

Decision-making support:

An educational resource for legal professionals working with people with cognitive disability



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About these guidelines

Often, people with cognitive disability want support to make decisions. Indeed all people often want or need support to make decisions. This booklet sets out guidelines for legal professionals to assist people with cognitive disability make decisions.

You can use these guidelines in several ways:

- To prepare yourself for a conversation about decision-making with a person with cognitive disability
- To gain practical guidance for supporting people with cognitive disability to make decisions
- To understand how to comply with your professional obligations to support clients with cognitive disability to make decisions

The term ‘cognitive disability’ is used in this booklet to refer to people with intellectual disability and those with acquired brain injury. It is important to note this booklet is designed to help support people with mild and moderate cognitive disability. It is not aimed at decision-making support for people with profound cognitive impairment, such as people who have extremely high support needs or are in a minimally conscious state.

It is also important to emphasise that this booklet provides guidelines for legal professionals who may be representing or advising a person with cognitive disability. The aim of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) was not to formalise decision-making processes for people with disability who may need support, but rather to provide principles and standards affirming that people with disability have the right to exercise legal capacity on an equal basis with others. Drawing from these principles and standards, as well as research, this booklet offers broad information and advice to legal professionals. It should not be relied upon as a source of legal advice.

This is a Victorian resource which references specific Victorian law. However, the tips and guidelines in this resource may be useful to lawyers practicing in other states and territories.

This resource is part of a set of written and multimedia materials designed to promote decision-making support for people with cognitive disability. The set also includes resources for families and carers and service providers. The other resources in this set can be accessed at www.scopevic.org.au.



Introduction to decision-making support

Being able to make decisions about our lives, and to have those decisions recognised, is an intrinsic feature of autonomy. The right to make decisions on an equal basis with others also rests on principles of dignity and equality. These principles are affirmed in the UNCRPD, to which Australia is a signatory. The UNCRPD affirms people with disability should be afforded legal recognition of their decisions on an equal basis with others. It also obliges states to ensure people with disability have support made available to them in making decisions.¹

Decision-making support involves helping someone to express their will and preferences, to have their decision understood, and acted upon. It is a way of supporting people with cognitive disability to make significant decisions and exercise their will and preference. It relies on the support of others (often a network of people) to gather and understand relevant information about the decision in question, think about different options, assist the person weigh up the benefits and risks and likely outcomes of a decision, and identify a plan for making the decision a reality. It can lead to increased self-determination, autonomy, confidence, improved decision-making skills, strengthened support networks and better engagement with the community.²



Decision-making support is premised on the idea that just as people with mobility difficulty should have access to ramps, assistance should be available to people who require support to make legally recognised decisions on an equal basis with others. It draws on a view of disability as something that comes from the interaction between a person's *impairment*, on the one hand, and the social and physical barriers to his/her full and effective participation in society, on the other. This view of disability aims to shift the emphasis from identifying deficits in the person with a disability to identifying *external* barriers – whether physical or social – to their participation on an equal basis with others. It looks at the types and levels of support required to address these barriers so that the person can make decisions about their life.

Some disabilities are associated with challenges in thought-related tasks, many of which have a direct impact on decision-making. Cognitive impairment as a result of intellectual disability or acquired brain injury (ABI) affects more than one million people in Australia, which equates to 5% of the Australian population³. Intellectual disability is “characterised by significant limitations in both intellectual functioning and adaptive behaviour, which covers many everyday and social skills”⁴. This disability originates before the age of 18. ABI refers to “any type of brain damage that occurs after birth”⁵. It can include damage sustained by infection, disease, lack of oxygen or a blow to the head. People with cognitive disability may require more support for decision-making than other adults in the community. Good support for decision-making has been found to positively affect self-identity, psychological well-being and quality of life.^{6,7}



Many legal professionals will represent or give advice to people with cognitive disability. This is because, like all citizens, people with cognitive disability need legal support for major life decisions that have significant and long-term implications. It is also the case that people with cognitive disability are over-represented in many parts of the justice system.⁸ Further, the development of Australia’s National Disability Insurance Scheme (NDIS), which seeks to give more power to people with disability to direct their own services and supports, is likely to increase the range and complexity of decisions people with cognitive disability require support with.⁹ The making of these decisions under the NDIS may require additional support from legal professionals.

Legal professionals tend to have a clear understanding of the rights-based approach underlying the UNCRPD.¹⁰ Yet, they may not be immediately clear how to comply with their professional obligations to support the decision-making of clients with cognitive disability.

