Supporter's Guide

How to Support Everyday **Decision Making**

Michelle Browning and Deb Rouget



Supported decision-making essentially shifts the focus from the capacity of the person being assisted to the adequacy or otherwise of the capacity of those providing assistance. (Terry Carney)



About the Authors

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Acknowledgements

The information in this guide comes from a range of sources and from our direct experience of working alongside people with intellectual disability supporting and strengthening their decision making.

We would like to acknowledge the traditional owners of the land on which this guide was written, the Wurundjeri people of the Kulin Nation. We would also like to acknowledge the leadership of people with a disability and families who work to create change and enable the inclusion and voice of all people.

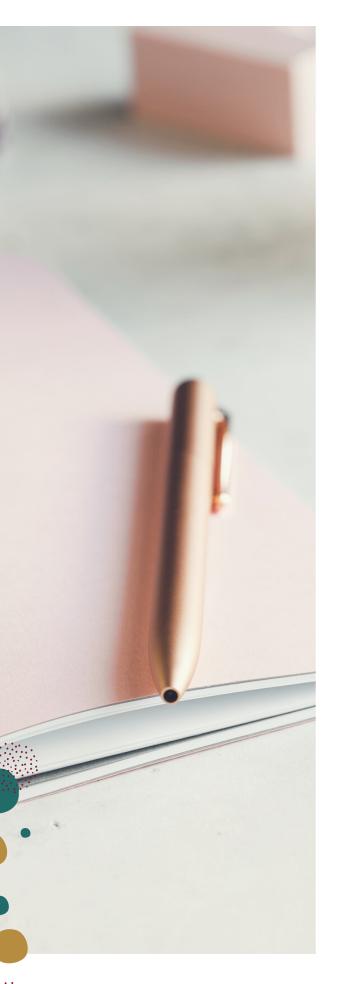
Disclaimer

The information provided in this guide does not intend to provide legal advice. Belonging Matters makes every effort to provide up to date and accurate material. All information in this guide is subject to change and our material is for general information purposes only. If you are wanting legal advice, we suggest you contact a legal advisor in your state.

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Making the Most of this Guide

This supported decision-making guide is written for people who provide assistance to others when making decisions in everyday life. It aims to provide:

- a framework for understanding the process of supported decision-making,
- a summary of its aims and principles and
- greater clarity regarding the role and responsibilities of decision supporters.

We suggest readers take their time exploring this guide. Perhaps only reading a section at a time, giving space to reflect on the ideas and go through the exercises in the workbook.

You will find it useful to complete the accompanying Workbook. You may also like to keep a journal or write down your thoughts and ideas in a notebook. In addition, you may find it useful to explore the other resources about supported decision-making in Part 8 of this guide.



Complete Exercises in Workbook

To download the Supported Decision-Making Guide for Decision Supporters visit https://www.belongingmatters.org/ books.

Index -----

Part 1	What is Supported-Decision Making?	Page 6
Part 2	Role of Decision Makers	Page 12
Part 3	Role of Decision Supporters	Page 20
Part 4	Decision Making Process	Page 27
Part 5	Dilemmas of Practice	Page 30
Part 6	Good Practice – An Example Story	Page 37
Part 7	Summary	Page 41
Part 8	Information and Resources	Page 42

Part 1: About Supported Decision-Making

What is supported decision-making?

Supported decision-making is about providing practical assistance with decision making. It offers people with disability a broad range of supports to be able to make their own decisions and stay in control of their lives.

Supported decision-making aims to replace substituted decision making - that is when others make decisions for people with disability instead of assisting people with disability to make decisions themselves. Our laws are starting to recognise the role support has in helping people with disability make their own decisions. ^[1]

By developing our skills as decision supporters, we can reduce the need for forms of substituted decision making such as guardianship and financial administration.

Supported decision-making aims to replace substituted decision making – that is when others make decisions for people with disability instead of assisting people with disability to make decisions themselves.

^[1] An example is the Guardianship and Administration Act 2019 in Victoria that has as its first general principle people with disability who require support to make decisions should be provided with practicable and appropriate support to enable the person to make and participate in decisions affecting them.

What might it mean to assist someone with decision-making?

When we assist someone to make decisions it can involve:

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(Making	sure	the	person	knows	they	have (a d	lecision	to	make.

- Understanding how a person makes a decision.
- Helping to get and explain information.
- Presenting information in an accessible way planning and breaking tasks down, choosing when and how to discuss things.
- Helping the person to understand and explore their options.
- Creating continuous opportunities to learn and make big and small decisions.
- Making sure the person has opportunities to try and experience a range of valued and typical opportunities, not just a limited choice from a "special" menu only offered to people with a disability.
- Helping problem solve.
- Keeping an eye on the person's safety and wellbeing.
- Reducing stress and anxiety.
- Assisting the decision maker to think through the good and bad things that may happen from a decision.
- Working through possible risks and how to reduce harm or damage to one's reputation.
- Helping weigh up the decision and think about longer-term goals rather than immediate gratification.
- Assisting people to change their mind.
- Making sure other people listen and understand the decision once it's made.

Why is supported decision-making important?

Many of us help family members and friends to make decisions. But few of us have had the opportunity to think about what makes a good decision-making process. We may not have clear strategies we can use when providing decision support to a person with intellectual disability or someone who has had little decision-making experience.



From the very beginning, in the early 1990s, advocates of supported decision-making in Canada had a big vision. They wanted people with disability to be supported to control their own lives. But they knew to achieve this they had to overcome the legal and practical barriers that stopped people with disability being seen as decision makers (Bach, 1998). Advocates wanted supported decision-making to be a way of obtaining equal legal rights for people with disability.

Supported decision-making was introduced to the world when drafting the Conventions on the Rights of Persons with Disabilities in 2006. United Nations delegates discussed supported decision-making as a legal alternative to substituted decision making (e.g., guardianship) when talking about people with disability having the right to be treated just like everyone else by the law.

Article 12 of the Convention (Equal Recognition before the Law) says that governments who sign up to the Convention, like Australia, must provide people with disability the support they need to exercise their legal capacity or legal decision—making rights. We exercise our legal capacity when we do things like marry, vote, open a bank account, sign a lease, or get a mobile phone plan.

