

Living with Disability

RESEARCH CENTRE

Supporting inclusion of people with cognitive disabilities



Support for Decision Making A Practice Framework

Professor Christine Bigby & Professor Jacinta Douglas

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Contact

Professor Christine Bigby

Director, Living with Disability Research Centre

School of Allied Health, La Trobe University, Bundoora 3086

T 03 9479 1016

E c.bigby@latrobe.edu.au



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Introduction and Aims

The need for good support for decision making has been highlighted through the National Disability Insurance Scheme's (NDIS) emphasis on choice and control and its imperative to generate support plans for all participants. Involvement in decision making enables people to have greater control over their own lives, improving their self-identity, psychological wellbeing and quality of life. The NDIS means that people with cognitive disability will have more opportunities to make decisions about the direction of their lives and the support they receive. A significant challenge is ensuring they have support to enable them to participate in decisions – at the preplanning, planning, implementation stage of their plans and in their day-to-day lives. This means not only understanding the processes of good support for decision making but also recognising the role of decision making supporters and developing their skills.

The right to make decisions about one's own life, particularly big decisions is regulated by the law. People with cognitive disability often have their right to make decisions removed through appointment of a guardian. However article 12 of the United Nations Convention on the Rights of Persons with Disability states that people with disability are equal before the law (acknowledged as having legal capacity and legal standing). The accompanying comment suggests that guardianship laws are contrary to this right. The UN Convention has generated debate about the concept of *supported decision making* and the need for legal reform. In 2014 the Australian Law Reform Commission proposed that **“the will, preferences and rights of persons who may require decision making support must direct decisions that affect their lives”** (ALRC, 2014, para 3).

Enabling people with cognitive disabilities to direct their own decisions will only happen if supporters have high expectations that people can participate in decision making, have strong commitments to making this happen, and have a tool box of strategies ready to be tailored to each individual and each decision. The aim of this *Support for Decision Making Practice Framework* is to lay foundations to guide practice for decision making supporters of people with cognitive disability. The framework is based on research undertaken by the authors, and their colleagues at the Living with Disability Research Centre¹ and our interpretations of the United Nations Convention on the Rights of Persons with Disabilities.

The framework can be used within existing legislation and will guide the work of the decision making facilitators employed by St Vincent de Paul Society NSW (the Society) to implement the pilot support for decision making project at Kanangra. In this project the facilitators have three key roles:

- *Working with families and staff* developing their skills and confidence as decision making supporters;
- *Helping to build a network* of supporters for people with limited family connections, and if necessary;
- *Building relationships with and acting directly* as decision making supporters for the people who have no network beyond the paid staff in the service.

The framework will also be a useful guide to others who provide support for decision making to people with cognitive disabilities, whether formally or informally, as volunteers, family members, support workers, paid decision making facilitators or guardians. It can be used in any of the various models of delivering support for decision making that are currently being piloted in Australia, and inform thinking about the practice of decision making supports for NDIS participants with cognitive disabilities.

Current Legal Context

Currently the right to make decisions is based on a person's mental capacity (decision making skills). Often, when there are doubts about mental capacity (because of difficulties understanding implications of decisions), legal capacity is overridden informally (by others such as family or staff making decisions for a person) or removed formally through guardianship (the appointment of a substitute decision maker). When this happens, those who make decisions for a person with cognitive disability are guided by an understanding of the person's preferences but also consideration of their 'best interests'. This reflects the idea of 'beneficence' where supporters' judgments

¹ Set out in the reference list

about what is good for a person with disability take precedence over their preferences. While this may not always be the case in the practice of Guardians it is the legal framework in which they work.

Examples²

Jane lives alone. When her mother died she stayed in her family home and continued to enjoy going out to the local shops, saying hello to the many people she knew, as well as cooking for herself. Her intellectual disability means she finds it difficult to manage money or plan ahead and sometimes does not see the importance of household routines. Despite a list of reminders and regular help from a support worker, the condition of her house and garden began to deteriorate. When the neighbours complained to her sister and the support worker refused to visit because of the hazards in the house, Jane's sister applied and became her guardian. Jane was keen to stay at home, but her sister decided she would be better off living somewhere else where other people could take care of her and she wouldn't have to worry about domestic tasks.

Edward loves to sit on the verandah of his new home and visits a local gym. His eyes light up when he sees the people he knows from his years in the institution who now live nearby. His friend Ellie visits once every 2 months, but she lives in a regional town so he doesn't see her around in his locality.