Supporting people with cognitive disability to make decisions may be a complex, dynamic and chaotic process, but very few (if any) practical resources exist for responding to these issues. As such, this booklet offers guidance for legal professionals who work with people with cognitive disability and need to provide decision-making support. At times, this process has been referred to as supported decision-making, but for this booklet, we will refer to it as decision-making support.

Decision-making support:

An approach to making decisions whereby a person with cognitive disability is supported by a person, or group of people, to express their will and preferences, and have these understood and acted upon. It is a way of supporting people with a cognitive disability to make significant decisions and exercise their will and preferences.

Law and ideas guiding decision-making support

Current law and policies

In general, law and policy in Australia promotes decision-making support for people with disability. This is in line with the UNCRPD, which Australia has ratified, and is reflected in different parts of Victorian and Commonwealth law. This legislation includes, at the national level, the *National Disability Insurance Scheme Act 2013* (Cth),⁹ and at the state level, the *Powers of Attorney Act 2014* (Vic),¹¹ the *Victorian Charter of Human Rights and Responsibilities Act 2006* (Vic),¹² the *Guardianship and Administration Act 1986* (Vic)¹³ and the *Disability Act 2006* (Vic).¹⁴ More recent legislation and policies guiding decision-making support are discussed as follows.



United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The purpose of the UNCRPD is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all people with disability, and to promote respect for their inherent dignity.¹

People with disability include those who have long-term physical, mental, intellectual or sensory impairments. The interaction of these impairments and environmental barriers may hinder the person's full and effective participation in society on an equal basis with others. The UNCRPD states people with disability must have all human rights and fundamental freedoms. Countries that ratify the UNCRPD agree to work against stereotypes and prejudices, and promote awareness of the capabilities of people with disability. Australia has ratified this agreement.



The right to make one's own decisions is a central premise of the UNCRPD. It is therefore important to provide the support necessary in order for the person to make an informed decision. The level of support required will vary depending on the decision to be made and the support needs of the person involved.

The UNCRPD affirms people with disability should be afforded legal recognition of their decisions on an equal basis with others. It also obliges States to ensure that people with disability should have support made available to them in making decisions. The UNCRPD is considered revolutionary, particularly Article 12 which asserts that all people with disability have a right to legal capacity.

Although, the terms 'decision-making support' or 'supported decision-making' do not appear in the UNCRPD, the concept is outlined in Article 12 around self-determination, support and certain safeguards. Article 12(2) of the UNCRPD directs that "States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Article 12(3) then mandates states to develop "appropriate measures to provide access by persons with disabilities to the *support they may require* in exercising their legal capacity." Article 12(4) sets out safeguards for a person's right to make decisions, and around the support provided. This includes support measures where decisions may be made for a person (for example, where there wishes and preferences are unknown or unclear and there is an imminent risk to life or safety), to ensure that these decisions occur based on their 'will, preferences and rights.' This may include, according to the Committee for the UNCRPD, instances in which the 'best interpretation of will and preferences' is used to guide decisions. Safeguards also require support that is "proportional" to the person's circumstances, applies for the shortest period of time, and is subject to review by a "competent, independent and impartial authority or judicial body".¹

The Australian Law Reform Commission and National Decision-Making Principles

There are various interpretations of decision-making support, and how it might be adopted into law and practice in Australia is still being debated. However, the Australian Law Reform Commission has clearly articulated four key national decision-making principles that capture a rights perspective to decision-making support.¹⁵ It is important to note that these principles are recommendations only and as yet have no actual status in law or policy. These principles are:

Principle 1: The equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

People who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for people who may require decision-making support, including to prevent abuse and undue influence.

As well as informing law and policy reform throughout Australia, these principles can help guide legal practice. This can be useful when there are disagreements about what decision-making support entails.

The National Disability Insurance Scheme (NDIS)

The NDIS operates under the the *National Disability Insurance Scheme Act 2013* (Cth) [NDIS Act] and a series of rules and guidelines. The NDIS Act outlines a set of principles that underpin the NDIS which includes peoples' right to be "supported in all their dealings and communications with the [National Disability Insurance] Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs"⁹.

The NDIS will create greater opportunities for people with disability who are eligible for support (i.e., participants) to exercise their rights and choice and control over their services, supports and lives. It is expected that NDIS participants "will determine their own best interests, including the right to exercise choice and control, and engage as equal partners in decisions that will affect their lives to the full extent of their capacity"⁹.

