



Family &
Community Services
Ageing, Disability & Home Care

Supported Decision Making

A handbook for supporters



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The basics

What is supported decision making?

We all get support to make decisions about things that affect our lives. 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. In this handbook we are focused on support for people with disability.

Supported decision making is a practical way for a person with a disability to be heard by those around them and make sure that they are at the centre of their decisions. 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.

Things to remember



1. At times we all need and want support to make decisions in our lives.
2. Some decisions may not take much time or thought. Other decisions will require a lot of time and a lot of support.

Something to think about



Who supports you to make decisions about your life? How do they help you? Jot your ideas down here.

What do you like about the support you have had? What **don't** you like about the support you have been given?

Think about how a person with disability might feel if you tried to support them to make decisions in ways they didn't like.

Why should we?

The decisions we make, big and small, add up to the type of life we lead and the people we are. When someone makes decisions for us we can feel as though we have no control and we might feel frustrated or confused about what we want. When we make decisions for ourselves we can feel strong and in control, more satisfied with our life and we may take more responsibility for our life. This is also true for people with disability.

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 they were born in Australia or overseas, if they are a young or aged, male or female or if they have a disability. Some people need support to make sure they can act on this right.

These rights are recorded in laws, conventions and policies. If you are interested you can read more about these by going to the tools & resources section.

Things to remember



- 1. Being able to make both big and small decisions can affect the way we feel about ourselves.
- 2. People with disability have the same rights as everyone else to make decisions that affect their lives.

Something to think about



Is it important to you that you make your own decisions? How would you feel if someone at work made all of your decisions for you?

The decision maker

Some people with a disability need or want support to make decisions. This may be because of an intellectual disability, brain injury, mental illness or other disability that affects their thinking. Sometimes 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 can help with this.

It is important to understand that the decision maker, the person with a disability, is the person who makes the decision, even if they are receiving support from others. Wherever possible the decision maker should drive the decision, getting the information and asking for the type of support that they desire.

Everyone is different. We all make decisions in different ways, at different times. Some people like to take their time, thinking about all possibilities and consulting with others. Other people like to jump in and try things out, or make decisions on the spur of the moment. Having a disability is just one of the things that affects the way a person makes decisions.

The decision maker may want support for their decision making for a variety of reasons. Maybe they feel as though no one is taking them seriously, maybe they are making a big decision for the first time, maybe they have difficulty understanding complex issues or maybe they just want to get better at making decisions.

Supported decision making helps decision makers to learn enough skills to feel confident about making decisions independently.

Things to remember



1. The decision maker makes the decisions and has the final say.
2. A decision maker may only require support for certain decisions or at certain times and be able to make decisions by themselves in other areas.
3. The decision maker decides who will support them, and how.
4. Developing experience with decision making may lead to more opportunity for decision making in other areas.

Something to think about



How do you like to make decisions? What is your decision making 'style'?

Can you think of someone who has a different decision making style? How would your decisions be different?

The supporter

That's you! Supporters are chosen by a decision maker because they want their support 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 have chosen you to support them in only one decision or in many decisions about their life. You may be the only supporter or you may be part of a group of supporters.

While supporters may have different characteristics, there are some things that good supporters have in common. Good supporters:

- Believe that people with disability have the right to make their own decisions
- Know about themselves and their personal values. They know what might impact on their ability to be a good supporter and they address these issues
- Support people with disability to speak up for themselves
- Like to listen to what other people think and are interested in others
- Are patient
- Respect the privacy of others, especially the decision maker they support
- Don't take over – knowing when to help and when to step back
- Like to support other people to develop new skills or improve existing skills
- Don't make assumptions – supporters try to figure out what the person wants in each new decision making situation, they don't assume that a past decision will dictate a future decision. They don't assume people will make the same decision they would.

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. You will find out more about what a supporter does in the following sections of this booklet.

You need to think about the type of support you give and how to make sure you won't influence the person you support into a particular decision.

Things to remember



1. Think about the type of person you are and how your values and attitudes will affect the way you support someone to make decisions.
2. Everyone makes decisions differently and you may need to adjust your style to suit the decision maker.
3. Being a supporter does not mean doing something for somebody; rather it is helping them to do it for themselves.

Something to think about



What skills or attributes do you have that will make you a good supporter?

What skills or attributes would you like to know more about?

Supported decision making in practice

Being a Supporter

Being a supporter for the first time can be daunting. Even if you have a long standing relationship with the decision maker, supported decision making can mean a change in the way you have been doing things or even a change in your relationship. In the following pages we talk about ways you might support a decision maker.

You may be involved in every activity we have listed or just a few. This may change depending on the type of choice the decision maker wants to make or the experience you both have with decision making. Just like learning to cook a new recipe, the suggested steps will be most helpful when you first start acting as a supporter. For experienced supporters they may also be helpful reminders.

Things to remember



1. Decision making steps should be driven by the decision maker wherever possible.
2. It is important that the decision maker feels comfortable enough to express themselves through each step. Encourage them to say what they think or feel, even if you don't agree with it.
3. Encourage the decision maker to keep other people in their life involved- it will help the decision making steps progress and ensure you don't feel overwhelmed with responsibility.
4. You may need to revisit a step more than once.
5. You can start small – try a few easy decisions before getting on to the big decisions.
6. Be flexible in your approach. Different steps may appeal more to the decision maker than to you. It is a good idea to try out each step when you are first getting started.
7. Some decisions will take time. Let the decision maker know that they don't have to rush and that you can support them in their own time.
8. It is ok for the decision maker to make a mistake or to change their mind – we all do!