Edward and Ellie both have severe intellectual disability and neither use words to communicate. They used to live in an institution where everyone knew they enjoyed each other's company. This connection was visible from their changed demeanour when they were together. When plans were made to close the institution neither Edward nor Ellie understood much about the proposed move, and the government department responsible for the closure asked their families to make decisions for them. Edward's sister thought it would be a good idea for him to live in the all-male household that was set up in the suburb close to the institution. Ellie's sister thought it would be better for Ellie to live in the regional town where she herself lives.

Key concepts in the current legal framework are assessment of mental capacity, informal or formal substitute decision making that can override or remove a person's legal capacity on the grounds of mental capacity, and decisions made on behalf of a person in their best interests. Mental and legal capacity are conflated, and problems with mental capacity can lead to removal of legal capacity.

New Paradigm of Supported Decision Making

By contrast the new paradigm of *supported decision making* starts from the premise that everyone has the right to participate in decision making. It draws on a support paradigm whereby provision of sufficient and effective support is seen to compensate for difficulties with decision making. People with cognitive disabilities are enabled to participate in all decisions, through changed expectations of others, development of their skills and experience, provision of support to express their will and preferences and, at times, through the interpretation of their will and preferences. In supported decision making the person with cognitive disability is at the centre of their own decision making:

- support is made available to enable the person to participate in decision making.
- support is tailored to the person and their situation.
- support varies in type and intensity depending on the type of decision.
- supporters enable the person to exercise choice and control based on the person's will and preference (not perceived best interests).
- in the purist form a person's legal capacity is not questioned because by definition it cannot be removed.

² Through the framework we illustrate issues and points using examples from our research which are composites of people with varying levels of intellectual disability. When first mentioned, the person is described in brief; the description is not repeated when the person is mentioned in later examples.

Legal frameworks for *supported decision making* give legal standing to supporters to act together with the person to make decisions. Such frameworks include structures or schemes that set out the responsibilities of supporters, recognise their legal standing and give others the right to challenge their actions. If a person cannot express their will and preference or it cannot be ascertained through knowledge of the person, supporters are empowered to make an interpretation of their will and preference that takes account of rights.

Supported decision making is a new paradigm – a new way of thinking about how people with cognitive disability are regarded by the law and supported to make decisions. It requires new legal structures to replace or add alternatives to guardianship. These might be concepts such as micro boards, shared decision making or representation agreements found in Canada which has led the way in *supported decision making* law reform.

The core concepts of supported decision making are a shift from a best interests model of support and substitute decision making to a model of support based on enhancing a person's skills and experience to make decisions, express their will and preference and the acknowledgement that part of the supporter's role may be to interpret the individual's will and preference.

Support for Decision Making

Australia is moving towards law reform about *supported decision making* as many of its elements are not reflected in current legal frameworks. For example, there is only very limited legal recognition of decision making supporters. Concepts such as shared decision making or representation do not have legal standing, and many people continue to have guardians as substitute decision makers who are bound to act in their 'best interests' in accordance with existing legislation or supporters who act as informal substitute decision makers.

Legal reform in Australia is pending. Some elements of *supported decision making* have to wait for law reform, but others do not. We refer to *supported decision making* as something that requires a new legal framework and *support for decision making* as something that can begin within existing frameworks.

Many of the ideas within *supported decision making* are not new and much support for decision making happens informally without formal sanction of legal frameworks. The importance of supporting people with cognitive disabilities to exercise choice and control is recognised as central to the practice of disability support workers (e.g. person centered active support) and individual planning (e.g. person centered planning). Many families provide support for day-to-day decision making as a matter of course and often in collaborative relationships with support services.

Examples

Jane's support worker talked to her about the idea of moving when she realised how difficult it was for her to maintain her parent's big house on her own. Jane made it clear she was happy where she was. When the worker contacted her supervisor and Jane's sister they realised Jane had never lived anywhere else and had little sense of the other options she might have. They began to take Jane to inspections of some of the new apartments that were being built in her neighbourhood and to visit some of the people she knew from her drama group who lived in group homes or shared units. They supported Jane to stay for weekends at a small respite house, at one of her friends units and on her own in an apartment owned by the service, and began to talk about where she might be able to afford to live if she sold her parents' house. After about 12 months, Jane rented out her parent's house and began renting a flat round the corner in a small block with on call support. Three years later she and her sister decided things were going so well that Jane would sell their parents' house and buy an apartment in the same block where she had been renting.

Ellie's support worker gets out three differently coloured shirts, two are the colours Ellie usually prefers and one is a colour she doesn't usually wear. The support worker watches Ellie's expression as he holds up each in turn, and makes a judgement that she would prefer to wear the new colour today.