Among other things, NDIS participants can choose:

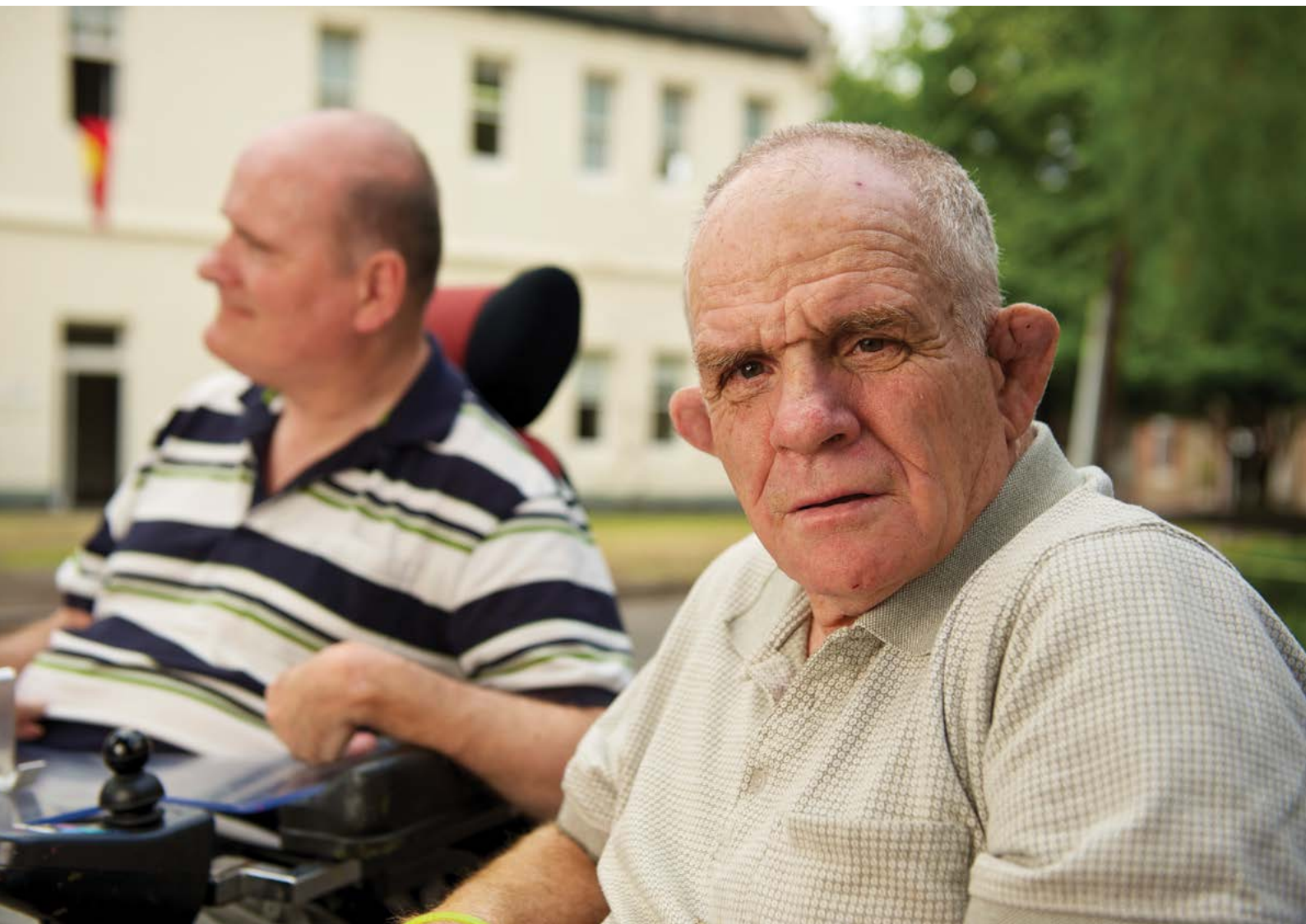
- The supports they need, as well as who provides their services and supports
- How they want their NDIS funds to be managed

The Powers of Attorney Act 2014

In Victoria, the *Powers of Attorney Act 2014*, which came into effect 1 September 2015, introduces a number of changes important for making decision-making support a reality. The Act combines the current enduring power of attorney (financial) and power of guardianship into one enduring power of attorney, improves protection against abuse of powers of attorney, and enables a principal to appoint a supportive attorney.

The improved protections against abuse involve a new definition of decision-making capacity, new principles which guide decision-making support, and more stringent requirements for making and revoking an enduring power of attorney. The Act also sets out the duties of enduring attorneys, (for example, to act honestly), imposes new criminal offences for dishonesty, provides additional Victorian Civil and Administrative Tribunal powers particularly in relation to compensation, and new provisions banning conflict of interest transactions.