Something to think about



What is your relationship with the decision maker? How might this change if you take on a role in supporting their decisions?

Chloe's story

Case study

Chloe is a 65 year old woman who recently found out she has dementia. Chloe's supporter, who is also her daughter, Tess has suggested that she move in to her house with her family so that they can help look after her when things get worse. Tess has been speaking to Chloe about the move but Chloe keeps forgetting where they were up to last time they had the conversation.

What do you think Tess could do to support Chloe to make her own decisions?

How could Tess and Chloe improve communication on this decision?

Communication

Anything we do with other people, including supported decision making, relies on good communication. We constantly communicate with others throughout the day, and take much of this for granted. Communication involves sharing ideas, emotions, wants and needs through talking, writing, behaviour and body language. For many people with disability, communication may take longer or need extra support. Some people use communication aids such as a talking device, braille or pictures. Sometimes people may appear to follow what is being said but in fact are struggling to understand.

Supported decision making relies on the supporter and decision maker being able to communicate effectively with one another. It makes sense to check on this before getting started on the other decision making activities.

If you already know the decision maker, there is a good chance you know how they like to communicate. It is important to make sure the decision maker can express their ideas and feelings to you and to understand what you are saying. Now is a good opportunity to get to know them again and find out what really matters to them, as this may have changed from when you first met them.

If you have only recently met the decision maker, take some time getting to know them. To be a good supporter you will need to invest some time at the beginning to develop good communication and to build a trusting relationship with the decision maker. Find out what the decision maker's hopes, dreams, interests and fears are. Find out the things about their day that they enjoy and the things they would like to change. Find out who is close to them and take ideas from how they communicate with the person and how they have built their relationship.

When we communicate well with a person we are less likely to make assumptions about what they want. Supported decision making starts with what the decision maker wants and needs. If you have good communication with the person then supported decision making will be more effective and more beneficial to them.

Your role

Your role is to make sure you can understand the decision maker and they can understand you. You could do this by:

- Asking the decision maker how they prefer to get information
- Learning from past experience of your interactions with the decision maker
- Using a communication aid to improve communication
- Asking others who know the decision maker for ideas about how the person likes to communicate
- Thinking about whether communication support would be beneficial
- Asking yourself if you understand everything the person is saying to you
- Spending time with the person and taking notice of not only what they say but how they act. People communicate through their words and actions.

Things to remember



1. First try to understand, then to be understood. Learn how to best communicate with the person.
2. Check along the way – do you understand what the person is communicating? Does the person understand what you are communicating?
3. Communication is vital to supported decision making.
4. Don't make assumptions about what the decision maker is saying, or what they want.

Something to think about



Have you ever been in a situation where you weren't able to communicate effectively? How did you feel? What did you do to improve the situation?

What are some things that make communicating difficult with the person you support? How can you overcome these?

Sam's story

Case study

Sam is a 12 year old boy who has autism and doesn't speak. He appears to listen to others and will follow simple requests, such as 'Sam, please put your shoes on'. Sam has a board in his bedroom with pictures representing different activities through out the day. He enjoys setting these pictures up every morning with his mother or father and this helps him to understand what is going to happen during the day.

What could Sam's parents do to learn more about his communication?

If you met Sam for the first time, how would you communicate with him?

Being ready to make decisions

A person is ready to make a decision when they feel they have the skills, knowledge and confidence they need. There are many things which can affect how ready a person feels to make a decision.

Every decision is different – some are small and will not affect your life much, while other decisions will lead to major changes in your life and possibly others. It is likely that a decision maker will feel ready to make some decisions and not others. Decision makers will often want support to make new or more difficult decisions. Sometimes, a person may ask for support to make a decision they have managed on their own in the past, because they are unwell or stressed by other things happening in their life.

It is possible for a decision maker to be ready or able, to make decisions in one area of life but not in another. For example they might be ready to make decisions about what to do on the weekend but not ready to make decisions about where to live. You might need to build the confidence of the person by supporting them to make smaller decisions and build up to tackling the bigger decisions. Sometimes talking about or getting information about the decision will also help them to become decision ready.

For many people with disability, making decisions is a new experience. They may live with others who make most of the important decisions for them, or they may not have had opportunities to try new things. The person may be in a routine which does not change much from week to week or even year to year. For people in these situations, it can be hard to picture themselves making decisions, or to understand what their options could be. As a supporter, your first step may be to help the person understand their rights to make their own decisions, and to open up the possibilities for them. You may need to spend a lot of time on this before the person is ready to make any decisions.

Sometimes, decisions need to be made because of things happening around us. For example, a family might need to move from a rented property because the owner is selling it. Or, a person may have to leave their job because there is no work available or their health has deteriorated. In these situations, a person may not be ready to make a decision because it is not something they want, or had planned to do. As a supporter, you might need to help the person adjust to the changing circumstances. This could mean having to support the person to make a decision in ways that are not ideal, such as not having time to explore all options, or only having one choice available.

Your role

You can help someone become decision ready by talking to them about:

- Supported decision making and how it works
- Their ability to make decisions about their own lives
- Things they would like to change in their lives
- Decisions, big and small, they have made in the past.