Participation by People with Cognitive Disabilities in Decision Making with Support

Recognising and sorting decisions

Living life means making decisions about many things. Decisions can be described in different ways – the scope, who is involved, constraining influences, time frame and consequences or outcomes. Very simply they can be sorted by scope into bigger and smaller decisions. Smaller decisions are usually day-to-day ones about things such as personal care, engagement with others or in activities. They occur in specific contexts, such as home, and may require immediate and sometimes frequent support from a small number of supporters in the immediate vicinity.

Examples

The support worker takes Edward's hand and places it on the knife. She puts her hand over his and starts to guide it over the bread spreading the peanut butter. Edward pulls his hand away. A few minutes later when the support worker takes his hand again he leaves his hand there for a short while and smiles.

Jane sees the bus coming and turns towards the support worker and says, "is this the one that goes into the city?" The support worker says "yes", and as Jane gets on the worker prompts her to get out her bus pass.

Bigger decisions are about more enduring things in a person's life, ranging from the décor of their home to where they live or what supports they receive. They are made over a longer time frame, and may occur at the interface between a number of systems or settings and involve multiple supporters. Bigger decisions often set parameters for smaller ones, making or curtailing other opportunities.

Example

Ellie has been experiencing some pain in her mouth as her wisdom teeth had come through crooked and were slowly decaying. She hated visiting the dentist but when she did it was clear she needed a lot of work to be done. The dentist advised her support staff that the best option would be to go to hospital for a few days and having all her teeth out which would save a lot of money and pain in the long run. Ellie together with her sister and support staff sought a second opinion and after several months decided together not to take this advice. Instead they have made a plan for Ellie to find a new dentist and have the necessary work done slowly over the next 12 months.

In many situations smaller decisions are the building blocks for bigger decisions, building a person's experience and confidence in decision making. Smaller decisions can also help to frame the options considered in bigger decisions.

Decisions are like Babushka (nesting) dolls embedded in each other. Bigger decisions open up opportunities for lots of other smaller decisions. They are also cumulative, decisions made in one part of a person's life will have implications in other parts, and often set parameters for smaller decisions by either making or curtailing other opportunities for decision making.

Example

When Jane decides to go to the cinema she must also decide when to go, which cinema to go to, what to see, who to go with and whether to go out for lunch beforehand.

When Edward moved to his new home, although his sister decided where it would be, there were many other decisions he could participate in such as, the colour to paint his bedroom and the living room, the type of furniture and how to arrange it, whether to have curtains or blinds and what colour they should be, and who would get the room with the door out to the garden.

Participation and support needs change with every decision

How a person participates in decision making and the support they need varies with every decision. Participation is influenced by the nature of the decision. Participation is also influenced by the person's skills, their experience of the issues bound up in the decision and the expectations of others. Support to participate in decision making must therefore be tailored to both the individual and the decision. People need different support for different decisions. The same person may participate at different times in making self-generated decisions, shared decisions and substitute decisions. Figure 1 gives a schematic overview of the ways people participate in decision making with support. At different times and depending on the decision, a person may participate in all of these ways. In this way of thinking about decision making support, some decisions will be self-generated and many decisions will be shared.

Self-generated Decisions

Supporters provide information and experience that enables the person to act on their own behalf based on their will, preferences and rights and taking account of resource constraints and consequences.

Shared Decisions

Supporters provide information and experience that enables the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences.

Substitute Decisions

Supporters provide information and experience and enable the person to express their will and preferences and if necessary interpret these, and assist in taking account of resource constraints and consequences.

Supporters moderate a person's will, preferences and rights if there are likely to be harmful consequences and the person does not have the ability to appreciate these.

Figure 1. Participation in Decision Making with Support

Participation in self-generated decisions with support

Sometimes a person will generate their own decision with support. For these **self-generated** decisions supporters provide opportunities for the person to access and understand information about the decision, possible constraints and consequences or widen their experiences of what might be possible. For some people and in some situations, decisions will become self-generating as their skills and experience develop.

Examples

When Jane is in the supermarket with her sister, they look at all the different brands of tea, and talk about how much more expensive the brand that Jane buys is. Her sister explains if Jane buys a cheaper brand she could afford to buy more fruit. Jane decides to buy the brand of tea she prefers even though it is more expensive than others.

The support worker lays out a pair of shorts and a skirt on Ellie's bed, and Ellie decides to put on the skirt.

The support worker helps Jane to go on the internet and view the trailers for each of the films at the cinema this week. They talk about each one and the worker supports Jane to click on the right boxes to make a booking for the one she has chosen.

