Supporters in this package contains detailed fact sheets on each of the decision making steps summarised below.

We make decisions a range of reasons. We may feel dissatisfied with something in our lives or want to expand the opportunities we already have. Decisions aren't always something we choose to do but can also be imposed on us by external factors. For example, a lease may end on our house and we need to find somewhere else to live, or a person we used to rely on for personal care is no longer able to do that.

No matter what decision needs to be made or the reason for making it, there are some basic steps to think about that may help a person make the right decision for them.

### Five steps to effective supported decision making

#### Step 1: Finding the options and getting information

The decision maker is supported to explore all possible options and to find relevant information about these options. Facilitators may be involved in providing information directly or showing the supporter where to access information such as websites or service directories. You may be able to assist in providing information in a more accessible format such as Easy Read or audio transcripts. As a facilitator, you could encourage the supporter to think creatively about options and to find ways of overcoming barriers. At this early stage the decision maker should be encouraged to think very broadly about possible options, but the practicality of each option will need to be considered. This may also include creative thinking about how to bring about an option that may at first seem unlikely.

#### Step 2: Weighing up choices

At this stage, the decision maker may be weighing up the pros and cons of each choice and thinking about the potential consequences, risk and benefits of their options. This step will be strongly influenced by the decision maker's style. The

decision maker may want to spend a lot of time deliberating, or make a quick decision. As a facilitator, you can encourage the supporter to be aware of the decision maker's style and to ensure that their support is in tune with the way the person wants to make decisions. You can also assist the supporter to reflect on their own values and beliefs and how these might impact on their approach. Simple 'pros and cons' list for each option, followed by weighing these options, can be an effective way of making considered decisions.

### Step 3: Deciding

This is the crunch time! Sometimes, the decision maker or the supporter will be anxious about making a final decision. The decision maker might not have had any experience in making decisions before. The supporter may be concerned about possible risks or negative consequences of a decision. Your role as a facilitator may be to provide reassurance and encouragement to the supporter or the decision maker, and to help them work through their concerns.

### Step 4: Acting on the decision

Once a decision has been made, the decision maker may need support to follow through on their decision. The decision maker or their supporter may experience barriers due to communication difficulties, the influence of others, or financial issues. Your role as a facilitator may be to encourage the supporter to consider creative solutions, provide information that may overcome barriers, or share ideas about communicating effectively.

It is not the role of the supporter to implement decisions, although the supporter may also have this role in the decision maker's life. As a facilitator, be aware that some decision makers may need to rely on others to help them implement the decision they make.

### Step 5: Reflecting

After a decision has been made, it is useful for the decision maker and the supporter to think about how it turned out, how well the supported decision making approach worked, and what could be done differently next time. This is not a natural step to many people, and facilitators can help by modelling good reflective thinking and encouraging the supporter to review their role in the decision making process.

### Things to remember



1. Refer to the Handbook for Supporters for more information on decision making steps.
2. The decision maker's style will influence how they move through these steps.
3. You do not have to make sure all steps are followed.

**Amal's story**

Amal is a recreation officer who supports people with disability to participate in a range of social and sporting activities. Amal supports John to take part in a local soccer team. John has been thinking of trying out for the Special Olympics soccer team, and his father Terry has been supporting him to make this decision. Amal gives Terry the details for the Special Olympics website so that he can support John to learn more about the process of joining a team. A couple of weeks later, Terry asks Amal for help to get funding for John to travel interstate for competitions.

How has Amal facilitated supported decision making for John and Terry?

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How could Amal respond to Terry's request?

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## Fact sheet 5: When things go wrong

Facilitating supported decision making can be a rewarding and positive experience. It is exciting to see a person gain new skills and confidence to make decisions and to exercise choice and control in their lives. However, problems can arise and the facilitator could be the person who first identifies an issue or is approached by the supporter or the decision maker for help. The Handbook for Supporters contains more information about some of the issues listed below.

### **Lack of supporters**

Some people with disability have very limited social networks and limited natural supports. As a facilitator, you might need to assist a decision maker who is not able to identify supporters. It may take time to develop a supported decision making relationship. You could assist by helping the person to identify existing supports, friendships or other relationships that could be strengthened over time. You may need to refer the decision maker to advocacy or other volunteer services that may be able to introduce them to a new supporter. For decision makers in this situation, it is very easy for facilitators to fall into a supporter role, and in practical terms it may be the only option if a decision is needed in the near future. If you find yourself taking on a more direct role as a decision making supporter, take time to consider the implications of this role, including your time, availability and the impact on your other roles with the decision maker.

### **The supported decision making relationship ends**

Supported decision making relationships can end for a variety of reasons. The supporter may not have the time or willingness to continue the relationship. There may be a conflict of interest or a fundamental difference in values and beliefs that prevent the supporter and the decision maker from working together. The supporter may be a paid worker who moves on to another job or career option. As a facilitator, you can encourage the supporter and the decision maker to end the relationship on a positive note by talking about the reasons why the relationship is ending and agreeing on how to end contact. You may then need to assist the decision maker to find new supporters.

