



Introduction to Decision-Making Supports and Supported Decision-Making



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Welcome!

This resource is an introduction to the ways that persons with a disability can be supported to have autonomy and the supports that they may require to make decisions. It also reviews how laws have removed people's rights to make decisions and how new laws (built on the concept of supported decision-making) are creating opportunities to enhance rights, dignity, and personal autonomy.

The goal of this resource is the following:

- To enhance understanding about the important link between personal autonomy and well-being for people with a disability.
- To provide an awareness of some of the historical approaches to decision-making for adults who face challenges making decisions independently.
- To explore and understand the change in thinking about human rights in the context of decision-making and of ideas relating to personal abilities to make decisions.
- To enhance learning and understanding about the practical aspects of providing supports for decision-making and considerations for providing effective support.
- To enhance learning and understanding about the legal aspects of supported decision-making and key differences between substitute decision-making and supported decision-making.

If you still have questions or wish to continue learning more about this topic, visit the **Additional Resources** page at the end of the document to explore additional learning opportunities.

Personal autonomy and self determination:

Why making decisions for ourselves is essential to our sense of well-being

The link between personal autonomy and wellness

Personal autonomy is the ability to make our own choices that are based on and driven by our own values and intentions. Autonomy is considered to be a significant aspect of well-being. Research has shown that autonomy increases our sense of well-being, which includes life satisfaction and happiness. Autonomy supports our individuality in various situations. It is considered to be an important part of shaping the psychological well-being of youth and young adults.

Autonomy and people with intellectual or cognitive disabilities

Similarly, personal autonomy plays an important role in the well-being of people with intellectual or cognitive disabilities. Studies have shown that having a higher level of personal autonomy (especially when supported by family and others) is linked to people with an intellectual disability having a better quality of life (QoL). Autonomy has a positive impact on the overall sense of well-being for people with intellectual or cognitive disabilities.

Autonomy and its link to personal well-being are also important to people with intellectual or cognitive disabilities who have more significant support needs. For some people, personal autonomy is highly connected to people having trusting personal relationships, with “support, advocacy and enablement” being some of the key requirements for autonomy to flourish. For some, autonomy is seen to be “relational” in nature. Relational autonomy means that relationships are “crucial for developing autonomy” and that autonomy is not just based on a person’s own ability for self-determination.



Decision-making can also have social and relational aspects:

Examples of supportive structures are family and friends, as well as emotional and financial support. Advocacy refers to the importance of interpretation and translation of meaning, as well as making space for the expression of the agent. This is of fundamental importance in the lives of those who cannot express themselves with words. It is very important that their specific interests be represented and their full humanity recognized.

People with cognitive or intellectual disabilities can and do face a number of challenges in achieving personal autonomy.

These challenges relate to:

Historical lack of autonomy and negative attitudes

Many people have been denied the opportunity to make their own decisions. In many ways, people with disabilities have historically been “under-estimated and over-controlled”, and the overall perception of people’s abilities has been limiting. While the law presumes adults to have decision-making capacity, the opposite has often been presumed of people with various types of disabilities.

Limited opportunities

The denial of opportunity has meant that many people have not had real-life opportunities to make decisions in many aspects of life: home, within community, at school, etc. This has deprived people with valuable life experiences, including experiences that help people to develop decision-making skills as they move from childhood into adulthood. Providing opportunities to make decisions across various environments is crucial for the development of self-determination and autonomy.

Communication challenges and their impact

A person who experiences challenges with using words to communicate may be seen by others to lack skills related to personal autonomy. This is becoming less of an issue as communication and assistive technologies improve. Yet, a person’s ability to express their intentions and choices can create barriers to their opportunity to make decisions.

Lack of personal relationships

When people need others in their life to support their autonomy, the lack of close relationships can increase barriers. In the context of “relational” autonomy, the role of supporters can be of significant importance. Supporters who have knowledge of the person can assist with communication, provide various types of assistance with decisions-making, advocate on behalf of the person, and help to interpret a person’s intentions, wishes, preferences, and choices. The absence of this support can have a serious impact on the exercise of autonomy.

Dependence on systems and services

People with intellectual, cognitive, or other disabilities have an increased dependence on formal social systems and paid services. The way these systems operate can have a positive or negative impact on personal autonomy. Systems can significantly interfere with a person’s decisions related to housing and living situations, education and employment opportunities, personal relationships, financial freedoms, etc.

