How I make decisions about my life

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This book belongs to:

ADVOCACY   KNOWLEDGE   COMMUNITY
DEVELOPMENTAL DISABILITY *wa*

This booklet is for supporters or a support network to collect information about how a person can get the support they need to make decisions.

Each person needs different types of support for different decisions.

It is advised to seek additional training and resources to have a good understanding of the principles and strategies to be a Support Person for an individual to make their own decisions.
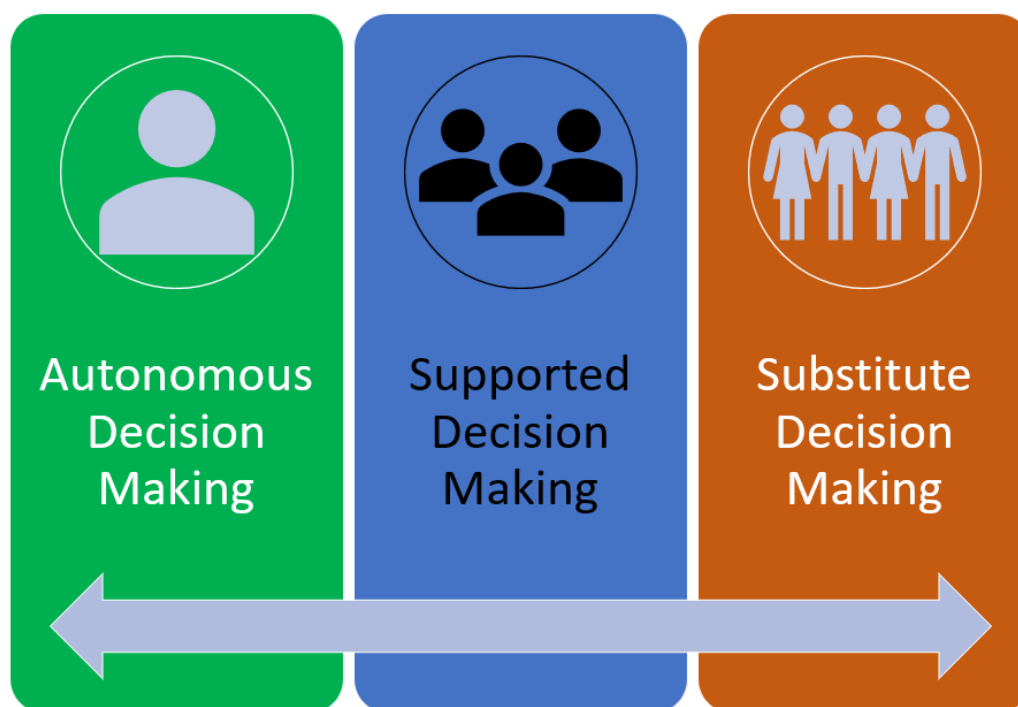
Supported Decision Making

People make decisions every day. Making decisions helps us:

- feel control in our lives
- shape our sense of identity
- improve our quality of life

Decision Making can be viewed as a continuum[8]:

- **Autonomous**: A person makes the decision themselves. They may still ask for advice from others and do their own research.
- **Supported**: A person gets the right support to make a decision.
- **Substitute:** Other people make the decision on behalf of a person. This should be a last resort[10,16].

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Supported Decision Making is a person-centred process, where a person receives the support they need to make a decision. It can be informal or formally organised.

Supported Decision Making Spectrum

Support for Decision Making is for all people.

The question is not: "Can people with disability be supported to make decisions?"
But… "How can we support people with disability to be involved in making decisions?"

Gorman (unpublished) designed a framework which sees Supported Decision Making as a spectrum or continuum. This framework aims to be inclusive of all people with a disability to be involved in Supported Decision Making. It maps the different stages in which supporters can engage the person. This way of seeing decision making helps to give supporters a framework to continue to build all people's decision making capacity.

People may be at different points on the Supported Decision Making spectrum for different decisions. It is a not a rigid framework, more of a guide and a way to give supporters a spectrum of how they can engage individuals to be a part of the Decision Making process. This framework can be used with people with varying skills, experience, and types of disability.

The aim is not for supporters and individuals to reach skills at the three different levels of the framework, but more to see how skills can be built within the level/s a support network can identify as a reasonable expectation of Supported Decision Making.