Participation in shared decisions with support

In some instances decisions will be **shared** and made jointly by the person and their supporters. In these types of decision, like self-generating ones, supporters provide opportunities for the person to access and understand information or widen their experiences of what might be possible. They will also work with the person to enable them to understand the decision or some parts of it, and to express their preferences. For some people, supporters may have to interpret with others from their observations and knowledge of the person what their preferences might be. In **shared decisions** the supporter also helps the person to identify and weigh up constraints and consequences that they may not fully understand, such as availability of resources or time frames involved. The supporter works with the person to balance constraints, consequences and preferences and together they will make a decision based as best as possible on preferences.

Example

Some funds were available to support Edward to make some more social connections with people in his local community. As he had little experience of the many different activities he might participate in each week his support worker brought pictures of different activities where people did things together, such as a painting group, a yoga class, a drama group, a bike club, and the senior citizens having lunch in the RSL club. They visited some of the groups and places, and took pictures of Edward at each place. At each place the support worker observed Edwards reactions and how other people had responded to Edward, and compiled more detailed information about the costs and regularity of each group. Each week they reviewed the pictures and photos until after six months, having weighed all the different places, costs, observations of Edward and other people at the various places, they decided that Edward would enrol in the drama group for a term.

The shift to shared decision making driven by preferences rather than best interests is fundamental to a new paradigm and effective support for decision making.

Participation in substitute or informal substitute decision making with support

In yet other instances a supporter may make a substitute decision for a person. Many of the strategies used in shared decision making will also be applicable to **substitute decision making**. Similarly, supporters provide opportunities for the person to access and understand information or widen their experiences of what might be possible, work with the person to enable them to understand the decision or some parts of it, and to express their preferences, or interpret their preferences based on overall knowledge and observations of the person. Supporters will also be involved in weighing up resources or other constraints on the decision. The difference from shared decision making is that supporters take a more directive stance and may moderate a person's preferences if acting on these is likely to result in seriously harmful consequences that the person does not fully appreciate. If this is the case, preferences continue to guide a decision but are moderated to reach a less harmful decision. When supporters weigh up options to find a safer alternative they are guided by rights and finding a least restrictive alternative. They might ask for example, whether a decision would undermine rights such as respect for a person's dignity, their liberty and security, independent living, liberty of movement, and which of these is most important to the person.

Examples

When the support worker realised the car had not taken notice of the stop sign and Jane was about to step off the pavement to get onto the tram he touched her arm and said stop.

Jane's sister was concerned when she realised that Jane's savings were sharply reducing and she had signed various agreements committing her to purchasing services offered by telephone and door to door sales people, as well as making donations to lots of different charities who had fund raising campaigns. When they talked about it Jane didn't see this as a problem, saying she still had enough money for food and the people who rang her up or came to her door were nice to talk to. Her sister decided to seek an administration order so they could find a way to manage Jane's money more carefully and protect Jane from being exploited. They set up direct debits for some bills, an account for everyday use with a budgeted monthly amount, and agreed to put all her other money in an account that could only be accessed jointly by Jane and her sister. Jane and her sister agreed that Jane would always check with her before signing contracts to buy items or regularly donate money.

People participate in shared and substitute decisions through their presence and expression of preferences or through the ascertainment or interpretation of their preferences by supporters. A person's preferences would only be overridden where they cannot be realised without harm to themselves or others or breaching the law and the person does not fully understand these consequences of their preferences.

The Process of Support for Decision Making

In the following sections we set out the process of support for decision making that can be applied by supporters of people with cognitive disabilities within current legal frameworks in Australia. There are three elements:

- Steps in support for decision making;
- Principles of support for decision making;
- Strategies for practice.

Figure 2 is a schematic representation of the process of support for decision making. The real world is less ordered, for example, though separated here the steps are iterative and often occur simultaneously – principles are firmly embedded in strategies for practice.