Laws and their impact

Over time, laws have created significant challenges for people with a disability in the exercise of personal autonomy. This will be more fully explored in the next section.

History of legal approaches to decision-making for adults

Decision-making rights have a long history in Canada and elsewhere. Within the common law system (law based on court decisions and legal precedents over time), adults are presumed to have capacity to make decisions unless proven otherwise. For many people with intellectual or cognitive disabilities, the presumption of capacity (or competence) around decision-making has been subject to laws and practices that have removed rights to make decisions in a number of ways.

The basis for the removal of a person's decision-making rights has been perceived lack of decision-making skills.

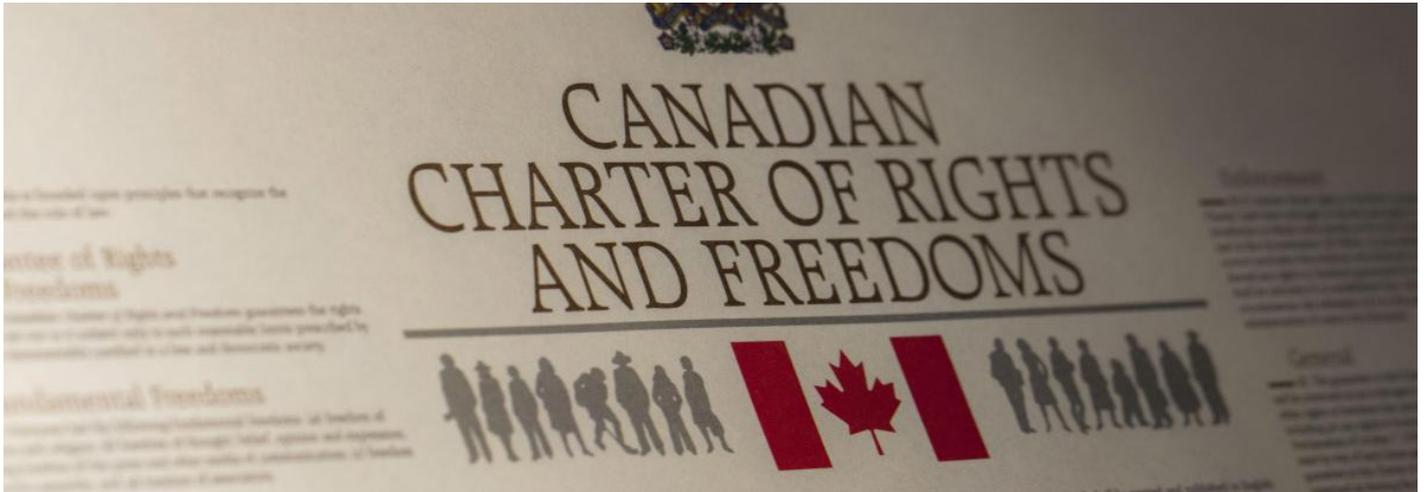
Historically, there have been a few ways in which a person's decision-making rights have been removed:

- 1 The "status" approach**
Under this approach, a diagnosis of a disability has been used to override the presumption of capacity in order to appoint a substitute decision-maker.
- 2 The "outcome" or "protection" approach**
Under this approach, a person makes decisions that are considered to have negative consequences (or is likely to do so) and requires care and supervision in order to protect their well-being or their property.
- 3 The "functional" approach**
Whereby a person is deemed to lack sufficient decision-making skills such that a substitute is required. This approach can be time- specific or issue-specific and reviews a person's ability to make decisions independently. A key aspect of this approach is the "understand and appreciate" test whereby a person is determined to have capacity to make decisions if they understand the information that is relevant to a specific decision and appreciate the reasonably foreseeable consequences of the decision.

The outcome of these approaches is that a person's right to make decisions is linked with their perceived ability or lack of ability to do so. In this respect, having a lack of ability has often meant that decision-making rights are not respected (and often removed). From a human rights perspective this is discriminatory as it does not consider support that people may need to properly exercise their autonomy.

Evolution of human rights and decision-making

Canadian Charter of Rights and Freedoms



Canadian law has been shaped significantly since the introduction of the *Charter of Rights and Freedoms* in 1982. Laws must generally conform with the Charter.

In the context of adult decision-making, section 7 of the Charter provides protection for “life, liberty, and security of the person”. Laws can only limit liberty rights when they do not violate “principles of fundamental justice”. This means that laws cannot be arbitrary or have an impact that is too broad or limiting on a person’s rights.