Things to remember



1. It may take time for a person to be ready to make decisions.
2. A person may need to practice decision making to build confidence.
3. Sometimes we have to make decisions even if we don't feel ready.

Something to think about



Have you ever had to make a decision when you felt weren't ready? What did you do to make yourself ready to make the decision?

Five steps to effective supported decision making

Step 1: Finding the options and getting information

When you are supporting someone to make a decision, the first step is for the decision maker to think about the options available to you and find out more information about each option. Sometimes they will need to do some research and find information to help them to identify options. At other times the decision maker will already know what options they want to choose from. Sometimes this information will be hard to find and understand. Other times, it may be easy to find. You can help the decision maker find information or consider options. As the decision maker learns more about each option or choice they may become better able to make an informed decision on their own.

Sometimes there may appear to be only one option available. As a supporter, you can help the decision maker to think about things differently or ask others for help. You could also support the decision maker by advocating for more choices. For example, the decision maker might want to join an art class, and there is only one class in their area. However, after helping them with further research you find there is a social group of artists who meet to paint and share ideas, an on-line art class and a one day workshop with a visiting artist later in the year. Sometimes as a supporter you may need to think about opening up and considering other options.

When the decision maker is identifying options you may need to support them to look more broadly for information. If you are supporting someone to identify options make sure that you do not limit their choices by keeping information from them or steering them in a certain direction.

The amount of information we seek for each decision varies based on the decision itself and personal preference. Some people like to know every little detail about a decision before they make it and others are happy to make a quick decision with limited knowledge.

By finding information and considering options, the decision maker is making an 'informed decision'. Making an informed decision means that the decision maker has thought about different options, and the good and bad consequences of the decision. However, even when a decision maker has all the information they may not make the decisions others see as the best decision. Despite years of public education about the dangers of skin cancer, many people still choose not to cover up or use sunscreen during the day.

Your role

Your role in this activity is to assist the decision maker to gather information about the decision and to find the options they want to choose from. Some things you might do directly, or assist the decision maker to do are:

- draw on your existing knowledge
- make phone calls
- search on the internet
- talk to other people about their ideas and their experiences
- visit a business or service
- generate a list of suitable options.

Things to remember



1. It can take time to get all the information we need to make an informed decision.
2. The level of information we seek varies from person to person. Some people are happy to make decisions with not much information at all or just based on one factor.
3. You don't need to be the one to find the information. You can support the decision maker to find the information for themselves.
4. This may be a new experience for the decision maker so be sure to go slow and check understanding.
5. Don't limit the decision maker's choice by limiting their access to information.

Something to think about



Have you ever had to make a decision when you didn't feel like you had all the information you needed? What happened?

People with disability may often be asked to make a decision without having all the relevant information at hand. Why do you think this happens? What can you do to change this?

Angus's story

Case study

Angus is a 22 year old man who loves routine and order. Angus likes to get all of the information relating to a decision before he makes up his mind. Angus' supporter is his girlfriend Maddie, who likes to make her decisions quickly. Angus wants to get a new phone and asks Maddie to support him. They go to a phone shop to look at different mobile plans. Angus wants to go to another shop to compare but Maddie says that one is enough. Angus feels that the salesperson isn't explaining the information very well. After half an hour Maddie tells Angus to make a decision and he ends up choosing a phone that costs more than he had expected to spend.

How was Angus supported to make a decision?

What could Maddie do differently?

Step 2: Weighing up choices

Once the decision maker has found all the possible options, they may start to think about the advantages and disadvantages of each option and about what matters to them most. This can be complicated, time consuming or even overwhelming for some people.

Weighing up choices is a very individual process and everyone will approach this task differently. Some people will want to think very carefully about each option while others may just want to go with the first available option. Generally speaking, people often weigh up options based on their **values and beliefs**. The way people do this depends on their individual **decision making style**, and the **process** they use to consider each option. Let's look at each of these issues in turn.

Each of us values things differently. We might value relationships, time, family, status, money or physical health. How much we value each of these things is a personal thing. The importance we give to each of these things (weighting) may be different to the importance our friends, family, or community give to them. For example, when buying a laptop one person may think the brand of a laptop is the most important thing while someone else thinks the cost of the laptop is more important.

We hold many beliefs about our lives which we have gained from our family, culture and life experience. For example, we might believe that it is dangerous to go out at night because we have seen lots of news items about people being assaulted at night. We might believe that it is important to always be financially independent and not rely on others for support.

We don't usually think about our values and beliefs when making decisions. They are in the back of our minds and unconsciously guide us when we are weighing up options. However, our values and beliefs can have a major impact on the decisions we make. Consider two people thinking about where to live. Joe believes that owning

your own home is very important. Sam has religious views which prevent him from borrowing money. Joe ends up taking out a mortgage to buy a flat, while Sam finds a house to rent.

When you are supporting someone to make a decision, you need to be aware of your values and beliefs, and make sure you let their values, not yours, guide the decision. You could spend some time talking to the decision maker about their values and beliefs so that you can understand their point of view.