### **When the supporter goes outside their role**

As a facilitator, you might notice that the supporter is acting outside their role or abusing their trusted relationship with the decision maker. This could range from trying to influence the decision maker to make a certain decision, imposing their own values and beliefs or abusing or exploiting the decision maker. You may need to discuss your concerns with the supporter and take action to remedy the situation. Action could include providing more education or training, or meeting with the decision maker to explain your concerns. If you have serious concerns about possible abuse, you can

contact such as the National Disability Abuse and Neglect hotline for advice ([www.disabilityhotline.net.au](http://www.disabilityhotline.net.au) ph: 1800 880 052).

Misuse of the supporter role is less likely to occur when the supporter and the decision maker have access to education and information about their roles. Other safeguarding strategies include:

- Encouraging the decision maker to have other people in their lives who are interested.
- Ensure the decision maker has access to information or education about their other rights to be safe, free from abuse and to make their own decisions.

### **Disagreements**

Disagreements can arise for a number of reasons. It could be that the supporter and the decision maker do not agree on a decision or the options available. The decision maker could end up in conflict with a parent or carer because of a decision they wish to make. As a facilitator, you may be called upon to help resolve these disagreements. Remember that you are not responsible for resolving everyone's differences or entering into conflict resolution with the people involved. Your role as a facilitator may be to guide the supporter in thinking about solutions to the disagreement, or to provide information on options such as dispute resolution or counselling services that may assist those involved to resolve their disagreement.

### **Conflicts of interest**

Sometimes, a conflict of interest may arise for the supporter in their role. For example, a supporter who works for an accommodation service may have a conflict of interest in supporting the decision maker to decide whether to leave the service and live somewhere else. These conflicts may be so significant that the supporter will need to step aside. If this happens, the facilitator may need to assist the decision maker to find a new supporter. Or, the conflict of interest may not be clear to the supporter or the decision maker and it may be your role as a facilitator to point this out and explore ways to make sure that it does not impact on the decision making process.

### **Barriers to decision making**

There are many potential barriers to decision making. Historically, people with disability have often experienced limited options or resistance from others when wanting to make decisions. Lack of information or experience are also barriers to decision making. The Handbook for Supporters has more detail about some common barriers and ways to overcome them. Your role as a facilitator could be to encourage the supporter to think about ways to overcome barriers, or to allow them to debrief about difficult situations they and the decision maker are facing. It is not your responsibility to remove barriers or to come up with solutions to every problem.

### When a decision maker is unable to make a decision

Despite making all efforts to support a person to make decisions for themselves, there may be times when a person with disability is unable to make a decision. This could be because they are unwell, or the decision is too complex for their level of understanding. The challenge for facilitators and supporters is to ensure that all efforts have been made to give the decision maker enough time to develop the skills and knowledge they need. As a facilitator you may also need to check that communication is effective, and that any barriers to decision making are addressed. It may be appropriate for supporters to make a decision jointly with the decision maker, taking into account any preferences, likes and dislikes of the person, and their previous experiences. Facilitators will need to closely monitor these situations to ensure that the supporter does not fall into the role of a substitute decision maker, and the ongoing efforts are made to build the skills and experience of the decision maker.

### Substitute decision making

The law in NSW currently allows for the appointment of substitute decision makers for a person with disability in certain circumstances. Under the NSW Guardianship Act 1987, guardians can be appointed to make lifestyle decisions and financial managers can be appointed to make financial decisions of behalf of a person who has been found to have a disability that affects their decision making. There is controversy regarding the appropriateness of this type of legislation, and many countries are moving away from legally appointed guardians and financial managers. The guardianship and financial management bodies in NSW and across Australia are currently reviewing their practices and the relevant legislation in light of the Convention on the Rights of Persons with Disabilities and laws such as the *NSW Disability Inclusion Act*.

As a facilitator, the question of guardianship or financial management for the person may arise if they are having ongoing difficulty making important decisions. Before considering making or supporting an application for guardianship or financial management, consider the following points:

- Have all efforts been made to support the person to make decisions?
- Has sufficient time been given to the person to build their skills and confidence in decision making?
- Are there any alternatives to substitute decision making? For example, could a consensus decision be reached with the person and their family, friends or supporters?
- Are there barriers to the implementation of decisions which can be removed?

Some decision makers will already have a guardian or financial manager in place. As a facilitator, you can work with the guardian or financial manager to explore ways in which supported decision making could be introduced to help the decision maker develop skills and eventually remove the need for substitute decision making



arrangements. This may involve identifying other supporters in the decision maker's life to work alongside substitute decision makers. Sometimes, a guardian or financial manager can take a supported decision making approach before making a substitute decision for the person.

Guardians and financial managers have specific areas of decision making, and do not have authority over all the possible decisions a person may make. Consider whether there are areas not covered by substitute decision making arrangements that could allow the person to develop some experience in making decisions for themselves.

### Managing risks in decision making

Supporters may be concerned about potentially 'risky' decisions. They may feel responsible for the decision maker if things go wrong, or wish to protect them from harm. Supporters and facilitators often grapple with the concept of 'duty of care' when supporting a person with disability.