In the same way a person with a physical disability may need a ramp to access a building, a person with a cognitive disability may need support to be able to exercise their legal capacity (Salzman, 2010).

When we understand that decision support is a fundamental human right, assisting someone with their decision-making takes on greater importance. We recognise that not being able to provide the right assistance may deny someone the opportunity to act as a legal citizen as well as reduce the control they have over their life. What we do or don't do can have a big impact.

We recognise that not being able to provide the right assistance may deny someone the opportunity to act as a legal citizen as well as reduce the control they have over their life.



Principles

Supported decision-making practice is guided by important principles. [2] It is important decision supporters are aware of these principles and seek to uphold them when providing decision support.

- All people are interdependent and will seek the support of others with their decision-making from time to time.
- Decision-making should be anchored in the person's vision for a full meaningful and inclusive life and hold the person in positive and valued regard.
- All people have a right to autonomy and self determination. [3]
- All people are entitled to the presumption that they are capable of making decisions and can access support to understand and make informed decisions.
- The person is at the centre of the decision-making process and their will and preferences direct the process.
- Support should seek to build the decision-making capability of the person at the centre of the process.
- Support should be entered into freely, and must be free from abuse and undue influence.
- Support should focus on the process rather than achieving any specific outcome.

Decision-making should be anchored in the person's vision for a full meaningful and inclusive life and hold the person in positive and valued regard.

^[2] The first set of Supported Decision–Making principles were written by the Canadian Association for Community Living Taskforce in 1992. The taskforce was focused on exploring alternatives to guardianship.

^[3] The right or ability of a person to control their own fate.

Two examples of supported decision-making [4]



Jacob

Jacob signs a mobile phone contract he can't pay. Over the course of three months, he is \$1,000 in debt. Jacob ignores the phone bills and, when his phone is disconnected, he tells his father, Simeon. Simeon did not know Jacob had a mobile phone or had signed a contract. Jacob couldn't find the contract and didn't know how much money he owed the phone company. Jacob, also, could not remember signing the contract. Jacob asked Simeon to call the company to try and sort things out.

Jacob and Simeon eventually found one of the bills and rang the phone company. The person from the phone company would not speak to Simeon because his name was not on the bill. Frustrated, Simeon looked up his options online and found out about supportive attorneys in the Powers of Attorney Act 2014 (Vic). Being a supportive attorney would allow him to help Jacob talk to the phone company.

Simeon explains to Jacob what supportive attorneys can do and Jacob decides he wants Simeon to become his supportive attorney. They go ahead with the paperwork and take the papers to a meeting with the phone company.

The phone company offers Jacob a payment plan which would let him pay off the money he owes over more time. Simeon isn't sure if Jacob should agree. He thinks Jacob should find out more about his rights before agreeing to another plan. Simeon suggests Jacob see a financial counsellor who can tell him about his options. Jacob agrees and after the counsellor has all the information, they think the contract Jacob signed may not be fair because he didn't understand it when he signed it. Jacob asks the financial counsellor to talk to the phone company for him. They find out because Jacob did not understand the contract when he signed it, the phone company can cancel the contract and debt. Jacob asks the financial counsellor to tell the phone company this is what he wants to do.

^[4] This example is an abridged version of a case study in the Supported Decision–Making in Victoria guide for families and carers.

Simeon used a range of supported decision-making strategies when assisting Jacob including:

- helping him to find and understand important information about his situation
- making sure he thought about all his options before agreeing to another plan
- · bringing in the assistance of a financial counsellor to know his rights, and
- helping him to communicate his decision to the phone company with the help of the financial counsellor.

Matt

Matt's facilitator noticed that he was not engaged in his Circle of Support meetings. He let other people make decisions for him and couldn't wait for the meetings to end. Although Circle members knew Matt well and were basing ideas on their knowledge about his interests, it was concerning that Matt showed little interest in the conversation. The facilitator tried a different technique to try and engage Matt and encourage his decision-making. Before the meeting, the facilitator created a large poster. She pasted photographs and pictures of all of the things Matt liked doing, plus some new things. Matt became fully engaged in the meeting and was able to give a yes or no response to ideas. For example, lawn bowls was an idea that had been talked about many times. When Matt saw the picture of lawn bowls he clearly said "no" and removed the picture. Actions were then written on sticky notes and Matt placed them next to each picture. This not only kept Matt engaged but assisted him to make decisions and express his preferences.



Matt's facilitator used a range of supported decision-making strategies when assisting Matt including:

- noticing his lack of engagement
- exploring more creative ways to communicate options, and
- using visual aids to clarify his preferences.

Part 2: Role of decision makers

Decision maker

Research into the practice of supported decision-making has found the role of decision makers is to express their will and preferences (Browning, 2020; Watson, 2016a). This understanding is important because it ensures the inclusion of people with complex communication support needs in the practice of supported decision-making.

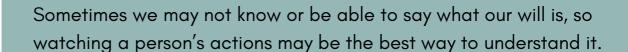
The start of a decision-making process may be a simple expression of preference such as a grimace or eye gaze. This preference can be explored and clarified and built into a choice and then into a more formal decision. It is in this way that supported decision-making can, and must always, be directed by the will and preferences of the decision maker.

We express our will and preferences all the time. Will and preferences spark our actions and non-verbal communication as well as the goals and desires that are important to us.

Our will is what drives us and gives our lives meaning. It is our deeply held beliefs, values and commitments. Sometimes we may not know or be able to say what our will is, so watching a person's actions may be the best way to understand it.

Our preferences are the things that are important to us in the present – our likes and dislikes. The way we show our preferences can look very different in different situations. We can say "I love" something or show other people what we like by laughing, nodding our head or crying out.

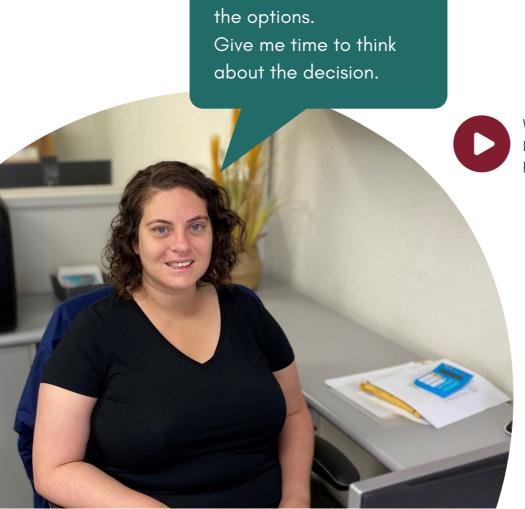
Some people with disability may not have been encouraged to think about and communicate their will and preferences. Often people with an intellectual disability have not had the same opportunities as their non-disabled peers and thus often don't have the same life experiences to learn from or draw on. They may need the help of others to work out, show, explore and refine their preferences.