The Supported Decision Making Spectrum is described in this diagram:

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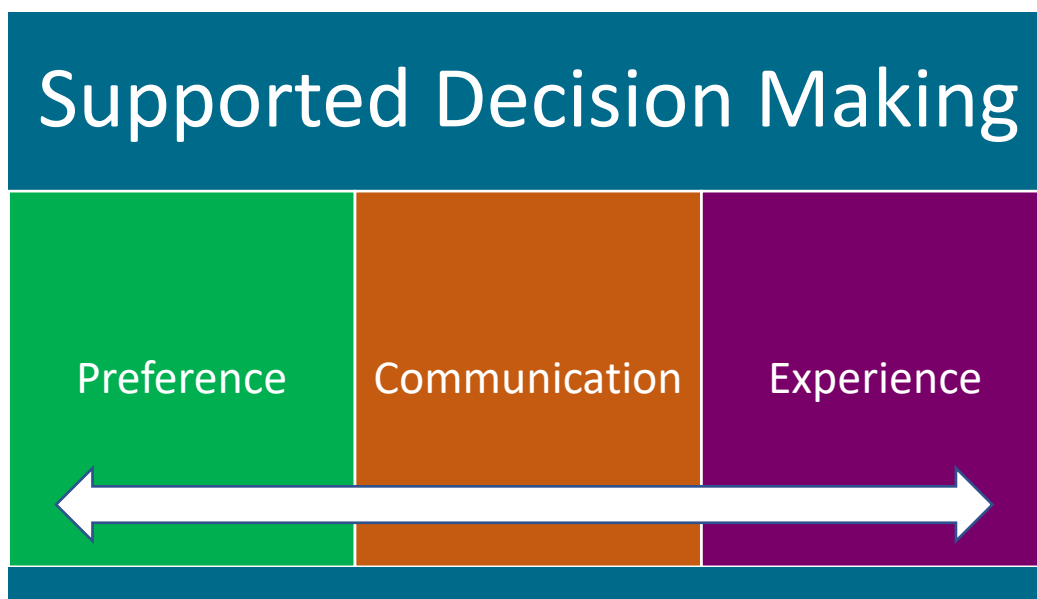
The stages of the framework are:

- ✓ Preference – Supported Decision Making may be relatively new for some people and they may not have had experience to make many decisions about their life. This can result in limited opportunities to be a part of and make decisions[7]. Some people may communicate using facial expression, body language, eye gaze, movement, physiological reactions, vocalisation or sign. Supporters may need to interpret a person's communication and develop an understanding of how a person is communicating their preferences[11,16]. This stage focuses on supporter/s recognising and interpreting communication into choices, and those choices into decisions[4]. It also recognises the need to collect information about how a person expresses their preferences and increase the person's opportunities to make decisions.

- ✓ Communication – This may be for a person who has some experience making decisions, and where supporters are more confident in understanding how the person communicates. The person may have experienced making decisions. Supporters may already have some strategies and tools which support the person to make decisions.

- ✓ Experience – A person may have had regular opportunities to make decisions about their life. People at this stage may use their past experiences and have specific supporters they wish to support them with a decision. Different strategies and techniques may support this person to weigh up pros, cons, and possible outcomes of decisions.

Why is Supported Decision Making important?

- All people have the right to make decisions about their life. Decision Making is a human right underpinned from the United Nations Convention of the Rights of Persons with Disabilities (Article 12, 2006)[9,14].
- The National Disability Insurance Scheme (NDIS) promotes choice and control for all participants[12].
- It can improve quality of life[13].
- It allows people to express their identify[13].
- It builds new skills[1].
- Supported Decision Making can reduce the need for substitute Decision Making[1,16].

Who can be involved? What is the Role of the Support Person?

A support person can be a family member, friend, support worker, health professional, coordinator, team leader – anyone who knows the person well!

They need to have certain characteristics:

The Right Support Person:

- ✓ Assumes the person has capacity to decide and be involved in the Decision Making process.
- ✓ Believes in the individual to make decisions about their own life[5,16].
- ✓ Supports the decision and does not use their own bias or opinion to sway the decision[5].
- ✓ Understands how the person communicates – they may need to interpret communication[5,11,16].
- ✓ Understands or is aware of the person's life history, characteristics and preferences[17].
- ✓ Provides individualised Decision Making support to the person[3,18].
- ✓ Listens to and supports the person to implement the decision.
- ✓ Is aware of safeguards to prevent abuse and undue influence[4].
- ✓ Has availability to support the person.
- ✓ Does not have a conflict of interest if they are in a paid role.
- ✓ Is the right person considering the significance or consequences of the decision.