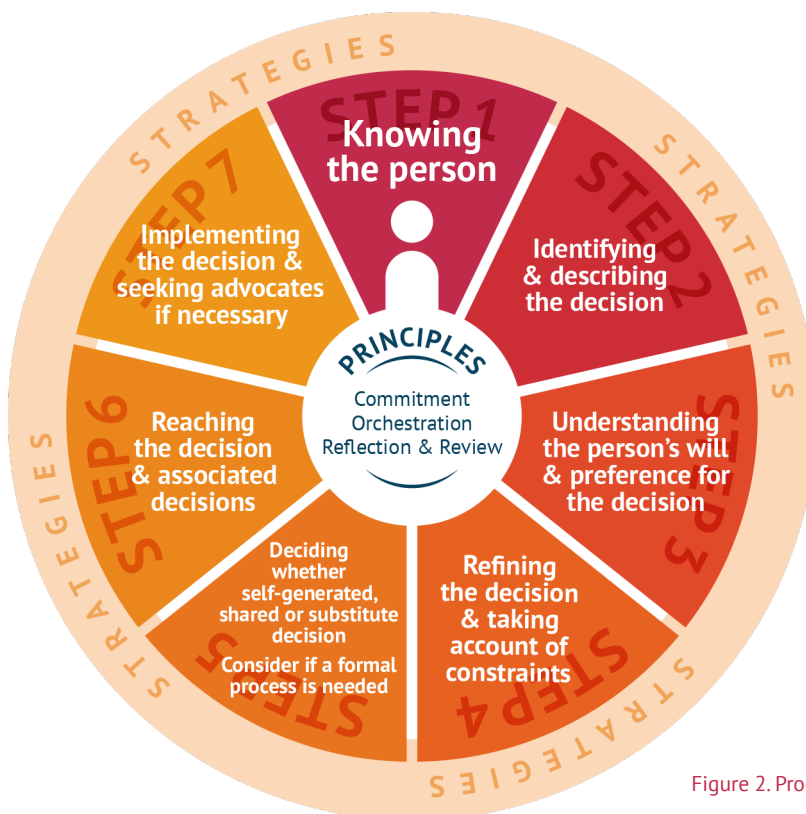


Figure 2. Process of support for decision making

The following sections outline each of the three elements of the process. These are considered in more detail in the accompanying training materials that has been piloted at Kanangra.

Steps in Support for Decision Making

Support for decision making has seven steps shown below in Figure 3.



Figure 3. Steps in support for decision making



Step 1. Knowing the person

Support for decision making is person centred. As Figure 4 illustrates supporters need to 'know' the person well. This means knowing all aspects of the person and having a sense of the person's self-identity or self- concept (*Who I am and how I feel about myself*). This usually encompasses knowing about – their attributes and style – personal characteristics – likes, dislikes, preferences - skills, the effect on their understanding of their specific cognitive impairments – social connections - history and personal story. Part of knowing a person also means understanding the way they are seen by others in their network including the various 'experts' who have been involved in their life. Knowledge of what defines the person provides the conceptual context for understanding their will and preference.



Figure 4. Knowing the person



Step 2. Identifying and describing the decision.

It is important to identify and describe the decision that is to be made, Figure 5. The nature of the primary decision such as where to live may be clear. However, describing the decision helps to see its features in full: its scope (how much will it impact on a person's life and the other decisions that might flow from it); who should be involved in helping the person to make the decision or the formal organisations that may be involved (such as the criminal justice system or health system); the constraining factors that will help shape

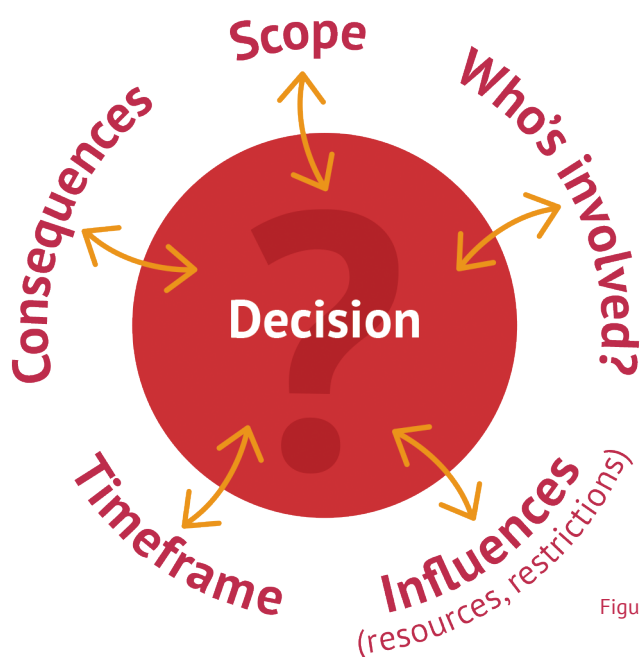


Figure 5. Describing the decision

the decision, or may be taken for granted and that may need to be challenged by supporters; the time frame to make the decision, and; the potential consequences of choosing one option over another. Describing a decision helps to focus attention on the core issues and helps to guide who to involve or who has the necessary knowledge. For bigger decisions it will also identify tensions that might arise, constraining factors that if tackled early might be amenable to change and the potential flow on effects of this decision to other parts of a person's life that will have to be considered.