A key feature of the Act is the introduction of the supportive attorney appointment. This enables a person to appoint a supportive attorney who can collect information, communicate information, support decision-making, and give effect to the decision if required. The supportive attorney doesn't have any decision-making powers. Thereby, the role of the supportive attorney is to facilitate the decision-making process where needed, whilst ensuring the decision is the person's.¹⁶



Shift from substitute to supported decision-making


In Australia, the law currently allows *substitute* decision-makers to make decisions on behalf of people with cognitive disability. Substituted decision-making may happen in both the formal and informal sphere.

In Victoria, formal substituted decision-making may occur under laws such as the *Guardianship and Administration Act 1986* (Vic),¹³ which authorises the making of decisions within certain areas of a person's life using a 'best interests' standard to guide decisions. Formal substituted decision-making processes are not confined to guardianship laws. Within Australia, for example, they are incorporated into state and territory mental health legislation, as well as the *National Disability Insurance Scheme Act 2013* (Cth), under which 'nominees' can be appointed to make decisions about the provision of services and supports on behalf of a person with disability.⁹

More commonly for people with cognitive disability, substitute decision-making occurs at the informal level, including within families, in disability and aged-support services, and in the provision of legal services. These informal substitute decisions may be small scale, for example, a mother may buy all her adult daughter's clothes without asking what clothes she likes. Another example would be a supported residential setting that enforces a strict schedule for eating breakfast at particular times. But such decisions can also be highly significant; an adult son and daughter may initiate the sale of an ageing mother's house without her full consent; a brother may withhold his sister's disability support pension from her and use it to pay for "her share" of rent and groceries.

This type of informal substitute decision-making may happen for a variety of reasons:

- Perceived efficiency when the alternative is considered overly resource intensive or time consuming
- Fear that the person will make a decision that is seemingly detrimental to his or her safety and wellbeing
- The person may lack confidence in making decisions and have had limited opportunities to experience options
- Widespread discrimination against people with cognitive disability and prejudicial behaviour may mean that others do not take their views seriously¹⁷
- Abuse, neglect or exploitation

 *"There are still people out there, working in the field who ... have the same mentality as 20 or 50 years ago working in the institutions which is: 'you come over here and sit down here and don't get that food on you, wipe that off your mouth, everyone get into your pyjamas now, it's time for bed'." (lawyer)*

Substitute decision-making processes have been criticised in recent years. Contemporary trends in law reform have responded to these criticisms, affirming that people with disability should have support made available to them to help make their own decisions rather than have their decision-making rights taken away from them.^{15, 18, 19} The term 'supported decision-making' or 'decision-making support' is increasingly used to describe this type of assistance.

Case study

Background

David is a 43 year old man with an intellectual disability and cerebral palsy. He communicates verbally, but has a significant speech impairment and it can be difficult for people who do not know him well to understand him. He lives in a shared home with four others, and has a small support network comprising his mother, brother and a close friend, who also acts as an informal advocate for him from time to time. He is used to making day to day choices like what to wear or what movies to watch, but has traditionally been assisted to make more significant life decisions, such as how to spend his money or where to live.

David needs help with managing his day to day finances, and has nominated his friend as the person who can informally deal with his money. David's mother feels he is at risk of being financially exploited under this arrangement. Her concern is that David is making a decision that is detrimental to his financial well-being. His mother is considering asking David to make her an enduring power of attorney, where she will make decisions about specific financial matters. David is very clear in his intention to continue to have his friend assist him, and has sought legal advice. He contacts a lawyer, John for legal advice.

“He communicates verbally, but has a significant speech impairment and it can be difficult for people who do not know him well to understand him.”

Strategies to assist with providing decision-making support

Getting to know the person

Decision-making support relies on a commitment to developing knowledge about a person. This can include learning about the person's disability, his or her life experiences, personality, strengths and support needs, and preferred ways of communicating.¹⁰

“To work with the person you're helping to make the decision, you need to have as much information about that person as possible and what their needs are.”
(family member)

Getting to know the person well may be challenging for legal professionals, who often meet people fleetingly under constrained circumstances. To overcome this barrier, strategies to build rapport quickly can be used, but these will vary depending on the person and their circumstances. It seems simple, but sometimes finding something in common with the person can help to build trust, which is often essential to good communication.

It is important to have an understanding of the person's values in order to support their decision-making. When people make decisions and choices they use their values and beliefs to do so. These have been built on life experience and their upbringing. It is important to respect the opinions, values, and choices of the person and not impose your own views or attitudes on the person.