Everyone has a different decision making 'style'. Some things that affect our style include our past experience, personality, values and beliefs. Some decision makers will want to take their time and ask the opinion of lots of other people before making up their mind. Others might want to quickly decide and act straight away. Some decision makers might need to experience the options before they can weigh them up. People will often have a preference to 'think with their heart' and make decisions based on emotions, feelings or intuition, where other people like to 'think with their heads', gathering all the facts and carefully analysing them before deciding.

Finally, decision makers apply different processes to their decisions. This may be affected by their style, or by the complexity of the decision, or by the time available. For example, a simple decision about what to eat may involve a quicker process than deciding what TAFE course to choose. This guide sets out a step by step process of decision making. This may not suit you or the person you support, and the 'steps' should be adapted to meet the needs of the decision maker.

Your role

Your role is to support the person to weigh up the options based on their values, needs and wants. These will be different to yours. You should make sure to ask the decision maker for their opinion first so that you don't sway their decision. The decision maker might like you to support them to weigh up choices by helping them to:

- Think about the possible outcomes of their decision and imagine what their life would be like if they made a certain choice. Some helpful questions include:
 - What are the good things that might happen with each choice?
 - What are the bad things that might happen?
 - How much time and effort will each choice involve?
 - What will each option cost?
 - What could go wrong?
 - How could you stop things from going wrong?
 - How might other people be affected?

- Trial the options available to them before making the final decision. For example, the person might want to organise to spend a day at a new workplace before deciding to accept a job.
- Talk to other people who have made similar decisions.
- Talk to someone who knows a lot about the decision which is being made (such as a travel agent for a decision about holidays).
- Record the process of weighing up options; they can then think about their options, make some notes and come back to it another time, starting where they left off.

Things to remember

1. Always ask for the person's opinion first, then you can offer your own ideas.
2. Be careful not to influence the decision.
3. It's ok if this activity takes a long time.

Something to think about

Think about a decision you made that involved a number of different options. How did you weigh up these options? What mattered most to you?

Samad's story

Case study

Samad likes swimming. His sister, Dhuka, is supporting him to decide where to go swimming on the weekend. Dhuka thought she would try using a simple 'pros and cons' table to help Samad think about the advantages and disadvantages of each option.

Have a go at adding to their ideas in the table below

Options	Going to the beach	Going to the pool
Pros (positives)	<ul style="list-style-type: none">• The water is refreshing• I will get to watch the waves• It's nice to be outdoors	<ul style="list-style-type: none">• The water is shallow• I feel safe• There is a diving board to jump off
Cons (negatives)	<ul style="list-style-type: none">• I'll get sandy• I might get sunburnt	<ul style="list-style-type: none">• Chlorine smells• I have to pay

Step 3: Deciding

This step is about supporting the person to make the final decision after thinking about the options. Ideally, the person will have enough time to feel comfortable with their choice and not feel rushed into making a decision. However, there are times when the time frame for a decision might be out of the person's control. Day to day examples include deciding whether to buy an item which is on sale 'for 24 hours only!', or deciding to accept a quote which is only valid for 7 days. More significant decisions could be needed when a person with disability is offered funding or supported accommodation, but the offer is only open for a certain amount of time. Your role as a supporter may be to help the person clarify or understand the time frame involved, or to explore ways of extending the time frame if needed.

There are times, particularly in the lives of people with disability, when options are limited. There may be only one option to choose from. As a supporter, you might be involved in helping the person to try to expand their choices, advocating for more options or removing barriers.

Making a final decision can often be a big step, especially for people who have not had experience in making decisions for themselves. Many people with disability will lack confidence to make decisions, or feel the need to seek approval from others.

Your role

Your role in this activity is limited; most of the hard work will have already been done. Deciding is mostly focused on confirming the option the decision maker wants to choose and supporting them to do so. Everyone will go about this step differently. Some people might by-pass the steps leading up to the decision, or change their minds several times before settling on an option. Some people will be happy to tell others of their decision, while other people might want to write their decision down or have it acknowledged in a contract or agreement.

Support the decision maker to think about:

- The best available option - sometimes choices are limited and the ideal option may not be available to the person. Try to maximise choices by exploring how barriers could be removed
- Everybody is different - the best option for one person isn't necessarily the best option for another
- Timing - sometimes timing might affect a decision, such as when an item is on sale for a limited time or if there are good rental properties available. The person might want to make the decision at a later date.

Once the decision has been made, you may need to help communicate that decision to others. This could be done in a letter, by talking to others or by using communication aids to help the person talk about their decision.

Things to remember



- 1. Respect the person’s decision. Sometimes you might think that the risks or disadvantages are too high but the decision maker will still want to proceed with that option.
- 2. People might have anxiety about taking the step to make the decision.
- 3. It’s not your decision. Be very careful not to lead the decision maker to a certain conclusion, be supportive but not directive. Remember, supported decision making is about assisting the decision maker to make the decision that they think is best for them, which may not be the same as the option you think is best for them.

Something to think about



What do you find difficult about making a final decision? How could you help the decision maker through this process?

Linh's story

Case study

Linh is an 18 year old woman who is leaving school at the end of the year. Linh and her supporter Hao went to an expo where several service providers had stalls promoting their programs for people leaving school. Linh really enjoyed talking to a woman on the first stall, and put her name down on a list to attend an information session later that week. After looking at all the stalls, Linh decided that she liked two other options better. She was worried about going back to the first stall and taking her name off the list. Hao supported Linh to feel confident in her choices, and together they went back to the first stall to politely decline any further contact.