Section 15 of the *Charter of Rights and Freedoms* is about equality rights. It states that all people are equal before and under the law and have the right to equal protection and benefit of the law. It prohibits laws from being discriminatory on the grounds of “mental and physical disability”.

The *Charter of Rights and Freedoms* has led both governments and courts to review laws that limit a person’s rights to make their own decisions. Provincial and territorial governments in Canada have responsibility for decision-making laws. They have slowly been making changes to laws to better protect people’s rights to make their own decisions. For example, New Brunswick’s new *Supported Decision-Making and Representation Act* (proclaimed in 2024) states that the purpose of the law is to:

... protect and promote the autonomy and dignity of persons who require support in relation to decision-making in accordance with the principle that persons should receive the support they need to make or to participate in decisions about their lives to the greatest extent possible.

Supported decision-making laws will be reviewed in section 8 of this resource.

UN Convention on the Rights of Persons with Disabilities (exercise of legal capacity)

The UNCRPD has significantly changed the way we look at people's rights to make and participate in decisions about their lives. Article 12 of the UNCRPD is about people with disabilities having "equal recognition before the law".

The Article states three important things about "equal recognition":

- People with disabilities have the right to recognition everywhere as persons before the law.
- People enjoy "legal capacity" on an equal basis with others in all aspects of life.
- Countries that ratify the Convention (such as Canada did in 2010) are obliged to provide access to people with disabilities "to the support they may require in exercising their legal capacity".

What does all this mean?

Having equal recognition as persons before the law is a basic but fundamental human right. When people don't have equal recognition as persons, many bad things can happen. Throughout history, some people have been treated as less human and worthy – for people with a disability this led to forced institutionalization, sterilization without consent, and wide-spread segregation. This right to equal recognition as persons was simply not respected. "Legal capacity" is an important part of someone having equal recognition before the law. To "enjoy" legal capacity on an equal basis means that people are able to do things and make decisions and choices that are respected under the law.

The UN Committee on the Rights of Persons with Disabilities has noted:

The denial of legal capacity to persons with disabilities has, in many cases, led to their being deprived of many fundamental rights, including the right to vote, the right to marry and found a family, reproductive rights, parental rights, the right to give consent for intimate relationships and medical treatment, and the right to liberty."

(Committee on the Rights of Persons with Disabilities, CRPD/C/GC/1 para 8).

Evolution in thinking regarding decision-making capacity & autonomy

With the increased focus on personal rights to autonomy and self-determination, there has been a shift in thinking about the concept of decision-making capacity.

This change has led to a greater understanding of how people make decisions, including the role that relationships and decision-making supports play in our lives. We have moved from a presumption (in law) that people have decision-making capacity, to understanding that decision-making for some people requires different forms of assistance and support. In this case the question becomes: how do we “enable and support people to guide their own lives, make their own decisions, and challenge others who would diminish or remove their autonomy?”

This does not mean that people should not or cannot make decisions independently and without the involvement of other people. It does mean, however, that autonomy rights for some people will depend on the availability of proper decision-making supports.

The nature of the support required will depend on a person’s own needs and circumstances. People with more significant disabilities may have a higher degree of reliance on the involvement of other people throughout the decision-making process.

There is a growing recognition that many people make decisions interdependently.

In this context, the language of “will and preferences” or “wishes and preferences” are increasing important terms the area of decision-making capacity:

Will refers to a longer term and more enduring sense of what I am trying to achieve in my life. For example, my will might be to be more independent from my parents (and so my preference is to move out of home into a unit). Understanding a person’s will helps to understand why they have particular preferences.

In some circumstances, support for decision-making capacity will involve the role of supporters in helping someone express their “will and preferences” or “wishes and preferences” (or providing their “best interpretation” of a person’s will/wishes and preferences).

This type of decision-making support relies heavily on people having trusting relationships with others who know them well. Assisting someone to express their will and preferences should involve a deep understanding of the person and how they communicate their choices and decisions.

Pathways to providing supports with decision-making

There are many ways that people can provide support with decision-making to individuals who may have difficulties making some or all of their decisions on their own. It is important to remember that providing supports for decision-making is not necessarily the same thing as formal and legally recognized supported decision-making arrangements (discussed in the next section). Many people with a disability “can act legally independently with one-time support, like communication assistance, planning support or independent advocacy”. A more formal legal arrangement may not be required, nor should it be forced upon someone where informal supports can adequately assist a person with making decisions.