TIPS

Getting to know the person can involve learning about:

- Their strengths
- Things they like or enjoy to do
- Things they dislike or do not like to do
- Their current living situation
- How they understand what is happening around them
- How they prefer to explain things to you
- How they prefer you to explain things to them

“He had footy posters all over the place so after I explained who I was and what I was doing, I said ‘how could you possibly barrack for Essendon, the Cats are the people we need to barrack for’, so I tried to build a bit of a rapport up, a bit of a banter.”
(lawyer)



Case study

Getting to know the person/communication

John arranges a time to meet with David. David attends with the house supervisor from his shared home. John has difficulty understanding David's speech, making communication between the pair difficult. David's attention is fleeting and John does not feel he is able to communicate with David and understand his beliefs effectively.

David gives John his 'Book about me'. This helps John to begin building rapport with David, allowing him to quickly understand David's strengths and interests. He learns that David is easily distracted by noises and movement in his environment. John learns that David is able to nod for yes, and shake his head for no. David is able to understand most of what is spoken to him. He is able to read basic sentences and uses email as a means of communication using his adaptive computer program.

After reading this book, John feels he has a better understanding of David. John makes some changes to the meeting. They move to a quiet office space where there are fewer distractions, and this improves David's attention. John asks David for permission for support from the house supervisor to understand David's speech. David nods and is happy for this to occur. David and John, with support from the house supervisor, begin discussing current and future financial options. John checks in with David regularly during the conversation to ensure he understands. John sends an email in plain language to David after the meeting with the key points from their discussion.

***“After reading this book
John feels he has a better
understanding of David.”***

Understanding and identifying cognitive disability

Understanding the person's disability and, in particular, how that disability affects the person, can provide guidance for how to best provide decision-making support. Each person is different and there is rarely a 'one size fits all' approach to decision-making support.

Cognitive disability is associated with limitations to thought-related tasks, many of which have a direct impact on decision-making.

People with a cognitive disability may present with difficulties in the following areas:

- Planning, organising and making decisions
- Problem solving
- Processing information
- Perceiving risk
- Understanding consequences
- Expressing will and preference
- Interpersonal skills
- Language and literacy
- Memory impairments
- Poor attention and concentration
- Reduced speed and flexibility of thought processing²⁰

Not all people who present with cognitive disability will identify themselves as having an intellectual disability or ABI. These people can be missed in the systems and processes. It is therefore important to be able to identify signs of disability in order to ensure that every person who would benefit from decision-making support receives that support. Some of the strategies in this resource may be useful to encourage decision-making support if you suspect cognitive difficulties.

TIPS

People with intellectual disability may struggle with learning and applying knowledge. Abstract concepts such as time and money may need to be explained by connecting them to something meaningful. An example is: "was that before or after dinner?"

Many people with cognitive disability may present with other disabilities, like physical or mental health disabilities. These may have a further impact on their decision-making support requirements. There are many existing fact sheets that provide useful information about various disabilities and their implications (e.g. <http://www.cddh.monash.org/products-resources/fact-sheets.html>).



Improving communication

People with cognitive disability may have difficulty expressing their will and preference.

They may need extra time to understand what is being said before formulating a response so it is important to allow additional time for communication.

TIPS

- When unsure of someone's ability to understand, assume competence and adjust language as required to meet their needs
- Ensure you have the person's attention before speaking
- Speak slowly – This allows more time to process information
- Speak in clear, concise sentences using simple words. Avoid using long complex sentences
- Ask one question at a time
- Use body language, gesture and facial expressions to support verbal communication
- Keep technical words and jargon to a minimum. If these words have to be used, their meaning should be explained using simple language
- Check in with the person to ensure understanding in the person's own words

Augmentative and alternative Communication (AAC)

AAC is an umbrella term that encompasses a range of communication methods used to support, supplement or replace speech.

Aided AAC - is any external item used to aid communication, including:

- Use of visuals, objects and symbols
- Electronic communication devices
- Communication boards
- Communication books
- Speech generating devices
- Key-ring mini-cards

Unaided AAC - refers to communication techniques that do not require the use of an external aid including:

- Facial expression and body language
- Sign language
- Eye contact
- Behaviour

Aided and/or unaided AAC may be used by the person with cognitive disability. A supporter who knows them well may assist with communication by acting as an interpreter, if required.

For more information about AAC, visit http://www.speechpathologyaustralia.org.au/library/2013Factsheets/Factsheet_AAC.pdf.

Understanding the person

It is sometimes difficult for someone unfamiliar with a person with cognitive disability to understand his/her speech or other communication method. This is because the person may communicate in ways you're not used to. Where this is the case, a variety of communication strategies can support understanding.