The importance of clarifying will and preferences.

"The woman whose microboard I sit on, we work very hard at supporting decision making for her. She can articulate things. It is quite easy for her to tell us what she wants. But when deciding where she wanted to live, she picked New Westminster which is very hilly and she uses a wheelchair. I remember thinking hmmm? Finally, it dawned on me and I asked have you ever been to New Westminster? She said, well no. So, I asked her where have you been? And we started talking about different places on the lower mainland. And I realised up until then it hadn't been a supported decision because she didn't really know or understand the options being presented. So, we literally physically drove her around Vancouver and looked at different communities so she got a sense of what they were like. And then based on that it was a very different outcome. She chose Richmond because it is flat."

Lydia, decision supporter



Check that I understand

Watch Emily's video on Supported Decision–Making, visit: https://youtu.be/rbfoPqmzD2o

Lack of life experience

In his article, Thinking About Decision–Making, John Armstrong (2013) discusses the impact of lack of life experience. He explains that there is a universal belief that we know our own needs and make wise decisions. If a person has been exposed to multiple opportunities to make choices, receive feedback and have responsibility during their life, their decision–making is more likely to have been strengthened. However, if life experience has been lacking and others have made decisions for the person, they have little experience to draw on and expressing their preferences will be more difficult. As a result, we may need to build decision making capability over time.

John Armstrong (2013) also talks about first and second order preferences. Often, people with intellectual disability are only offered first order preferences because they're easier to offer or they will only be offered choices from a set menu of service options. Although first order preferences can offer decision-making opportunity, it's important that people have the opportunity to determine deeper preferences regarding living a full meaningful and inclusive life.

Cameron was assisted to make decisions about where he wanted to live and who with. Rather than living on his parents farm, he was given information about a range of options. Eventually, after careful consideration, he decided to move to a regional town where he could find employment, rent a home and live with a housemate without a disability who could provide companionship and support.



It may also mean that as decision supporters, our knowledge of what is possible is limited. For example, we may only think that it's possible for people with intellectual disability to live in group homes, when the evidence shows that there are people with complex needs living in their own home with a range of flexible and creative supports (Cocks et al, 2017). Exploring what is possible is vital to providing good decision-making support.

Although first order preferences can offer decision-making opportunity, it's important that people have the opportunity to determine deeper preferences regarding living a full, meaningful and inclusive life e.g. where to live and who with.

The importance of vision

Our will and preferences are usually anchored in our vision for a full, meaningful and inclusive life. Michael Kendrick (2011) describes vision as a mental picture of life in the future that is life giving, helps us to reach our full potential and builds on our strengths, interests and gifts. He suggests that "people with disabilities are not some strange versions of humanity, requiring their own exotic responses to everyday needs. What is satisfying to countless other people will also likely work equally well for them" (Kendrick, 2011, p. 19). Hence, when assisting a person with a disability to create a vision, we should align it to what is common or typical, rather than presuming the only way for them to live is to be "special."



Armstrong (2013) also highlights the work of Hamilton (2008) in regard to the importance of first and second order preferences. First order preferences are often influenced by the market place and lead to superficial or compulsive decisions that we can't resist. Often with hindsight and help from others, we learn to delay instant gratification and start to develop second order preferences. Second order preferences are more about our long-term vision, our moral self and indicate we're more in control of our will. For example, not buying a new pair of shoes that aren't needed because we're saving for a holiday or house.

Learning about decision makers

It is important to get to know the person you are supporting with decision-making and for them to get to know you. The more you know the person, the better you can understand their preferences in context and create unique ways to help them to understand the decision and its possible consequences. The decision maker also needs to get to know you as their decision supporter. Knowing you helps to build trust, makes it easier for them to tell you their thoughts and feelings and to ask for help.

When getting to know decision makers you want to learn about their:

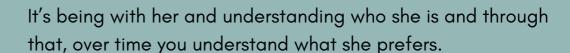
- history, life story and previous experiences
- the vision they have for their life goals, priorities and expectations
- decision-making experiences and how they make decisions (or lack of)
- abilities, important qualities and health
- needs including how they need to be supported with decision making
- unique language and way of communicating
- values and beliefs
- likes and dislikes



A close relationship allows us to understand preferences in context.

"...the way Emily makes decisions isn't by saying yes or no necessarily. I think she shows preferences for things in her own way which she communicates. It's being with her and understanding who she is and through that, over time you understand what she prefers. And it's not a fast decision making process, it's over time. It is understanding her. Developing a relationship with her. It is the only way you would get to know what it is that she wants to do. And it's the only way we can help her make decisions."

Sally, decision supporter



A close relationship helped Sally know the way options were presented was very important to working out Emily's preferences.

"She never chooses the first thing, so we realised that if you flip the choices and then she chooses the first thing that is really what she would like because that's not the last choice anymore. So, if I say to her "do you want eggs or oatmeal" and she still says "eggs" then I know that she actually wants that."

Sally, decision supporter

Understanding how the decision maker likes to be supported

We all like to be supported differently. What one person finds helpful may be unhelpful to another. It is important to understand how the person you support likes to be assisted with decision making.

A decision maker, also called Emily, created a list of what was important to her when she was making decisions - a manifesto. Emily gives her Decision-Making Manifesto to decision supporters to help them understand how she likes to be supported.



How to best support me to make decisions

Emily Raymond shares her experience as a person with a disability being supported in her decision- making, why this is important, and narrates both positive and negative real life experiences of decision making.



http:// https://youtu.be/rbfoPqmzD2o

Emily gives her Decision-Making Manifesto to decision supporters to help them understand how she likes to be supported.

Emily's Decision-Making Manifesto

When you help me to make decisions, it is important that they align with my vision.