Step 3. Understanding a person's will and preferences about the decision

This is a 'blue sky' step in the process of decision making support. The person and their supporters think as widely as possible about the decision, all the possible options that need to be explored, the person's preferences about all the things that will be encompassed in the decision, and consequences of different options. Everyone has preferences. They stem from experiences, knowledge and available information, personal values or cultural norms. They are communicated in many ways – through words, signs, gestures, expressions, behaviour, actions or lack thereof. For some people preferences have to be interpreted by supporters based on their knowledge of the person, or garnered from the perspectives of others who know the person well or in a different context. At times there may be apparent conflict between immediate and longer term preferences that have to be weighed up. These are described by Jane Tracy (2015) who talks about her son's longer term preference for independence but his dislike of the medical treatment that might support his independence.

In this step preferences and options considered should not be constrained by parameters imposed by things such as resources or risks. This step in bigger decisions could be seen as similar to the dreaming or aspirational elements of some approaches to person centered planning but more focused on a specific decision.

Example

Where to live in the future. Ellie found it hard to conceptualise living somewhere else and had no experience to draw on. Those who knew her well described some of her preferences that they thought would be important in making the decision - she doesn't like being around lots of other people, she likes walking, she hates cars, she likes being with Edward now and again.



Step 4. Refining the decision and taking account of constraints

Nevertheless a decision is more than a dream or hopeful statement in a plan. It must be implementable. In this step preferences are prioritised, refined and shaped by constraints such as time, money, impact on other people, and safety. Ways are found to ensure the decision will be implemented, and potential constraints might be questioned or creatively managed.

Examples

Jane's decision about where to live if she sold the family home was shaped by how much she could sell the house for, the price of smaller apartments in her local area, and the amount of money she wanted to put aside to make sure she could afford a holiday every year and the maintenance on her new home. She cannot afford the newer apartments she likes unless she finds someone to share with her, but if she bought an older unit she could afford to live alone.

Ellie's decision about where she would live was shaped by her lack of money to purchase her own house and reliance on social housing. Luckily there was more social housing on the fringes of the city where she lived where there are more walking tracks. The cost of visiting old friends living in the inner city was one of the issues considered in deciding to move to the outer suburbs.



Step 5. Deciding whether a self-generated, shared or substitute decision is to be made

This step distils the knowledge gained in earlier steps about the decision, preferences, priorities, constraints and consequences. Based on the knowledge accumulated it will be clearer whether the combination of this specific decision and the person's own skills means they can be supported to make a self-generating decision or a shared decision, which may resemble an informal substitute decision, or, whether due to the anticipated harm to themselves or others they need support for a more formal process of making a substitute decision. If there is conflict about reaching a shared decision then at this stage it may be appropriate to seek a more formal decision making process such as an application for a guardian. If a person already has a guardian in place, then at this stage the decision making supporter should reach out to the guardian providing them with all the relevant information so they are in the best possible position to make a decision that reflects the person's will and preference.

Example

Jane and her sister decided together to buy an older unit in the area where Jane had always lived which would mean Jane could live on her own.



Step 6. Reaching the decision and associated decisions

At this step, the decision is made to reflect prioritised preferences as closely as possible. The many consequential decisions that will flow from a major decision will become clearer. In supporting each of these smaller decisions the support for decision making cycle loops back to step 1 and is repeated. At this step, depending on the decision, it may be formally recorded and communicated to others involved in the person's life, in a formal or informal capacity who will support its implementation.

Example

Having decided to sell the family home and buy an older unit, Jane must decide how much money to invest on making the house look less run down so she can get the maximum price, and how to go about finding a unit to buy.



Step 7. Implementing a decision and seeking out advocates if necessary

It is at this point that decision making often falters as the tasks, the power, or resources necessary to implement the decision may be beyond the scope of the supporters involved in earlier stages of the decision. Importantly, implementation may not rest with decision making supporters but with the NDIS, a case manager or service provider. At this stage, decision making supporters may seek out advocates to support implementation of the decision or others in a person's circle may shift into an advocacy role to make sure the decision is followed through. The processes of support do not stop here; as the person being supported is likely to be involved in making consequential decisions for which support might be needed and other unrelated decisions as their life unfolds. Having an advocate or a case manager to help implement a decision may not negate the need for continuing support with decision making.

Example

Jane will need access to expert advice and intensive support to make all the arrangements to sell the house and buy a new unit. She will also need help to navigate the legal contracts to ensure the new unit is put in her name.

Principles of Support for Decision Making

As indicated earlier in this document the values embedded in the United Nations Convention on the Rights of Persons with Disabilities underpin support for decision making. In addition, three principles inform all support for decision making, as illustrated in Figure 6.



Figure 6: Principles of support for decision making

1. Commitment

Effective support for decision making is contingent on the relationship between the person and their supporters. This means that first and foremost, supporters must have a relationship with the person and a commitment to upholding their rights. The relationship does not have to be 'excellent' or 'perfect' but it has to be underpinned by unconditional regard for the person as a human being of equal value and a holder of rights. With equality and rights as foundational beliefs, supporters are more likely to have positive expectations about the person's participation in decision making and to respect their opinions and preferences rather than subordinating them to others in the decision making space (e.g., family members, staff, experts).