TIPS

- Provide ample time for the person to formulate and respond to questions that have been asked
- Ask the person if they use any AAC that may help you to understand them. If the person uses AAC, ensure they have access to it during meetings. It's generally much slower than spoken communication and the additional time required should be taken into consideration when interacting with someone who uses an AAC system
- Observe facial expressions and body language for clues about what is being said
- Ask the person to demonstrate how they say yes or no. Having this information allows you to clarify any ambiguities using closed yes/no questions
- If you can not understand what someone is saying:
 - › Ask them to repeat what they have said
 - › Ask them to say it in another way, using different words (you could use tools to support this such as visuals, chat board, drawing etc.)
 - › Ask the person for permission to ask someone familiar with their communication to help interpret the message
- Never pretend to understand if you haven't understood what has been said²¹

“If he doesn't want to get up he will go stiff which says to you: 'I'm not interested in getting up for any reason, just want to stay put', so it is about reading his body language, his facial expressions and gestures.”
(family member)



Ensuring the person understands


The communication challenges faced by people with cognitive disability are not confined to their expression. A person must also be able to understand the information that has been presented if he or she is to make an informed decision.

It is also important to confirm the person has understood what you have said. Keep in mind some people with cognitive disability may have learned to agree with people or nod in a gesture of understanding when in fact they have not understood. This may occur because;

- The person does not understand the question
- The person may not be aware of the type of answer required
- The person may easily forget information that would assist them to answer the question
- The question may be too long or complex for them to understand

Therefore, it is critical to regularly check whether the person has understood the conversation. Inaccurate understanding may lead to a decision being made with a lack of information.

The environment in which meetings and consultations take place should also be considered. Something as simple as how comfortable and at-ease a person feels may mean the difference between failing and succeeding to establish good communication. In some settings, distractions such as noises can detract from exercising choice and planning.²²

 *“Usually people say yes and nod and then you will try and say ‘can you tell me in your own words what I’m saying ...’, just focusing on as best you can simple language and maybe repetition of what you’ve said and searching for clues as to what degree you’re being understood, asking people to repeat things back to you in their own formulation, their own expression.”*
(lawyer)

TIPS

- Ask the person to repeat what has been said in their own words
- Ask the person questions about the issue you have discussed
- If the information has not been understood, re-explain and check understanding again
- Refrain from asking if the person has understood as they will likely say they have regardless
- At the end of any meeting, check they can remember the key points you have discussed and what they need to do before their next meeting with you
- It may be beneficial to write down key points to assist the person to remember what has been discussed

Written information

People with cognitive disability often have difficulty understanding written information, particularly if it is complex. Written information can be made simpler by using plain language or Easy English resources. Plain language resources are materials written in generally accessible language. Easy English goes one step further and typically entails plain language sentences accompanied by pictures, photos, drawings or diagrams to represent words and sentences.



“Some might just need information to make a decision, but others will need information explained maybe through pictures or audio or whatever.” (worker)

Example of Plain English

- At court you will give information about the crime that police think was committed.
- You will be asked questions about what happened and when it happened.
You will be asked questions about who was involved.

Example of Easy English



At the hearing

- You will talk about what happened to you.
- The person who did the crime will talk about what happened.


Source: Victorian Equal Opportunity & Human Rights Commission. (2014). Beyond Doubt – Telling Police about crime. The Victorian Equal Opportunity & Human Rights Commission: Melbourne, Victoria Retrieved from <http://www.humanrightsccommission.vic.gov.au/index.php/our-resources-and-publications/reports/item/894-beyond-doubt-the-experiences-of-people-with-disabilities-reporting-crime>

Several services have expertise in the development of Easy English and plain language documents, as well as other communication materials that you may find useful when working with people with cognitive disability (eg. <http://www.scopevic.org.au/service/accessible-information/>).

Collaboration with supporters

People with cognitive disability may have others in their life who can provide decision-making support. These include family members, other carers, disability support workers, day service workers and advocates. Supporters are people who are known and trusted by the person with cognitive disability and are willing to respect and promote the person's will and preference. Talking to and working with other supporters may expedite the process of getting to know someone and communicating effectively. Connecting to those who provide support to the person beyond the legal environment may compensate for the limited time you may have to get to know the person. By working with and talking to trusted people in the person's life, it is possible to gain knowledge about his or her preferences, history and life story, which provides a good basis for offering meaningful decision-making support.

It is important to note, however, that reaching out to other people in the person's life should occur if the person consents. There may be instances in which people in the person's life either do not support the will and preferences of the person or the person does not want support from particular people.