My vision for the future is to live in my own home, close to my family. Find a paid job based on my interests. Be well known and connected to my local neighbourhood. Make a valued contribution to the community. Have a range of friendships and find a partner.

To help me make a decision:

- 1 Only give me one decision at a time.
- Understand that I like to keep everyone happy, so I may say yes to the first thing you say but will later avoid doing it or going if it's not what I want.
- 3 Explain the decision slowly. Photographs might help me to make a decsion.
- Take me to visit options and try things out. This makes understanding my options easier.
- Don't just explain the decision. Help me understand the good and bad things that might happen.
- Give me time to make a decision. This means giving me a day or two to think about the information. Don't rush me.
- If the decision is hard, you might have to break it down.
- 8 Don't get angry if I make mistakes, but help me to learn from them.
- The people I like to help me make big decisions are my Mum and support worker.

"I like to go with my gut feeling when making decisions but sometimes I need help if it's a tough decision. I get support from my family to help me to be independent. Me and my family think about what a good life looks like for me. My family helps me to know the choices so I can make my decisions about them."

Emily, decision maker



Exercise 1: Creating a manifesto



Consider creating a manifesto with your decision maker. You could start by exploring some questions together.

You can find all of the questions to complete in the workbook on pages 1 and 2.

When you are exploring these questions with the decision maker, draw on your experience supporting them in the past. Add your reflections to the conversation and see if the way you see things rings true for the decision maker.

For example, I noticed when we were deciding about dinner last night you seemed distracted by the noise in the lounge room. Do you think you find it hard to make decisions if there is a lot happening around you?

Part 3: Role of decision supporters

When we engage in supported decision-making we need to understand about our role as decision supporters and the principles which are meant to guide how we provide support.

Research into supported decision–making has described the main role of a decision supporter is to respond to the decision maker's will and preferences (Browning, 2020; Watson, 2016a). Decision makers tell and show us their preferences all the time and we need to be paying attention and respond to what they are communicating. We need to work with the person to refine their will and preferences and take action on what we find out.

Supported decision-making isn't just acting on whatever the person says they want. Decision supporters need to help the decision maker to become clearer about their preferences in light of the options, constraints and the possible consequences of the decision.

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Perception of your role

How supporters think about their role shapes how they respond to the decision maker's will and preferences when providing support. Here are four different examples.

Lisa, a disability support worker, believes her role is to help guide Cecily in a "more healthy direction". When Lisa speaks about Cecily's preferences, she describes them as something "to be shaped or tweaked".

Terry, a friend, thinks her role as a supporter is to be "a sounding board" for Betty. She responds to Betty's will and preferences by listening while Betty "figures the decision out" herself.

Annie, a rehabilitation aide, who helps Natalie with physical therapy believes her role as a supporter is to "always try and remain neutral". She thinks Natalie's will and preferences are "vulnerable to being influenced" so responds by using a number of strategies to try and minimise her influence, such as being aware of what she says and how she says things.

And lastly Jack, Vanessa's brother, believes his role as a decision supporter is to ensure Vanessa doesn't get the decision "wrong". As such, Jack thinks Vanessa's will and preferences sometimes need to be "corrected".

How supporters think about their role shapes how they respond to the decision maker's will and preferences when providing support.



Exercise 2: Reflecting on your role



Please spend some time thinking about your role as a decision supporter up until now. Imagine you are talking with a friend; how would you describe what you are meant to do as a decision supporter?

You can complete this exercise in the workbook on page 3.

Neutrality

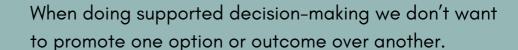
While there are lots of different ways of thinking about being a decision supporter, perhaps the best approach is to try and be neutral. In practice, being neutral can be very difficult because we all have biases which we explore a little later. When doing supported decision-making we don't want to promote one option or outcome over another. We always want to try and reduce the influence we have over the decision-making process.

Being neutral means being reflective about how and when we give advice as decision supporters. Advice about how to engage in a good process can be very helpful in building a person's decision making capability. For example, advice about how to understand information or work through potential consequences. However, advice about what to do or think when weighing up the decision, that aims to change the person's will and preferences, would be counter to good supported decision-making practice. It is this type of advice that is contrary to having a stance of neutrality.

Reducing stress and maintaining neutrality

"While I am trying to help her decide... I have to be really careful about and be aware that I don't put my preference on to her. So, I always try to remain neutral. Often, she will say, what would I do? Or what do I think? Or what would I like? And I will just joke around with her when she asks those questions. I'm like it doesn't matter what I like, I'm a vegetarian what do I know? I just throw it out left field and then she is redirected and we laugh and we joke and we go back to it again in a few moments when she is not as stressed out and she feels calmer again."

Annie, decision supporter



Assumptions and beliefs

In addition to how we think about our role, the assumptions and beliefs we have about decision makers can shape our responsiveness. For example, if we believe all people with disability should live together or socialise in segregated programs, it will significantly limit the options and opportunities we offer to decision makers. Research has demonstrated if supporters do not believe the person they support has decision-making capacity, they are less responsive to their expressions of will and preferences (Watson, 2016b).

If we believe all people with disability should live together or socialise in segregated programs it will significantly limit the options and opportunities we offer to decision makers.



Exercise 3: Identifying your assumptions and beliefs



Please think about the person you support with decision-making. Can you identify the assumptions and beliefs you have about their decision making ability?

When you are very honest with yourself, if you don't believe they are capable of making decisions, let's take a moment to examine why. This exercise is not about trying to make you feel bad. It is about creating an opportunity to see things differently.

You can complete this exercise in the workbook on pages 4 and 5.

Thinking about decision-making differently

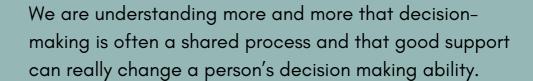
Our assumptions and beliefs can be influenced by how we have been taught to think about decision-making. Our society has seen decision-making as something we do by ourselves in our heads. Many laws require capacity assessments to identify a person's deficits, the things they can't do, in order to see if they have the ability to make certain legal decisions. They attempt to assess if the person is able to independently understand the decision and its consequences. More recently, these ideas about decision-making and decision making capacity are being challenged by academics, practitioners and even some lawyers (Arstein-Kerslake & Flynn, 2016; Bach & Kerzner, 2010; Craigie et al, 2019; Series, 2015).