Effective support relationships are characterised by trust, genuine positive regard and honest interpersonal interactions. Knowing a person is dynamic and ever changing, a supporter must be committed to continually learning about the person's changing self, often in terms of skills, preferences and circumstances.

2. Orchestration

Support for decision making is a shared task, involving a range of people from different parts of a person's life. Importantly too it will involve people who know the person in different ways, such as a friend, a sister, and perhaps more instrumentally as a client who requires intensive and costly support with everyday activities. Supporters may include immediate or extended family, direct support workers, managerial staff, and subject matter experts. A primary supporter leads and orchestrates support, drawing in other supporters, both formal and informal from various parts of the person's life, as well as mediating any differences. If such a lead person is not evident then, for some decisions, it will be necessary to find someone willing to take on that role.

3. Reflection and Review

Supporters can, consciously or unconsciously, exercise enormous influence on people with cognitive disabilities during the process of supporting decision making. Continuous reflection by supporters on their own values, their own stake in the decision and potential to influence the person they are supporting will help ensure the decision making agenda remains based on the will, preference and rights of the person they are supporting.

Reflexivity, which is *self-awareness and continuous reflection*, helps supporters to adopt a *neutral non-judgmental stance* that puts aside their own preferences and assumes a neutral view on the costs and benefits of risk taking.

These principles mean that supporters must employ a self-questioning strategy, applying *self-checks and balances* to each decision situation. Also, they must identify points in the process of support where they are particularly vulnerable to providing biased, value-laden, or constrained support. The principles of reflective practice help also to identify occasions when unchallenged implicit assumptions and worldviews are at play.

Support for decision making should be transparent and accountable, which means supporters must be both self-reflective about their support and open to review by others. Supporters should be able to articulate their reasoning processes and describe the observations, experience and knowledge they have used to inform their support and track this through to the point of decision.

Strategies for Practice

Strategies are needed for each step of support for decision making and for putting the principles into practice. As illustrated in Figure 1, very broadly strategies can be seen as providing access to information and or opportunities to widen experiences of what might be possible; enabling, ascertaining or interpreting a person's preferences and helping to understand constraints and consequences. But supporters need a wide repertoire of more nuanced strategies that can be tailored to the person they support and the decision at hand. Strategies must be person centred and will depend on timing and situational factors, the significance, scope and nature of the decision, and who else might be involved in or affected by the decision.

Here, in Figure 7, we categorise and illustrate the range of strategies that have been identified from research.