 *"... If we don't understand fully how to work with someone who uses a particular form of communication, we'll get advice and support from somebody who does before we meet with them and when we meet with them". (lawyer)*

Key strategies to support collaboration

The following are key characteristics of collaboration:

1. **Shared vision** - It is important all supporters have a shared understanding of the purpose of the team coming together and understand their roles
2. **Clear goals** - Goals help to guide discussions to ensure the purpose of coming together is being met
3. **Open communication pathways** - Good communication helps to achieve common understanding
4. **Clear expectations** - Ensure everyone on the team is aware of their roles, what they have to do and when it needs to be completed
5. **Trust** - Trust implies an interpersonal dynamic whereby there is the belief the trusted person will look out for the best interests of another within a specific area

Case study

Collaboration

John asks David about people who have supported his decisions in the past. These include his mother, brother, close friend and house supervisor. With David's permission, John arranges a meeting with key supporters in order to collaborate and work together in supporting decision-making.

Breaking a decision into smaller components

Decision-making processes can be made more accessible by breaking a decision into smaller components. A person may be overwhelmed by a large amount of information at one time, or even by a major decision. As such, it might be necessary to break a decision down into smaller steps. This approach to decision-making may take more time than is typical, however the outcome will better reflect the person's true decision.

Providing people with a clear sense of the consequences and practicalities of a decision may enhance understanding. Ensuring a person understands the possible outcomes of one decision over another is particularly important when it comes to major life decisions, such as housing, healthcare and financial decisions. By breaking a decision down through using tools such as pros and cons lists, the person truly understands what each option involves. Outlining, as clearly as possible, the consequences of one option over another, including both positive and negative outcomes, is essential to good decision-making support.

“Breaking it down ... ‘You understand this, let’s move slowly through this’; not doing it in great chunks. Just doing it slowly over a period of time. It takes a while... ”
(lawyer)



Case study

Steps to breaking down a decision

During the meeting, with the team having a shared vision of the purpose of the group, David is supported to discuss his possible options. David is supported to ensure his views and thoughts are heard and understood. David's mother also had an opportunity to discuss her concerns. John uses diagrams and pictures to support David's understanding and regularly asks him open-ended questions to elicit responses and ensure he has understood.

During this meeting they discuss the options available, including the possible positives and negatives of each of these options.

Through being supported to understand and explore available options, David, with the support of his lawyer, was able to develop a plan which allowed him to expand his skills. This helped create independence and set up a framework for future decision-making support.

“The level of support a person needs to make a decision is not clear cut.”



Dilemmas and tensions in providing decision-making support

There are dilemmas that can arise when supporting someone with cognitive disability to make decisions.

Keeping the focus on the person's will and preferences

It is particularly important to enhance (rather than take over) the decision-making of people with cognitive disability, who have often experienced a lifetime of decisions being made on their behalf. The role of legal practitioners is typically to advise. Advising is different from persuading. Advising means providing recommendations about possible courses of action, whereas persuading is influencing someone to do something through argument. The distinction may not always be clear in all circumstances but nonetheless, it is important to maintain neutral in providing decision-making support at all times. Provided that it's within professional obligations, this includes when people are making decisions that seem wrong or harmful.

“Everybody has the right to make a bad decision, people should be supported to make their own decisions and that they can make the wrong decision, it's their decision, doesn't matter if you disagree with it.” (lawyer)

The level of support a person needs to make a decision is not clear cut. It is sometimes ambiguous, and an informed decision about the person's ability will have to be made based on the information at hand. It should also be noted that guardianship law in Victoria and throughout Australia is being reviewed in light of Australia's obligations under the UNCPRD, legal practitioners, in the meantime, can explore a range of alternatives to guardianship as set out in this booklet.



Being neutral

The notion of remaining impartial - for all clients - is a typical feature of contemporary legal training. However, 'being neutral' is a particularly important principle when providing support to people with cognitive disability to make a decision. Being neutral implies *avoiding* imposing beliefs about what may be in the person's 'best interests' and instead remaining as a more objective source of support for the person's will and preferences. This does not mean withholding advice about what a legal professional believes to be the best course of action. Instead, it means that such advice is offered respectfully, with the view that ultimately it is the person who must make decisions about his or her life.

“... Always having in mind it's *what that person wants, not what I want, or my boss wants, or their mother wants or what a service provider wants.*” (lawyer)

Being neutral may involve becoming aware of, and reflecting on, one's values and opinions as a supporter, and the potential impact of these on the support process. It may be useful to write these reflections down before a meeting with a client to serve as a reminder of any potential personal biases that may affect neutrality.

It is also the case that other people in the person's life - whom it may be useful to collaborate with - may have difficulty providing 'neutral' support. Negotiating these potentially imbalanced relationships is one of the dilemmas and tensions that may arise when supporting the decision-making of people with cognitive disability.


Managing conflicting perspectives among supporters

For people with cognitive disability, decision-making can be fraught where issues of risk are involved. Conflicts may occur between family and other supporters where different views about rights, risk and 'best interests' arise. Where conflicts between supporters escalate, or where there is some ambiguity about balancing different rights in risky situations, advocacy organisations such as the Victorian Office of the Public Advocate might be a useful source of advice and information. Carers and family supporters can also be directed to support services, including Carers Victoria and other family representative organisations.