We are understanding more and more that decision-making is often a shared process and that good support can really change a person's decision-making ability. As such, supported decision-making has a different starting point. We don't start by assessing a person's decision-making capacity. We start by assuming the person is able to make decisions and directing our energy towards understanding the support they need to become better at making decisions.

Twenty years ago, Stephanie Beamer and Mark Brookes said,

"The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices."

Beamer & Brookes, 2001, p.4.



Qualities of a good decision-making supporter

Good decision-making supporters:

- Have a quality relationship with the person they support. They are committed to knowing the person well, respecting their autonomy [5] and seeing beyond their disability. Mutual respect and trust are the solid ground in which their relationship grows.
- Are very tuned in to the person they support. They are active listeners and find creative ways to communicate honestly and effectively. They do not assume to know what the person wants but proactively explore and clarify their will and preferences.
- Act on what the person communicates they want and help them to explore the decision so that they are fully informed. They demonstrate respect for their right to direct their own life by not coercing the person to "fit" predetermined options or to choose from a limited menu.
- Create regular and frequent opportunities to practice making decisions so the person learns and develops their skills. They understand the importance of creating decision opportunities in the person's life.
- Hold a vision for a full, meaningful and inclusive life seeking to broaden options and opportunities to the good things in life. Without this assistance the person they support may be deciding from a very limited understanding of what's possible and become limited to segregated options.
- Act with an intention of being neutral trying to minimise their influence over the decision-making process. They provide all the information a person might need to make a decision and present it in an unbiased way. Paying attention to what and how they discuss the decision.

^[5] Autonomy is the ability to act and make decisions without being controlled by anyone else.

Understand that risks are a natural part of life and that risks can have positive, as well as negative effects in a person's life. They include the person in the process of considering potential risks and how they could be reduced. Helping the person reflect on the impact of their decisions is how they can build confidence and greater skill.

Understand the aims and principles of supported decision making. They always seek to build the decision-making capability of the person they support.

Good decision-making supporters are very tuned into the person they support. They are active listeners and find creative ways to communicate honestly and effectively.

Some tips for setting the scene for good decision-making

Find the best time to support the person to make the decision. It's not a great idea to do this at the end of the day when everyone is tired, or if in a bad mood.

Find a place that's free from distraction to focus on the decision e.g. find a quiet space where the person feels comfortable, relaxed and can concentrate.

Give people time to make the decision e.g. give them time to think about the decision before or after a conversation.

Don't stay locked in the past. Sometimes even if someone has tried something before doesn't mean they might not want to try something again or that it might not succeed now.

Have the big picture and vision in mind. Be open to innovation. We can get stuck in models and options of the past.

Part 4: Decision-making process

When we make decisions, we don't follow steps in a linear way. We move through elements bouncing backwards and forwards depending on the circumstances. Exploring a person's options may change the decision they want to make. Working through barriers and risks may change the options being considered, and therefore, the person's preferences.

Some decision-making processes are short and occur in a single conversation. Others take years, and each element of the process involves significant time and effort to do well. The complexity of the decision, how much support the decision maker needs to work out their will and preferences and the resources available will all influence how much time the process takes.

Understanding the key elements of the supported decision-making process is about giving you confidence so you can address all the important aspects of providing good decision support.

There are six key elements in the supported decision-making process that all actively involve the decision maker.





Exercise 4: Decision-making process



Let's examine the decision-making process.

Looking into and understanding the decision to be made

- Why is the decision important or needed?
- What might it mean for the person?
- What might it mean for other people in the person's life?
- Who needs to be involved in making the decision?
- What might help the process, e.g. involving the right people?
- What might hinder the process, e.g. available time and money?

Understanding the person's will and preferences about the decision

- What are the person's preferences?
- How does the decision align with the person's vision?
- How does the decision relate to the person's values, beliefs, goals and previous experiences?
- Is your understanding of the person's will and preferences the same as theirs? Have you reflected your understanding of their will and preferences back to the person to check it is correct?

Gathering information and exploring options

- How many options would be helpful to explore with the person?
- How can you creatively present information, e.g. use photographs, video, social stories, Easy Read format? As well as talk about them, how might you support the person to experience and try options?
- What are the good things that might come from making the decision?
- What are the bad things that might come from making the decision?



Exercise 4: Decision-making process continued



Working through barriers and risks

- What are the barriers to acting on the person's will and preferences, e.g. finances to rent or purchase a house?
- How can the barriers be overcome, e.g. finding a job, renting a flat with a flatmate, exploring rental assistance and funding programs?
- What are the risks, e.g. damage to the person's reputation or health, isolates the person? How serious are the risks? How can you overcome the risks?
- How can the risks be reduced and managed? Or what safeguards might need to be put in place, e.g. trying the option with support?

Weighing it all up and making a decision

- Have you explained to the person what the decision might mean for them and other people in their life? Has the person understood your explanation? What were their thoughts?
- Have you weighed up the benefits and risks with the person?
- What is the final decision?
- How can the person communicate their decision to others?

Reflecting on the decision and what happens

- Has the decision been acted on by others?
- Do you need to advocate alongside the person for others to take action?
- Are there more decisions to be made as a result of the decision, e.g. the decision to quit your job creates other decisions about what to do next?
- What has been the impact of the decision for the person and others?
- If the outcome of the decision is not what the person wanted, what are the next steps?

Part 5: Dilemmas of practice

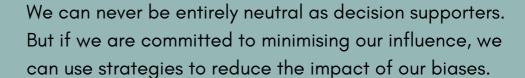
Bias

Both decision makers and their supporters can have biases, as we all favour what we believe is true and correct and thus can be reluctant to seeing other options, receiving advice or trying new things (Armstrong, 2013).

We have already discussed how, as decision supporters, we need to try and be neutral. This can be difficult because we all come to decision-making with biases. Biases are our own values, goals, priorities and preferences that influence the support we provide. Some common examples of biases include wanting one option more than another for the person, being directly impacted by the decision, having the same or different values as the person and having a specific vision for the person and their life. We can never be entirely neutral as decision supporters. But if we are committed to minimising our influence, we can use strategies to reduce the impact of our biases.