We all have the right to make decisions that involve risk, and this is often part of living a full and active life. In the past, people with disability have often been prevented from making decisions as a way of protecting them from risks. Duty of care has often been seen as an overriding responsibility by carers and support workers.

It is not the role of supporters or facilitators to remove risks or stop the person from making mistakes. However, there will always be ethical dilemmas and tensions arising between the desire to support a decision maker and the desire to prevent them from foreseeable harm.

As a facilitator, you can reassure the supporter that they are not responsible for the consequences of the decision maker's actions. You can provide information on managing risks or minimising harm and encourage the supporter to talk to the decision maker about possible consequences of their decisions.

If you or a supporter is worried about unacceptable risk to the decision maker, you can consider the following points:

- Has the decision maker understood the potential harm?
- Have the supporter and the decision maker considered all possible strategies to minimise harm?
- What safeguards exist in the community that might reduce harm to the decision maker?

ADHC has several policies and procedures that provide guidance on risk issues. They can be accessed here: [http://www.adhc.nsw.gov.au/publications/policies/policies\\_a-z](http://www.adhc.nsw.gov.au/publications/policies/policies_a-z).

You can refer to the Abuse and neglect policy, Behaviour support policy, Client risk policy and procedures, and the Decision making and consent policy.

**When decisions go wrong**

Sometimes, a decision may not turn out the way the decision maker expected. There may be negative consequences for the decision maker or others. As a facilitator, your role may be to allow the supporter to debrief, reflect on the process or work out ways to amend the situation with the decision maker. It is not your responsibility to ‘fix’ the situation or reprimand the supporter for allowing things to go wrong.

One of the underlying principles of supported decision making is that people can learn from their mistakes and decision making skills can be developed through ‘trial and error’. However, for some decision makers this learning process could be very difficult, for example due to problems with comprehension or memory. It may not be helpful for the person to continue to make the same mistake over and over, particularly if this is causing harm. As a facilitator, you may need to explore alternative strategies with the supporter and the decision maker.

Things to consider include:

- Is communication with the person effective? Do they understand what is being communicated?
- What is causing the decision maker to repeat their mistakes?
- Could the person develop more skills in weighing up choices or considering consequences?
- Are there safeguards that could be put into place?

**Things to remember**



1. Use existing safeguards to resolve concerns.
2. Seek supervision or support when faced with difficult situations.

**Something to think about**



What stops you from making bad decisions?

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What safeguards can you identify in your community that could assist when things go wrong with supported decision making?

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## Fact sheet 6: developing reflective practice

Facilitating supported decision making involves taking on a new role and working closely with other people around issues that could have a profound impact on their lives. In all of our work, it is important to reflect on our own skills and knowledge, how well we are doing in our roles, and what we could do to improve. There are some specific challenges involved in facilitating supported decision making as discussed below.

### Roles and boundaries

The roles of decision maker, supporter and facilitator can easily become blurred. As a facilitator you might see the need for a particular outcome and provide information to the supporter which will lead the decision maker in that direction. If you think the supporter is not being very effective, you might be tempted to take over their role with the decision maker. Take time throughout the process to check that everyone is clear about their roles and is acting within these boundaries. Most importantly, take a person centred approach and if things seem to be getting off track, come back to the decision maker to focus on their goals, wishes and preferences.

### Level of involvement

As a facilitator, your aim is to develop the skills and knowledge of the supporter and the decision maker to the point that they no longer need you to be involved. Your relationship should be short term and should decrease over time. You are also not directly involved in the decision making, so you should not find yourself having in-depth conversations with the decision maker and the supporter over every step in their decision making process.

### Time management

Facilitating supported decision making is likely to be one of many tasks that you have in your role as a support worker or service provider. Because it is a new concept to many people, you may find that supporters or decision makers will have many questions or issues to discuss, especially early in their relationship. Be clear about how much time you can commit to this and how you will be available for phone calls, meetings or training sessions.

Something to think about



How do you reflect on your work now?

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What could you do to develop or continue good reflective practice?

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**Ben's story**

Ben's work was very busy. When he was in the office, the phone rang all the time. He also spent a lot of time out of the office meeting people and networking in his area. Ben had been facilitating a supported decision making relationship between Judy and her sister Anna. Anna rang frequently to ask questions about her role as supporter and to get Ben's ideas. Judy was thinking about making a decision to leave the supported accommodation service she was living in, and Anna was very worried about whether this was the right decision. Ben gave Anna his personal mobile phone so that she could contact him for advice after hours if needed. Ben began to dread hearing from Anna. Late one afternoon, his mobile rang and he could see it was Anna. He decided not to take the call and left the office for a drink at the pub.

What do you think is happening here?

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What could Ben do to manage this situation?

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## Some useful tools and resources

Ageing, Disability and Home Care (ADHC) has person centred tools to help communicate with the decision maker, think about their goals and dreams, plan and make decisions. These tools can be found on ADHC's website under Publications, Lifestyle planning tools at: [www.adhc.nsw.gov.au/publications/policies/policies\\_a-z/?result\\_237652\\_result\\_page=L](http://www.adhc.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=L) Helen Sanderson Associates tools are available to purchase from HSA Press: <http://www.hsapress.co.uk/>







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