Step 4: Acting on the decision

After the decision has been made it needs to be acted on, or implemented. Acting on decisions is an important decision making activity as it is the step where people get to make the change they want.

Acting on decisions can make the decision maker feel more in control and allow them to see themselves as instrumental in making changes in their own lives. This can be a significant change for some people with disability.

When acting on decisions sometimes barriers can emerge that may prevent the decision from happening. We talk more about barriers later on in this booklet.

Your role

Sometimes you might not have to do much. The decision maker may have the confidence and skills to put their decision into action. They may want you to support them to work out the next steps or find out who to go to. The decision maker may want you to help them get started. For example, a person has decided to start a course but asks you to come with them to enrolment day to assist with filling in the forms.

Sometimes your role in implementing decisions is to support the decision maker to be aware of and overcome barriers. Barriers could be created by a range of things including lack of money, a negative attitude from other people, organisational policies or social isolation. Each situation will be different, but you will know when you are experiencing a barrier because the person can't put their decision into action. Some general ideas to help break through barriers include:

- Speak up – you can combat other people's attitudes! Help the decision maker to stand strong and ask for what they want.
- Be creative – find solutions to the barrier. Is there a cheaper option? Is there a way to get support from others? Are there alternatives?

- Use solutions that already exist in our community. For example, if a service does not want to accept the person into their program, use the complaints or decision review processes.

Things to remember



1. If other people resist the decision maker's choice you may need to support them to speak out.
2. Be creative – try to find ways to make sure the decision maker is in control of the situation and is seen as central to the process. This will help to make sure others are more helpful.

Something to think about



Have you ever been stuck because of a barrier to a decision you have made? What was stopping you? What did you do?

Naomi's story

Case study

Naomi is a young woman who wants to study hair dressing. She lives with her boyfriend Rob. Naomi's mother Genevieve is her supporter and together they have spoken about Naomi's options and they have found a course at a local college. Rob tells Naomi she can't go to college because it is too far away and he won't be able to drive her.

What do you think is happening here? Who gets to make the decision?

What do you think Genevieve should do?

Step 5: Reflecting

Reflecting on the decision and the decision making activities can help to build a successful support relationship, and help the decision maker to grow their confidence and skills. We all need to practice new skills, think about what went well and what could have been done better. We learn from our mistakes, but we also learn from our successes. This is the process of reflection. It could involve thinking about your role as a supporter, what skills the decision maker used, and how the process helped the decision maker to learn more about making their own decisions.

After the decision has been implemented new information might come up. This information could change the way the decision maker feels about a choice they've made and may need support to make a new decision. This could mean the decision maker may need to change their decision or make a new one. Sometimes you may need to reassure the decision maker that they made the best decision at the time.

Reflecting can also benefit you, the supporter, by:

- Allowing you to gain a better understanding of the needs and preferences of the decision maker.
- Encouraging you to think about how you supported the decision maker and what you could have done differently, which could help you to develop your skills as a supporter.

Your role

Once a decision has been made, it can be helpful to sit with the decision maker and to reflect on the outcome of the decision. Questions you can ask the decision maker and yourself include:

- Did the decision work out the way the person wanted? Why or why not?
- If the decision didn't work out, what could have been done differently?
- Does the person need to make any other decisions about the issue?
- How were other people affected?
- Do we need to check in in a few months to make sure the person is still happy with their decision?

You can reflect on how well the decision making process worked. Ask yourself:

- Was the person happy with the support I provided?
- How easy was it to make the decision?
- Was there anything else that might have helped the process?

You could also ask the decision maker similar questions so they can help you improve for future.

Things to remember



1. It's ok to make mistakes; it doesn't mean that the decision was 'wrong'.
2. Reflecting will help you and the decisions maker to develop skills.
3. Be honest, you will gain more from the experience.

Something to think about



Was there a time when new information became available or circumstances changed after you made a decision that caused you to rethink the decision? What process did you go through?

How could you assist the decision maker through such a process?

June story

Case study

June recently made a decision to join a photography class; she was supported by her friend Ahmed. June is very happy with the class and has been improving her photography skills. Ahmed makes some time to ask June about what she thinks about the way supported decision making worked but June just wants to show him all the photos she has taken.

What do you think Ahmed should do in this situation?

The tricky bits

Privacy

People have the right to privacy and generally expect that their personal details will remain confidential. People with disability often receive support services from organisations and government agencies. These services are bound by law to keep personal information secure, and not to share it with others unless the person has given permission. As a supporter, your role is more informal and your responsibility to keep the decision maker's information confidential is less clear. If you are a supporter who also has a paid role in the person's life, such as a support worker, you will be bound by the privacy policies and guidelines of your organisation. If you are a friend or family member of the person, you need to talk to the person about their privacy and who they are willing to share information with. You should not talk about the decision maker's life, their decisions or other issues with anyone else unless the decision maker has agreed that this is ok.

Your role

As you become involved in the types of activities discussed in this guide, there will be times that you will be talking to others about the decision maker or their circumstances. This could happen if you are assisting the decision maker to find out about options that are suitable to them, or if you are supporting the person to communicate their decision to family or friends.

As a supporter, you might also want to seek ideas or help to overcome a problem or barrier in the decision making process. At all times, you should consult with the decision maker about who they want to share information with, and what details they want to share. This may vary over time, or depending on the nature of the decision. Always check each time you want to share personal information about the decision maker.