Tips for addressing bias

- Focus on the process rather than the outcome. Gather factual evidence about options so you can make an informed decision. For example, if you're going to start a business, it's important to know that only 45% of businesses succeed in the first five years (Armstrong, 2013). Think about the decision and whether you have a strong opinion on the options. If you do, think about why and whether you have any possible biases.
- If you do have a bias own it admit it to yourself and others.
- Explore any possible biases how strong are they? How much impact are they likely to have over the way you explore the decision with the decision maker?
- Talk to the decision maker and their other supporters about their and your biases do they think bias is a problem?



- Ask who is best placed to provide the decision maker with neutral, unbiased support?
- If you think someone else might be better placed to support the person, consider taking a step back and allowing them to take the lead.
- If taking a step back isn't an option, think about what you could do to reduce the bias. For example, making sure the decision maker hears from other people with different ideas to you.

"I supported some self-advocates during a political process and there were some pretty heated discussions and I had some pretty strong opinions on things. And I had warned them ahead of time. I said look we are going to be talking about this, I have an opinion on that and I don't want my opinion to colour yours. And what I would like to do is bring someone in who doesn't share my opinion. So that you are hearing from both of us, what the pros and cons are around that issue. Because I am conscious of how strongly I feel about this issue."

Lydia, decision supporter

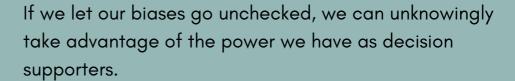


When supporters start a decision-making process believing one option or outcome is the right one, it can lead to them trying to change the decision maker's preferences to align with it. They might offer encouragement, rewards or bargain with things they know the person likes. They might present the right outcome as if it was the decision maker's idea or the only one on offer.

When supporters are heavily invested in a certain option or outcome, they might withhold information about other options from the person or become frustrated and angry when discussing these alternatives. By using these approaches supporters are taking away control from the decision maker. They are heavily influencing the decision-making process. To avoid bias occurring, it is very important that you approach the process from a neutral standpoint, and focus on the process rather than the outcome.

In summary, we all have the potential to negatively influence the supported decision-making process. If we let our biases go unchecked, we can unknowingly take advantage of the power we have as decision supporters. To stop this occurring, we need to act with the intention of being neutral, own our biases, actively work to reduce the impact of them and focus on the process rather than the outcome.

To avoid bias occurring, it is very important that you approach the process from a neutral standpoint, and focus on the process rather than the outcome.





Exercise 5: Who's really in control



Please use the table in the workbook to think deeply about who currently makes decisions in a range of life areas that effect the person you support. Think about whose responsibility is it really to make these decisions? Describe what type of assistance the person would need to be able to make these decisions?

If you identify you have a bias that may influence how you approach these areas, it might be helpful to think about what is typical and ordinary for most individuals at the same age. For example, your anxiety and fears about personal safety have kept you from allowing your son to meet with peers you haven't met. Would this be typical for your son's peers without disability?

Fears

Decision-making can be hard and acting as a decision supporter is a big responsibility (Bigby et al., 2021). It is natural to experience some fears, anxieties and concerns when trying to do supported decision-making. Some people may fear making bad decisions, others may be concerned about letting go of control or potential risks. We can be anxious about not knowing where to start or what to do. Let's do an exercise to help you better understand your fears, anxieties and concerns so you can develop strategies to overcome them.

For example, perhaps you are feeling anxious about your decision maker not understanding the risks involved in a big decision like moving out of home. One way you could start addressing this concern, could be to start small and practice exploring risks together with less significant decisions. Over time you will both develop your ability and confidence to see and talk about risks. By starting small you will have the chance to practice problem solving together and how you can avoid and reduce risks. We will explore this further in the next section of our guide. In this podcast, <u>Brodie Moves Out</u> (https://podcasts.apple.com/us/podcast/brodie-movesout/id1634126628?i=1000569862731), his mum Justine discusses her fears and how she addressed them.



Exercise 6: Exploring fears, anxieties and concerns

Please use the table in the workbook to list your biggest fears, anxieties and concerns as a decision supporter and explore how you might be able to address them.

Enabling risk

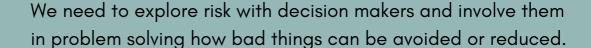
Supported decision-making sees risk as something that can bring good things to a person's life not only bad things. Many of the things we achieve in life, and are proud of, involve taking risks. If we look back over our life, we will see that taking risks has helped us to learn about the consequences of certain actions. We want to make sure the people we support have those same opportunities and are well supported to take risks.

Supported decision-making asks decision supporters to approach risk in a proactive, supportive and collaborative way. We need to be free to talk about risk and not let our fears shut down important conversations. We need to explore risk with decision makers and involve them in problem solving how bad things can be avoided or reduced. When we do this together, we find better solutions that work for the person involved. It gives decision makers the opportunity to learn about risks and what can happen in concrete situations. Over time this builds their confidence and skill in seeing and managing risks.

When exploring risks, we are guided by the decision maker's will, preferences and vision. We are guided by what they are saying they want in the context of what we know about the bigger picture of their life. We need to know why the decision maker wants to engage in the activity that involves risk. What about the activity is important to them and why?

Supported decision-making asks decision supporters to approach risk in a proactive, supportive and collaborative way.

We can use a range of strategies to help the decision maker understand possible risks and what might happen if they choose different options (Bigby et al., 2021). We can talk about risks, watch videos, speak to others who have made a similar decision and try similar activities and reflect on how they went.



After doing these things, if you feel confident the decision maker understands the risks and what might happen and is still wanting to engage in the activity, they are making an informed decision. A risk enablement approach says you should respect the person's decision even if it may bring bad things. It also means engaging in conversation, providing support and letting them know that you're there for them.

However, if you have concerns or doubts about the decision maker's understanding of the risks and what might happen, you may need to help them develop strategies to avoid or reduce the harm while respecting their will and preferences.

We need to work with the decision maker to find other ways to achieve what they want that respects their will and preferences and reduces harm. When problem solving, we are looking for solutions that make the least change to the decision maker's will and preferences. If someone is going to make a decision that may cause harm, then you may want to seek advice.

Often when we analyse a risk, it's not as bad as it seems and we can put in place strategies and safeguards to lessen the risk. Using a risk analysis matrix can be a useful way of thoughtfully considering a risk, rather than just reacting or denying the person a decision. A matrix can help you to think through a particular risk and the likelihood and consequence of it happening and what you might put in place to reduce or minimise the risk.