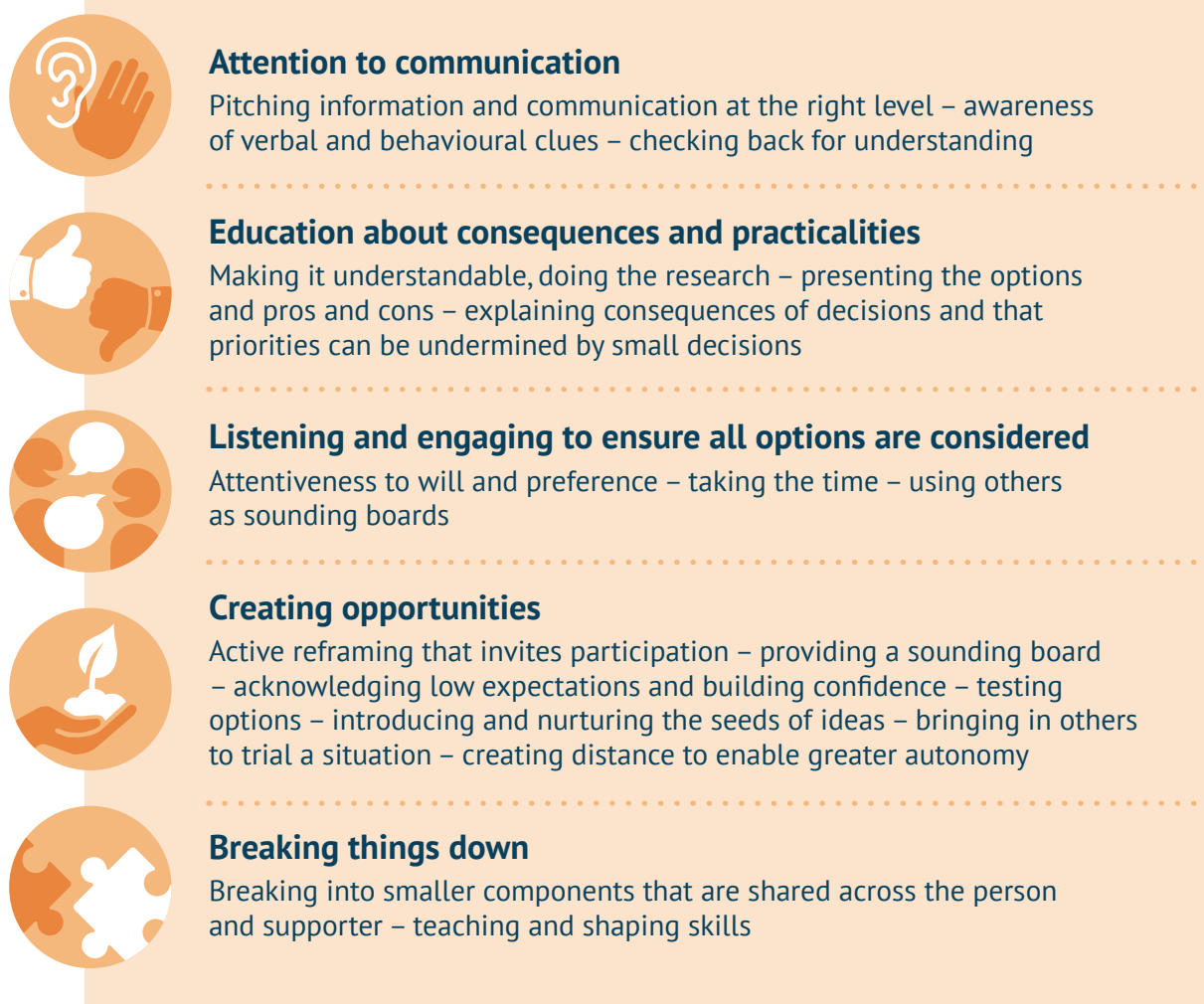


Figure 7: Strategies in support for decision making

Safeguards and Accountability of Support for Decision Making Supporters

Support for decision making rests on the commitment of supporters to furthering the rights of the person to participate in decision making and to being directed by their will and preferences. A high level of trust and responsibility is vested in supporters.

This framework for support has embedded safeguards. In summary these are:

- **Continual process of review and reflection** by supporters – requiring supporters to reflect on whether their support is driven by a supported decision making paradigm based on commitment, knowledge of the person and respect for will, preference and rights, or whether it is sliding into the old paradigm, driven by 'best interest' perspectives.
- **Accountability** – requiring supporters to be able to explain how they come to know claims about the person's preferences, the rationale for their support and give evidence about how they provide any support that lies behind shared or substitute decisions made with a person.

- **Orchestration** – requiring supporters to act in concert with others and not alone. This should mean supporters work as part of an orchestration of support with others who know the person well and are involved in their lives.
- **Person centred strategies** – requiring supporters to tailor support strategies to the person and the decision.
- **Rights and least restrictive alternatives** – requiring the values of the United Nations Convention to underpin all support for decision making, that supporters promote human rights and if they are involved in formal or informal substitute decisions that curtail rights, they do so in the least restrictive way possible.

Training Modules and Materials

Training for facilitators and supporters within this framework uses a case-based, interactive approach. Elements are identified and exemplified through the experiences of both supporters and those who they support. Training is ideally delivered through small face-to face groups but is designed to be appropriate for individual and/or distance web-based delivery with minimal modification.

Interactive, case-based methods have been adopted because these methods support deep learning and the development of critical reasoning skills, and promote motivation and enthusiasm. The cases can be presented in a variety of formats (e.g., printed or video) and serve as the stimulus for acquiring the basic knowledge needed to understand support for decision making. They also serve as the focus for developing self-awareness and reflective practice skills.

The training program includes a series of resources which act as a toolkit to provide guidance to facilitators and supporters. These resources provide systematic guides to support for decision making across the elements of the framework and are designed for broad application.

That is, they can be applied equally to provision of support for person's with high or low support needs, making small or large decisions, in differing environments (e.g., institution, family home), across varying systems (e.g., NDIS, Health) and legal jurisdictions. The resources within the toolkit take various forms to support practice and include flow charts, templates, tip sheets, checklists, practice summaries (e.g., signs and pitfalls) and practice recommendations.

The training modules designed for family members, direct care staff, appointed guardians and decision making facilitators will further exemplify support for decision making practice. Piloting and evaluating the framework at Kanangra Centre, whose residents and their families reflect one microcosm of people with cognitive disabilities, will enable it to be refined to apply more widely to other NDIS participants.