Things to remember



1. Think before you speak – has the decision maker agreed that you can share information?
2. Don't assume that because the decision maker has agreed to share information in the past that they will agree in the future.

Vlad's story

Case study

Vlad is a 22 year old man who is supported in many of his decisions by his brother Alex. They both live at home and have a close relationship with their parents. Vlad and Alex usually talk through Vlad's decisions with their mother and father. Vlad has recently been dating a young woman and they are thinking about starting a sexual relationship. Vlad talks to Alex about this, but doesn't want his parents to know. Their mother knows Vlad is getting 'serious' about his girlfriend, and asks Alex whether they have discussed safe sex and consent issues.

What could Alex do in this situation?

Managing disagreements

Disagreements or differences of opinion can occur in a supported decision making relationship. This can happen when the needs or wishes of the decision maker are different to those of the people around them, including you as the supporter. If you or other people involved in supported decision making activities have a personal interest in the outcome of the decision being made, you need to discuss it with the decision maker. You need to be sure that the decision maker understands how other people's needs and wishes (including yours) may affect their decision. You will also need to make sure that you are not pushing the decision maker to make the decision you would prefer. Sometimes, it can help to have a third person involved, who is not affected by the decision, to make sure the needs and wishes of the decision maker are met. The decision maker would need to agree to other people being involved and privacy considerations would apply.

Sometimes these differences of opinions lead to what is known as a 'conflict of interest'. This can happen for both paid and unpaid supporters. A decision that will impact on the supporter is likely to be a conflict of interest. This could be a negative or positive impact. For example:

- A decision maker asks for your support to decide how to give away money they have won in a raffle, and offers to give some money to you.
- A decision maker wants your support to leave the service that you work for, which would mean you would lose the hours of work that you spend with the person.

Conflicts of interest may also happen outside the supporter and decision maker relationship (such as conflicts of interest between the decision maker and people required to act on the decision), possibly making it difficult for a decision to be implemented. For example a dance teacher may not be willing to provide information about alternative dance services because they would lose business or a parent may not want the decision maker to catch the bus home from work if they decide to work later at night because it means they will have to stay up late and wait for them.

There are times when the constraints of a business or service mean that it is not possible to implement the decision the person has made. For example, a person may decide that they would like to have paid support to go out on Sundays, however the service they use does not operate on weekends.

Your role

The decision maker may seek your help to work through disagreements or conflicts. Some ways you could do this include:

- Identify the assumptions, hopes and fears of the people involved. Look for similarities and differences.
- Be clear about the differences in the needs and interests of those involved and discuss it as early as possible.
- Be aware of your own values and position on the decision and how this might affect the decision maker.
- Decide if you can still be involved in the particular decision. Is it possible to separate your views and interests from those of the decision maker? Are you so heavily involved that you need to step aside?
- Involve other people. If you or the decision maker are concerned about your differences of opinion during decision making you can involve someone else to help you monitor the decision making process.
- Support the decision maker to consider the impact of their decision on other people before making a decision.

Things to remember



1. It is a good idea to talk about any disagreements and to bring any issues out into the open.
2. You can still support someone if you don't agree, if you can work out how to keep the decision maker's needs and interests up front.
3. You can involve somebody else to monitor how your disagreements are being managed in the decision making process.

Sophie's story

Case study

Sophie is a woman in her 30's who has been working at a small, local business "Greg's Fruit Shop" for the last 10 years. While Sophie enjoys her job, she thinks it is time for a change. She would like to work in a supermarket where she can gain more experience. Sophie asks Greg, the owner of the fruit shop, for help in exploring other job options. Greg doesn't want Sophie to leave as she has been a good worker and it will take time and effort to find someone else to do the job.

What should Greg do in this situation?

Jeremiah's story

Case study

Jeremiah is a 28 year old man who loves playing rugby league, spending time outdoors and working at Australia Post. Jeremiah really values his independence and likes to have time alone. Sometimes when Jeremiah gets angry or upset he likes to leave his home and walk to a local park so he can calm down. The staff at Jeremiah's house are concerned that he will get hit by a car on these walks and that they will get into trouble for not looking after him properly. They want him to stop leaving the house when he is angry.

What are Jeremiah's needs and interests?

What are the needs and interests of the staff?

How could the staff make sure that Jerimiah got to make the decisions he wants?

Risky business

Sometimes we make decisions that could cause us harm. Deciding to drive in a storm, to drink alcohol or smoke, to sky dive or to swim in the surf are decisions which all carry some level of risk to our health or wellbeing. When we think about these decisions we weigh up the risks according to our own personal values, interests, skills and abilities. We can work out ways of making the decision less risky, by putting in safeguards. For example if we want to go for a run in the dark we might tell people where we are going, take a torch and a phone and wear reflective clothing. All these things help to reduce the level of risk of going for a run at night time.

When it comes to risk we may seek advice from others but usually the final decision is our own. We have the right to take risks within the boundaries of the law.

Everybody is entitled to experience different situations even if the situation may be risky. If a situation has the potential to cause harm, the decision maker could be supported to think about the risks and to take them into account when making the decision.

Some options for dealing with risk include:

- Putting measures in place to minimise the risk
- Deciding not to take up the risky option
- Going ahead with the decision regardless of the risks.