For example, Stakeholder Map provide various templates.



Stakeholder Map

To download the templates visit https://www.stakeholdermap.com/risk/4x4-risk-assessment-matrix-download.pdf

Exploring the least change to will and preferences

An example

A person you support comes to you and says they want to travel overseas on their own. When you think about this idea, you're excited about the opportunity for them but can identify three risks of concern – how they would manage their medication, their money, and their vulnerability to being taken advantage of by others. When supporting the person to make this type of decision a number of conversations would be needed to better understand their will and preferences and the extent of the risks.

You would need to understand more about the person's desire to travel alone. Is their primary motivation to see new places, to be independent, to spend time at a particular place which happens to be overseas, be able to relate to the experiences of peers who have travelled abroad, or not to travel with mum or dad!

In addition, you need to explore how to reduce each of the possible risks that could happen on the overseas trip. For example, they could connect with others regularly throughout the trip, have specific meet up points, have a companion the same age for part or all of the trip, use financial options with built-in limits, take a medication Webster pack, do assertiveness training, etc.

After exploring all of these aspects, if you understand the decision maker's key motivation was independent travel, then suggesting they take a travel companion to reduce risk would not be considered the least change to their will and preferences. Instead, exploring independent travelling within Australia may be the most preferable option to stay true to what the person wants while reducing risks. If they have never travelled independently before, perhaps they could begin by taking short trips with a companion to practice.

However, if seeing a specific place overseas was the key reason, having a companion the same age may significantly reduce risks without greatly changing the person's will and preferences. Especially if they can choose who it is that would join them on the trip.



Part 6: Good practice

Example of supported decision-making

Supporting Natalie to decide if she wants to leave her job

One day Natalie woke up and said to her mum "I'm not going to work today; it's boring." Natalie had been working in the same organisation for five years doing office admin two days a week. Natalie's mum noticed Natalie had been becoming less excited about going to work over the last six months. She was not surprised by Natalie's comment and realised what she might be saying was 'I don't want to work there anymore'.

Natalie's mum asked her more about how she was feeling and Natalie confirmed she was not enjoying work. Natalie and her mum saw the situation as a decision opportunity. Did Natalie want to leave her job?

Looking into and understanding the decision

Natalie contacted her workplace and said she wouldn't be coming in that day. Instead, she and her mum spent some time talking about what Natalie wanted to do. Natalie was unclear what leaving a job meant.

Natalie's mum suggested it might be helpful to hear from a couple of different people about their experiences leaving jobs to work out if that's what she wanted to do. Natalie thought this was a good idea.

Natalie thought it would be good to speak to her brother Joel who works at a café and her neighbour Carly who has a full-time job at a trendy retail clothing store. She would see Joel on the weekend and she would have to text Carly to find out when they could catch up. She started to realise the decision would take longer than she hoped.

Natalie's mum thought it would be good to talk about what it would mean to leave her job and not have another job to go to straight away. Her decision would affect her income and she wouldn't have enough money to go on the holiday she had been planning. It would also affect the rest of the family if she wanted to stay home on her own.

Understanding Natalie's will and preferences

Natalie's mum asked her to tell her more about how she was feeling. Natalie said she didn't want to be bored anymore. She had liked shredding and filing when she first started her job five years ago. Now it was the same every day. She wanted a job that was based on her interest in fashion. She wanted a job where she was with people her own age.

Natalie's mum asked about who she spent time with at work. Natalie said she used to have lunch with Lou but she had left to have her baby. She missed Lou.

Natalie's mum asked about her boss Deborah who she often talked about fondly. Natalie said Deborah was too busy to talk to her now. She had a bigger job.

Natalie's mum reflected back to Natalie that she felt bored at work and missed seeing Lou and Deborah. Natalie confirmed this was how she felt.

Gathering information and exploring options

On the weekend when Joel came home during lunch, Natalie asked him about when he decided to leave the fish and chip shop. He told her he didn't like the shifts he was getting, it took him too long to get there on the bus and his best mate had started at a local café and really liked it. So, he thought it was worth applying for a job at the café and asked them if they needed anyone. He didn't leave his job at the fish and chip shop before he got the job at the café as he needed the money to pay rent and was also saving for a holiday.

The following week Natalie and her mum invited Carly over for tea. Natalie asked her if she had ever left a job. Carly said she had left two jobs. One because she didn't like washing dishes enough to stay when they were only paying her \$20 an hour. And the other because she had an argument with the boss. With the first job, she had another job to go to straight away. When she had the argument with her boss, she hadn't planned on quitting so she was without work for a few months. She enjoyed the time off at first but she did not have an income so could not go out with her friends. After a while, she got bored and hated not having anyone to catch up with during the day. Eventually she got her current job at a trendy clothing store in a major shopping centre which she was loving. She had also been offered a promotion!

After Carly left, Natalie's mum asked her what she thought of Carly and Joel's stories. Natalie liked that Carly left dish washing when she didn't like it. She hadn't thought about being bored at home if she left her job. She hadn't thought about not having money for a while either.

Natalie and her mum listed all the options. One, leave the job straight away and look for a job later. Two, stay at the job while she is looking for another job. Three, stay at the job and ask for work that is less boring and try to make new friends.

Working through barriers and risks

Natalie and her mum talked about the risks of leaving her job without having another to go to straight away, such as not having any money coming in, being bored at home alone and it taking a long time to find another job. They talked about how they could reduce the risk of not getting a job for some time. She could ask her friend Sally who was a store manager for a large fashion retailer. She could also ask her neighbour Lee who ran a recruitment company.

Natalie's mum said she could work from home two days a week to help Natalie stay on track with finding a new job but that she would only be able to do this for six weeks at most.

They talked about finding another job and whether staying in the job now would help (she could add it to her resume as current employment) or make it harder (less time to make job applications). They also talked about the possibility of asking her boss for different work and whether it seemed possible to make new friends where she worked now.

Weighing it all up and making the decision

After thinking through all the information Natalie decided she wanted to leave the job as soon as possible. She didn't think improving things at the office was possible. She wasn't enjoying work anymore and she wanted more time to be able to explore her options. But she decided to speak to Sally and her neighbour Lee at the recruitment company first to see what skills she would require and how long it might take to find a job.