Here are a few ways in which decision-making supports can be provided:

Accommodations

These are things that other people do to assist someone make a decision. The law says that people in various situations have a “duty to accommodate” individuals who have a disability. In this case, this responsibility to support is on other people who are involved in a decision-making process.

For example

A doctor who is providing medical services can help people with decision-making by adjusting the way they provide information to help their patient better understand what is happening. They can use plain language, visual aids, communication devices, or an interpreter to explain a treatment or procedure that they are recommending. These accommodations can support someone in making an informed choice about their medical care.

The same processes can happen in other situations such as financial institutions, government service providers, landlords, etc. The difficulty with accommodations arises when third parties don’t take the time or effort to make accommodations or simply are not aware of what accommodations are (along with their duty to make these accommodations).

This often requires education and advocacy to build better understanding and expectations about accommodations for people with a disability. Sometimes people just don’t know. People with a disability and their allies are often put into situations where they have to educate others about basic accommodations that can be made to support people make decisions and enter into legal arrangements.



Planning support

At times, people are unsure about what they want to do. They may lack some life experiences that can help guide them with making decisions or they may need the help of others to guide them with making decisions. Planning support is often a useful tool to help get people better prepared to make decisions. It often involves exploring the person's own vision for the future, different options based on their wishes and preferences, and setting a direction for future actions. This can involve many things such as deciding where to live, getting a job, saving money, having relationships, and so on. Planning can help set people up for making decisions or entering into legal arrangements down the road.

To be most useful, planning support needs to be “person-centred” and “person-directed”. This means that the person is fully at the centre of the planning and chooses who they want to help them plan, identifies their own goals and priorities, and sets out the actions and steps that will be taken to put the plan into effect. The role of others is to provide information and perspectives about goals based on what they know about the person. Planning support should never involve undue influence, coercion, or other people inserting their own beliefs about what the person should do or decide.

Assistance with understanding relevant information and decision consequences

Decisions can often involve information that is at times complex or difficult to understand for many people. This can be particularly true with information about legal arrangements or decisions that have legal consequences. Yet, people can receive and understand information in different ways.

Helping with understanding information and decision consequences can involve a number of strategies:

- Putting information in language that a person can better (or best) understand. This usually involves using simpler words to express something relevant to a decision (called “plain language”). Sometimes, this can also involve breaking down the decision subject into smaller pieces to allow people to better process information a bit at a time.
- Helping people consider options relevant to a specific decision. This can be helpful if someone does not have a lot of experience with a specific type of decision. Options can provide a roadmap for people to think about what they want to do. This can also assist with helping people better understand different consequences of a decision.
- Using visual aids to support words or in place of words. Some people are visual learners and can be greatly assisted if they can see what is being considered. This can be as simple as using photographs or sketches that depict information that is relevant. Sometimes, short videos can also be useful as can providing someone with opportunities to physically see or experience things for themselves.
- Giving people time to consider information. Some people are not ready to decide in the time others would like. This is okay unless there is a valid reason to have a decision made quickly. Providing extra time and revisiting things later can allow people to decide when they feel ready and more comfortable with the information provided.

Communication assistance and support

Communication assistance can take many forms and will depend on the unique ways that a person communicates their intentions, wishes, preferences, and choices. Some communication relies on having other people understand a person's speech (if they use words), sounds, facial expressions, and body language. When people are well known by other trusted people they can communicate their choices and decisions because someone else knows their communication style.

This is sometimes referred to as **Augmentative and Alternative Communication (AAC)** which is defined as:

... all of the ways that someone communicates besides talking. People of all ages can use AAC if they have trouble with speech or language skills. Augmentative means to add to someone's speech. Alternative means to be used instead of speech. Some people use AAC throughout their life. Others may use AAC only for a short time, like when they have surgery and can't talk. There are a lot of different types of AAC.

No-tech and low-tech options include things like:

- gestures and facial expressions,
- writing,
- drawing,
- spelling words by pointing to letters, and
- pointing to photos, pictures, or written words.

Increasingly, assistive communication technologies are supporting people to communicate their intentions and decisions. Various phone or tablet applications can be used along with computer technologies that provide a "voice" through a speech-generating device.

Understanding and expressing a person's will/wishes, intentions, and preferences

As noted earlier, this level of support requires in-depth knowledge of a person on the part of others who are typically in a relationship of trust with them.