Your role

Your role is to support the decision maker to make the decision they want, even if there are risks associated. You can talk to the decision maker about:

- The options and which option is the safest.
- How they could make their desired option safer
- How other people might feel about them making a risky decision.

Your role is NOT to stop the person from making a decision you think is risky but to support them to understand the possible risks and consequences.

You do not have to support someone to make a decision that you don't agree with, or that is against the law. However, you could assist the decision maker to find another supporter. The section on 'managing disagreements' has more ideas about what to do if you don't agree with the decision maker.

Things to remember



1. We all have the right to make decisions that others (or ourselves) find risky.
2. It's important to make an informed decision about risk.
3. Sometimes we can find ways to make the choice safer.
4. It's ok if something goes wrong, we can learn from our mistakes.

Something to think about



Have you made a risky decision in the past? How did it work out? Would you have changed anything about your decision? Why/why not?

How would you support someone to make a decision that you think is too risky for them?

Franco's story

Case study

Franco is a 24 year old man who likes to live life on the edge. Franco is really keen to sky dive but his mother is worried that something might go wrong or that Franco won't be able to understand the instructor. She talks to Franco about all of her fears and he decides not to go skydiving.

Who do you think made the decision in this situation?

Do you think they made the right decision?

How could Franco and his mother approach this decision differently?

When it's not working – overcoming barriers to supported decision making

Sometimes despite your best efforts you may find you are having trouble supporting someone to make decisions. The 'ready reference' guide below lists some common problems faced by supporters and decision makers and suggests some possible ways to overcome the barrier.

Barrier	What	Things to try
Time restraints of the supporter	Supporters often report that they do not have enough time to support the person to the full extent of their ability. This can be true of both paid and unpaid supporters.	<ul style="list-style-type: none">• others – family, friends, service providers, and businesses are all examples of other people who might be able to assist in the decision making process. (Check with the decision maker first that this is ok).
Availability	Sometimes the option chosen by the decision maker is not available at the time.	<ul style="list-style-type: none">• The decision maker may need to wait or to choose another option.• Be sure to clarify availability when getting information about options.• Look for alternatives or second preferences during the information gathering stage.

Barrier	What	Things to try
The decision maker doesn't have the power	If the decision maker can't get support from anyone else, particularly the people who have the power to implement the decision, then the decision may not happen.	<ul style="list-style-type: none"> ● Be aware that people with disability often feel powerless in their own lives. ● Look for ways to give the person control over their decision making. ● Question authority – just because someone is used to being in charge doesn't mean they really have the final say. ● Use complaints and review processes to give the decision maker more power when dealing with organisations.
Social isolation	Implementing the decision may rely on the input of others; if the person is isolated there might not be anyone around to support them.	<ul style="list-style-type: none"> ● Ask the person if they want to make links with others in the community – maybe through a community visitors scheme or through social / sporting clubs. ● Talk with the person about who they like and value in their life and see if these people could become supporters.
Not being ready to make a decision	The decision maker may not feel ready or prepared to make the decision and choose to do nothing.	<ul style="list-style-type: none"> ● Spend some time with the person talking about decision making and explore why they don't feel ready. ● Tackle the issues – whether it is lack of confidence, fear of reprimand or being overwhelmed by information. ● Support the decision maker to review their options.
Restrictions of a provider or business	A decision may not be possible if the service or business does not offer the appropriate service or product.	<ul style="list-style-type: none"> ● Investigate other options with alternative providers or businesses. ● Ask the provider if they can be flexible – there may be other people who would like the same option.

Barrier	What	Things to try
Communication Issues	The person is unable to communicate their decision to relevant others.	<ul style="list-style-type: none"> ● Support the person to find ways to communicate - for example using speech aids, writing the decision down, or asking others to communicate the decision on their behalf. ● Look for specialist help such as speech therapy if needed.
Attitude of others	Someone in the decision maker's life may put a stop to the decision if they don't agree with it. Some supporters, particularly those who are paid, report that they feel they lack authority to assist with implementation of decisions.	<ul style="list-style-type: none"> ● Support the decision maker to speak up for themselves and to communicate the reasons for their choice. ● Bring others on board as early as possible so that the option can be discussed prior to the final decision being made. This will allow concerns to be raised and resolved early. ● Identify who will need to be involved in implementing the decision and make sure they are part of the process.
Financial difficulties	You might discover that implementing the decision is more costly than first thought or that the decision maker doesn't have enough money to pay for it.	<ul style="list-style-type: none"> ● Don't skip fact finding exercises get the detail at the beginning to avoid disappointment later on. ● Chat to the person about what their second preference is. ● Speak to the person about their budget and how they would like to spend their money prior to the decision being made.

Prue's story

Case study

Prue is a 28 year old woman who wants to marry her boyfriend Ben who recently proposed. Prue is excited about marrying Ben and moving into his apartment when they get married. Prue's mum doesn't think Prue should move out and says that she doesn't want to come to the wedding. Prue has saved up some money for the wedding but was hoping her parents would also help with the cost. Prue's dad wanted to give them some money but now he says that he can't give her anything because her mum won't let him. Prue feels like she doesn't have anyone else to talk to.

What are some of the barriers that you can see in this situation?

If you were supporting Prue what steps would you take?