Even though she had money saved that she could use for a few months, she didn't know how long it would take her to find a job in the fashion industry. She thought it would be better not to leave her job until she had done further investigation. Hopefully, by knowing people she would get a job quicker.

Natalie's mum helped Natalie prepare her questions for Sally and Lee and also prepare her resignation letter and what she was going to say to her boss when she was ready to leave.

Reflecting on the decision and what happens

Natalie was able to find a job through Sally in three weeks. In the meantime she signed up for a retail assistance course to learn more about working in a clothing store. Natalie left her job and never looked back. She is currently working in a large retail clothing store unpacking, ironing and putting the clothes on display.

Natalie is working towards serving customers.



She loves working with lots of other young people and hanging out at the local mall. She knows she doesn't want to work in the clothing store forever but will stay there while she works out her next move.



Exercise 7: Exploring a decision with a person

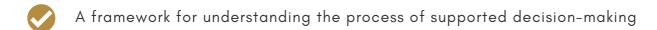


Please think of a decision you are working through at the moment with your decision maker. Try using the template in the workbook to think about and work through the different elements of the decision making process.

Part 7: Summary

Supported decision-making is about providing practical assistance with decision making. It offers people with disability a broad range of supports to be able to make their own decisions and stay in control of their lives.

This guide has aimed to provide:





Greater clarity regarding the role and responsibilities of decision supporters including taking a neutral stance, addressing bias and minimising their influence over the decision-making process

Providing decision-making support can be challenging and we hope that this guide helps people feel more confident and skilled when engaging in supported decisionmaking.

For further information or to order this guide please contact:



Belonging Matters Inc

info@belongingmatters.org



belongingmatters.org



Part 8: Information and Resources



Organisations and Websites

The La Trobe Support for Decision Making Practice Framework Learning Resource

A research-based practice model for supported decision-making



http://www.supportfordecisionmakingresource.com.au/

Enabling risk: putting positives first

An online learning resource for disability support workers on how to support positive risk taking while minimising potential harm.



http://khttp://www.enablingriskresource.com.au/

WA Individualised Services

Practical resources and guidance when providing decision-making support



http://kaindividualisedservices.org.au/resources/supported-decision-making/

SDM Resource Hub

My rights: supported decision making



http://khttps://supporteddecisionmaking.com.au/

Office of the Public Advocate

Legal context of supported decision-making in Victoria for families and carers



https://www.publicadvocate.vic.gov.au/joomlatools-files/docman-files/general/Supported_Decision_Making_in_Victoria.pdf

Indigo Solutions

Resources for improving participation in decision making for people with complex communication support needs.



https://www.indigosolutions.org.au/resources/autonomy-in-decision-



Organisations and Websites

Decision Agency

Supported decision-making training, practice group facilitation and supervision



http://khttps://www.decisionagency.com.au/

Council for Intellectual Disability

People with intellectual disability co-designing supported decision-making resources



http://khttps://cid.org.au/our-stories/co-design-my-life-my-choices/

Inclusion Australia

Supported decision-making resource directory for people with intellectual disability and their supporters



https://www.inclusionaustralia.org.au/wp-content/uploads/2022/02/Our-Resources_Supported-Decision-Making-Resource-Directory.pdf

Developmental Disability WA

Free online course for decision supporters developed by Developmental Disability WA



http://ddwa.org.au/online-learning/supported-decision-making-course-outline/



How to best support me to make decisions

Emily Raymond shares her experience as a person with a disability being supported in her decision making, why this is important, and narrates both positive and negative real life experiences of decision making.



https://youtu.be/rbfoPqmzD2o

Decisions Decisions Decisions

A video for decision makers about decision making by Speakout Advocacy



https://www.youtube.com/watch?v=WmWO3E1kJT4

Andrew - making brave decisions

A video about Andrew and his sister who supports him making decisions by Council for Intellectual Disability



http://khttps://cid.org.au/our-stories/andrew-making-brave-decisions/

Representing the Rights of Persons with Disabilities by Financial Counselling Australia

Dr Jo Watson explains the importance of autonomy and the right of people with complex disabilities to receive the support they need to make decisions and determine their own lives.



http:// https://www.youtube.com/watch?v=qMerG7CULJE

Looking Differently at Disability and Decision Making by Open Society Foundations

Dr Michael Bach discusses how support to exercise legal capacity was an important aim in the development of supported decision-making in Canada.



http:// https://www.youtube.com/watch?v=JrZINQC6oRs



Articles and Periodicals

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https://www.belongingmatters.org/product-page/periodical-16-decision-making

A process of decision-making support: Exploring supported decision-making practice in Canada.



http://www.tandfonline.com/doi/full/10.3109/13668250.2020.1789269

Supported decision-making: A Copernican revolution **Decision Agency**



http://khttps://www.decisionagency.com.au/articles/supported-decision-making-a-copernican-revolution

"I used to call him a non-decision maker - I never do that anymore": parental reflections about training to support decision making of their adult offspring with intellectual disabilities.



https://www.tandfonline.com/doi/full/10.1080/09638288.2021.1964623

Parental strategies that support adults with intellectual disabilities to explore decision preferences, constraints and consequences



http://www.tandfonline.com/doi/pdf/10.3109/13668250.2021.1954481

Assumptions of decision-making capacity: the role supporter attitudes play in the realisation of Article 12 for people with severe or profound intellectual disability.



https://dro.deakin.edu.au/eserv/DU:30081501/watson-assumptionsof-2016.pdf



Global perspectives on legal capacity reform: Our voices, our stories (2019)



http://www.routledge.com/Global-Perspectives-on-Legal-Capacity-Reform-Our-Voices-Our-Stories/Flynn-Arstein-Kerslake-Bhailis-Serra/p/book/9780367473709

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Supported decision-making: Theory, Research and Practice to Enhance Self-**Determination and Quality of Life.**



https://www.cambridge.org/core/books/supported-decisionmaking/AD67D3899C925FEB5821BE0C29667BF8



Advocacy for Inclusion Podcast explores practical ideas related to supporting people with disability to make decisions.



https://www.advocacyforinclusion.org/staying-connected-podcast/



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