Conflict may arise when there are differences in opinions between supporters, or between supporters and the person making the decision. Thought should be given to how to resolve conflict, if it arises.



Time and resource constraints


 *“It’s often very challenging because you normally meet the clients in these cases for the first time on a day when you are on the roster ... kids have usually been taken from their parents the night before, often the parent doesn’t know where they have been placed so it is very emotionally charged, they haven’t met you at all, it is busy at court, you’re trying to find a private quiet space and you’re often sitting literally in the hallways of court trying to get instruction, so it’s not ideal.” (lawyer)*

Legal professionals tend to have limited and short-term relationships with clients with cognitive disability. In contrast, family members tend to have long-term, highly involved relationships with a person. The result of having limited time makes it difficult to build relationships of trust and create opportunities to get to know the person being represented. Trusting relationships can be fundamental to good decision-making support. Hence, the legal system itself can create obstacles to being able to achieve decision-making support effectively. Notwithstanding the need for structural change, the strategies outlined in this booklet are meant to provide ways to establish good support within existing structures.

Recognising that disability discrimination is widespread

People with disability in general, and people with cognitive disability in particular, face considerable discrimination.¹⁶ This discrimination occurs at the structural level but also expresses itself at the micro-level in daily interactions throughout a person’s life. The cumulative burden of this discrimination – including a lack of reasonable accommodations – tends to flatten confidence, cause stress and diminish health, which in turn may diminish their ability to make decisions.²³

People with cognitive disability may have reacted to this burden by acting in a compliant, submissive role. They may have missed opportunities to learn decision-making skills because they had the “habitual expectation that others will make decisions for them²³”. It may be necessary, therefore, to challenge this sense of powerlessness by boosting a person’s confidence to make decisions. Many of the strategies already outlined can help achieve this (such as breaking decisions into smaller components, improving communication, and so on).

 *“ ... They’re not used to making those decisions or haven’t been given the choice or the power to make decisions - (even) something simple.” (worker)*

It may also be important to challenge the low expectations many people hold about the decision-making abilities of people with cognitive disability. Legal professionals, as with all others, can benefit from questioning their own assumptions about the capabilities of a person with cognitive disability. Any assumptions about a person’s decision-making skills should be carefully scrutinised to promote decision-making support based on an air of respectful curiosity.

Case study

Final decision:

David decides that:

- He, his friend and brother will act jointly — they will make day to day financial decisions together
- David will get independent financial advice for specific financial decisions involving larger sums of money
- David will develop his skills to manage his own financial affairs as much as possible
- His friend will be made an enduring power of attorney, in the event he loses capacity

“David will develop his skills to manage his own financial affairs as much as possible”

Additional selected resources

Victoria

- Scope Victoria, Types of Communication aids: <http://www.scopevic.org.au/communication-aids/>
- Office of the Public Advocate, Victoria – Publications and forms:
 - › <http://www.publicadvocate.vic.gov.au/our-services/publications-forms>
 - › <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/89-take-control?path=>
- Department of Human Services – Supporting Decision-making: A guide to supporting people with a disability to make their own decisions:
http://www.dhs.vic.gov.au/__data/assets/pdf_file/0011/690680/dsd_cis_supporting_decision_making_0212.pdf
- Centre for Developmental Disability Health Victoria:
<http://www.cddh.monash.org/products-resources/fact-sheets.html>
- Carers Victoria : <http://www.carersvictoria.org.au/>
- Villamanta Disability Rights Legal Service and Mental Health Legal Centre:
http://www.villamanta.org.au/Main.asp?_=Resources

Australia

- The Australian Law Reform Commission. “Equality, Capacity and Disability in Commonwealth Law”:
<https://www.alrc.gov.au/inquiries/legal-barriers-people-disability>
- The Intellectual Disability Rights Service (IDRS): <http://www.idrs.org.au/home/index.php>
- Government of South Australia –Augmentative and Alternative Communication:
https://www.sa.gov.au/__data/assets/pdf_file/0013/17122/augmentative-alternative-communication.pdf

For People with disability

- The A.C.T. Disability, Aged and Carer Advocacy Service (ADACAS) - Support My Decisions - a an online tool to help people make decisions with support: <http://www.support-my-decision.org.au/>
- Advocacy for Inclusion - Supported Decision Making App:
<http://www.advocacyforinclusion.org/index.php/resources/supported-decision-making-app>

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“Often, people with cognitive disability want or need support to make decisions.”