This in-depth knowledge stems from knowing:

- what the person likes/dislikes;
- what they have experienced in the past (both positive and negative);
- what situations work best for the person or what should be avoided;
- how they communicate their intentions and preferences (especially if they do not use words or only a few words); and
- what intentions, wishes, and preferences the person is expressing or has previously expressed.

This support can involve some level of interpretation on the part of supporters given their personal knowledge of the person. In some cases, supporters will give their "best interpretation" of the person's intentions and preferences. Support also involves expressing these intentions and preferences to other people in order to communicate the person's choices and decisions.

Meet Wanda

Wanda is an autistic person who doesn't communicate with words. She can point to pictures of things she wants, and she can shake her head to say no. Wanda uses support to make her decisions. Wanda needs to hire a support person. Her sister helps her find four different people who want the job.

Wanda and her sister spend time hanging out with each support person. Her sister asks them questions about things that are important to Wanda, and writes down their answers. After each person leaves, her sister asks Wanda if she liked the person. Wanda chooses a picture that shows how she feels.

After all four people have visited, Wanda and her sister sit down. Wanda's sister shows her pictures of each person. She reminds Wanda how Wanda felt about each person. She reminds Wanda how each person answered important questions.

Then, Wanda picks the picture of the person she wants to work with. Wanda's sister calls that person to tell them that Wanda decided to hire them.



Some considerations for providing supports for decision-making and ways of strengthening personal autonomy

The various ways to support people to have choices and make decisions are not always simple or straight-forward. In fact, there are many difficulties or 'dilemmas' that can arise when assisting someone to make decisions and choices.

The following information is drawn largely from the work of Dr. Michael Kendrick who has spent many years teaching on topics relevant to improving the ways that individuals and organizations can support people with a disability to have a good inclusive life in the community.

Providing effective decision-making supports can involve considerations about:

- As a supporter, guarding against imposing your own values and preferences on the person being supported
- Understanding that there may be a 'learning curve' for people about decision-making (and therefore the need to work with people patiently as they develop skills in this area)
- Helping people understand the difference between preferences and priorities and wants and needs (especially in the context of spending money)
- Being aware of the suggestibility of the person being supported, and ensuring that people can have or develop their own will and sense of self
- Understanding that providing choice without good support can be neglectful
- Where necessary, helping people understand that there are responsibilities that may stem from many decisions (e.g., if I rent an apartment I have to pay my rent)
- Understanding that some choices and decisions may be more complex and require a longer-term investment by people and their supporters (such as choosing a new place to live)
- Having choices does not mean that a person can do anything they want and there may be limitations that have to be considered and addressed
- Supporting people in the context of their life circumstances and personal experiences (such as lack of experience, anxieties, lack of information, capacities around making good judgements, impulsivities, etc.)
- Being aware of the things that will strengthen someone's autonomy and sense of confidence in their ability to make decisions.
- Providing opportunities and good guidance for people without replacing them in the decision-making process.

Supported decision-making and the law

In Canada and other parts of the world, supported decision-making is increasingly being recognized in laws. There are **two main ways** that laws will recognize formal supported decision-making arrangements:

Most often, these laws provide ways for people to make supported decision-making agreements or to otherwise appoint their own supporters. For the most part, people who make agreements or appoint supporters are required to meet a test of capacity to have a valid supported decision-making arrangement.

This usually means that people are required to understand information relevant to the agreement/appointment and appreciate the reasonably foreseeable consequences of the legal arrangement. This requirement will make it difficult for some people with more significant disabilities to enter into a supported decision-making arrangement. These laws set out the circumstances under which supported decision-making can operate.

For example

A supporter may be permitted by law to help gather information on behalf of another person and to assist the person to communicate their decision. The decisions made are seen to be those of the person being supported and are valid decisions under the law.

A second and less common way to have a legally valid supported decision-making arrangement is through an interdependent decision-making process.

This involves a potential decision-making supporter applying to a court or administrative body to be appointed a supporter through an order. These types of arrangements have been developed in recent years in a number of jurisdictions such as New Brunswick in Canada (where a court can make an order appointing a decision-making supporter), Mexico, Columbia, Peru, Romania, and the Czech Republic.

By design, the role of a decision-making supporter in these situations is meant to assist people who experience more significant intellectual or cognitive challenges with decision-making. People who will typically benefit from this type of arrangement are those that will not meet the test of capacity for making their own decision-making agreement or authorization.