Substitute decision making

Substituted decision making is when one person makes decisions for another person. This is different from supported decision making. This can happen to all of us – we might defer to a parent, partner or colleague because we can't or don't want to make the decision ourselves.

In Australia, we have laws which allow other people to make decisions about a person with disability in certain situations. This may involve a court appointing a guardian as a substitute decision maker. People can also nominate a friend or relative to be an 'enduring guardian' to make decisions if they lose the ability to make these decisions for themselves; for example due to accident or illness.

Every adult in Australia is assumed to be capable of making their own decisions, and very few people have guardianship orders in place. Despite this, there are times when people make substituted decisions for others for a variety of reasons including:

- Ease – it can be quick and easier to make a decision for someone rather than taking the time to get to know what they think as well as making sure they understand their decision, options and final choice.
- Time – it can take a lot of time to support a decision maker to find all the information relevant to their decision and then make the decision.
- Fear – some people are concerned that they will be blamed if the decision maker comes to harm because of a decision they supported. Some people are also afraid that their relationship with the decision maker will change.
- Habit – sometimes we get in the habit of doing things for other people and forgetting to ask them if they would like to do things differently.
- Assumptions – some people assume that others are not able to make decisions about their own lives and therefore make the decisions on their behalf.

Your role

As a supporter, your role is to make sure the person makes their own decision. Unless you are a guardian, you do not have the right to make substituted decisions for them. If the decision maker has a guardian, your role may be to communicate with the guardian about your role and the supported decision making process.

Things to remember

1. Sometimes you can make substituted decisions without realising it – always check to make sure the decision maker is in charge.
2. Sometimes the decision maker might want you to make the decision because it is hard for them. Take time to work through their concerns and encourage them to keep going.

3. If a person seems unable to make a decision, seek help to make sure you have tried all possible ways of supporting them to make the decision.

Anthony's story

Case study

Anthony is a 32 year old man who wants to buy a laptop so that he can play games on it. He asks his sister Imogen for help. Imogen goes out and buys Anthony a desktop computer, thinking that this will be a better option because Anthony will only be playing games at home, and won't need to move the computer around. Anthony is happy with his computer.

Is this supported or substituted decision making?

What could Imogen have done differently?

If Anthony is happy with the decision does that make it ok? Why/why not?

Can supported decision making work if the person has a guardian?

The short answer is yes, supported decision making **can** work if a person has a guardian. A guardian is someone who has been legally appointed to make decisions on behalf of a person with a disability. Guardians can only make substitute decisions in certain areas of a person's life. These areas are written in a guardianship order or enduring guardianship appointment. A guardian could be appointed to make decisions about where the person lives, the types of services they receive, or what medication they should take.

Guardians must seek the person's views before they make a decision. Wherever possible, a guardian should make a decision based on the type of decision the person would have made for themselves if they could. Supported decision making is a great way to ensure that the person has the opportunity to think about their views and to express them to the guardian.

Building up a good supported decision making arrangement could mean that the person no longer needs a guardian.

Your role

As a supporter, you may be working alongside the guardian to support the decision maker. You will need to be clear about the decision making areas that the guardian is responsible for. If you are not sure about this, you could ask the decision maker to see a copy of the guardianship order. The decision maker may want you to communicate with the guardian about the supported decision making process and the types of decisions you have supported them to make. As in all other areas, the decision maker has the right to choose how you are involved in working with the guardian. However, the guardian has a legal role to become involved in areas covered in the guardianship order. The guardian may choose to contact you to find out more about your role.

Things to remember



- 1. The guardian must be informed when the person wants to make a decision which is within the guardian's authority.
- 2. The guardian does not have to be involved if the decision is outside their authority, however the person may wish to keep their guardian informed of the decision.
- 3. Supported decision making and guardianship can work side by side.

Something to think about



How would you explain the benefits of supported decision making to a guardian?

Gemma's story

Case study

Gemma is a 26 year old woman who loves going out for dinner and working on her computer. Gemma recently finished TAFE and got a job at a software company. At the moment Gemma lives in a group home where she does her own laundry, cooks her own meals and does her share of the cleaning. She now feels ready to move into her own apartment. However the staff at the group home have told Gemma's guardian that they don't think she is capable of moving into her own place. The guardian accepts what the staff are saying and tells Gemma that she should stay in her group home.

What would you do if you were Gemma's supporter?

Are there any other people who should be involved? Should the guardian be talking to anyone else?

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 URL: http://www.adhc.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=L

Where to get help

Ageing, Disability and Home Care can help provide support and information for people with disability. As a supporter, you could ask for ideas about:

- Finding supports and services
- Communication assessment and support
- Advocacy and information services
- Behaviour support
- Support for carers.

For information about how to contact ADHC go to the website at URL: http://www.adhc.nsw.gov.au/contact_us

Ability Links NSW works with people with disability, their families and carers to plan their future, build on their strengths and skills and develop networks within their community. Information on Ability Links NSW in your area is available on ADHC's website at URL: http://www.adhc.nsw.gov.au/individuals/inclusion_and_participation/ability_links_nsw You can email AbilityLinksNSW@fac.s.nsw.gov.au or AbilityLinksNSW-Aboriginal@fac.s.nsw.gov.au

Laws and conventions

For information about laws and conventions, visit URL: www.unicef.org/publications/index_43893.html and URL: www.legislation.nsw.gov.au



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