These individuals may often have more challenges with communication and rely on others to understand, interpret, and communicate their will/wishes and preferences. This interpretive and communication support means that people make decisions through an interdependent decision-making process that involves a meaningful relationship between the supported person and a supporter. There may be significant reliance on the decision-making supporter to lead the decision-making process and provide a variety of types of assistance.

In this situation, the decision-making capacity is still relevant to various decisions, but capacity is addressed through the relationship that exists between a person and their supporter. This recognizes that a person's right to autonomy is exercised through their relationship with other trusted people in their lives.

Advanced supported decision-making laws recognize the role of these supporters and validates decisions that are made through a supported process. This means that other people and organizations (such as financial institutions and health care providers) can rely on these decisions as those of the person being supported.

Another feature that shows up in laws is the “less intrusive” or “less restrictive” measures principle (sometimes called the “alternative course of action” principle).

This usually applies when there are court applications for the appointment of a substitute decision-maker, co-decision maker, or (as in the case of New Brunswick's new Act), a decision-making supporter. The essence of this feature is to limit the impact on a person's right to make their own decisions. A court is obliged to ensure that the measure or action that has the least impact on a person's rights is chosen, so long as the person's needs are appropriately met.

Under supported decision-making arrangements, supporters generally have duties and obligations to follow.

These can include:

- Act diligently, honestly, and in good faith;
- Adhere to all applicable legislation and any court or tribunal orders;
- Adhere to any relevant agreements or authorizations (legal documents that create a support arrangement)
- Keep information about the adult person and their affairs confidential;
- Keep records in relation to all aspects of their role; and,
- Involve supportive family members and friends.

Understanding differences between substitute and supported decision-making

There are some key differences between traditional substitute decision-making and supported decision-making.

Substitute decision-making for adults is characterized by the following features:

It is a legally recognized arrangement or situation that involves someone making decisions on behalf of another person who is either deemed not able to make decisions for themselves or who has legal status to make decisions in other circumstances (such as a temporary Power of Attorney for property or finances).

In most places, the main current legal avenues are Powers of Attorney (which are granted by the person in a legal document) and court orders under substitute decision laws (for the appointment of a substitute decision-maker, guardian, committee, etc.). These legal avenues can be used to make both financial or personal/health care decisions for others. Other laws that permit substitute decision-making are mental health laws and adult protection laws (where they exist).

Traditionally, a substitute decision-maker is required to make decisions that are deemed to be in the person's best interests. Increasingly, laws are requiring that substitute decision-makers make decisions that align with the person's wishes and preferences where these are known or expressed. Where the person's wishes and preferences are unknown or are believed to be potentially harmful, the traditional "best interest" requirement is used.

A substitute decision-maker may not always know the person's specific wishes, values, or preferences (e.g., a Public Trustee or Public Guardian).

By contrast, supported decision-making involves the following features:

- People are supported to make their own decisions through the help of people known to them (and who they likely trust).
- They are legally recognized arrangements where certain people are designated or recognized as decision-making assistants/supporters.
- In many circumstances, people choose and appoint someone to provide support.
- Supporters help the person understand information related to a decision and the potential consequences of the decision.
- Supporters do not make decisions on behalf of the person.
- A person's will (or wishes) and preferences are at the centre of all decisions that concern them.
- In some circumstances, decisions are made through an interdependent decision-making process.

Additional Resources & Information

Inclusion NB/Inclusive Communities Institute Resources

- Plain Language Guide on Decision-Making Assistant Authorizations in New Brunswick: coming soon
- The *Supported Decision-Making and Representation Act* – A Course for the Legal Profession in New Brunswick.
- The *Supported Decision-Making and Representation Act* – A Course for the Individuals and Families.

Web Resources

- Open Future Learning – series of videos and modules on supported decision-making (requires sign-in and payment of fee): [Open Future Learning](#)
- Inclusion Australia: The 5 Steps of Supported Decision-Making – series of fact sheets and videos: [The 5 Steps of Supported Decision Making – Inclusion Australia](#)
- IRIS Institute: My Life My Decisions Course: [My Life My Decisions – Course Overview – IRIS Institute](#)
- IRIS Institute: Reports and analysis on the right to legal capacity - [Resources – IRIS Institute](#)
- The La Trobe Support for Decision-Making Practice Framework Learning Resource. La Trobe University, Living with Disability Research Centre- [The La Trobe Support for Decision Making Practice Framework Learning Resource - ABOUT \(supportfordecisionmakingresource.com.au\)](#)

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