Safeguarding

We want people to be safe and protected from abuse and inappropriate influences throughout any supported Decision Making process. We want to minimise risk, but not necessarily avoid it altogether. This can be termed 'dignity of risk'.

We all have the opportunity to make mistakes in our lives, and it is often mistakes which help us to learn to make better decisions.

In fact, risk taking is considered an essential part of learning how to make decisions. If we disagree with a person's decision, 'duty of care' is not always a justifiable reason to withdraw support for decision making or to stop engaging in the process completely. In this case, supporters can help the person to think about the risks and see if there are ways to minimise or avoid them. Every situation is different, but if it turns out that a person's physical or mental well-being is at significant risk as the result of a decision, then safeguarding measures will usually need to be taken. If supporters are very concerned about the risks of a decision being made, then delaying the decision and seeking some further advice may be necessary.

The Decision Making Process

The Decision Making process can guide supporters with the steps and stages to think about when providing Decision Making support.

Capacity of the person is assumed, unless proven otherwise, and capacity is decision specific[15].

What is the decision

Who should be involved

How does information need to be presented

What is the information- pros, cons & possible consequences

How will the decision be communicated

Implement decision

Reflect & review

How I make decisions

Preferences – Communication includes preferences, and these can be built into expressions of choice, and these into decisions[4].

How are preferences communicated?

Some people may talk to you about their preferences, and others may use other forms of communication such as body language, eye pointing, gestures, sign, facial expression, vocalisations, communication books or communication devices.

Understanding how someone expresses their preferences is very important when supporting that person to make decisions.

How do we know when something is enjoyed or liked?
(e.g. high-pitched sound, laughing, clapping hands, moving around.)
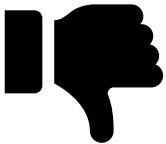
How do we know when something is disliked?
(e.g. ignore, look away, leaves the room)

How do we know when the person is unsure or confused? (e.g. quiet, looks at you, leaves the room)

Factors which can help Supported Decision Making

The people involved – the person may feel more comfortable with particular people in their life. Supporter bias needs careful consideration, (e.g. sibling, parent, support worker, friend)

Environment/ place/ what has happened that day? Has the routine been changed? This can influence a person's ability to focus and take in information. e.g. time of day, change of routine, late to an event which caused distress, worked with new person, missing out on event)

Which current tools support communication? (e.g. photos, videos, symbols, communication books/devices, objects, online information, booklets, pamphlets)

What helps the individual understand information?
(e.g. attending a venue/location, seeing videos, repeated information, opportunities to talk it through with different people)

What helps expression?
(e.g. photos, videos, symbols, communication books/devices, objects, online information, booklets, pamphlets)

Time (time of day, any time pressures) – length of time the person requires usually (this may differ for different decisions e.g. day to day vs. activity & lifestyle decisions)

Other tools to facilitate the Decision Making process? For example:

- Rating scales (e.g. hate it, don't like it, it's ok, like it, love it)
- Readers, information booklets & plain language information[3]
- Social story
- Talking Mat®
- Written options (keeping in mind how many choices can be presented at one time?)
- Communication tools (choice cards, communication boards, communication book or communication device)
- Making sure that words which make sense to the person are used and that language makes is accessible

Examples of decisions

This section is to provide some examples of decisions, as well as the strategies used by supporters to assist the person to make their decision.

SUMMARY SHEET – How I make decisions

How I communicate my preferences	Factors to help me with making decisions
When I like something, I will:	People:
	Place (and other factors about the day):
When I don't like something, I will:	Things which help me communicate:
When I am unsure or confused I will:	It helps me understand when you:
	It helps me express what I want to say when you:

Other tools:

Other important information you need to know:

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RECORDING SHEET – Decisions

Decision	
Date	
Who was involved?	
Decision category	☐ Food or drink ☐ Movement or position ☐ Seeing or interacting with a person ☐ Do something ☐ Go somewhere ☐ Buy or get something ☐ Plan something ☐ Other
How was information about the decision presented?	☐ Verbally, talked about it ☐ Individual used body (e.g. moved to a place) ☐ Used communication book or device ☐ Used gestures and environmental cues ☐ Vocalisations ☐ Signs (Key word, AUSLAN) ☐ Other visuals e.g. photos ☐ Other (please explain)
Pros, cons & outcomes discussed	☐ Yes ☐ Partially ☐ No

How did the person communication their decision?	☐ Body language or gesture (e.g. nod head) ☐ Decision Making board (yes, maybe, no, I don't know, need more time etc.) ☐ Communication book or device ☐ Signs (Key word, AUSLAN) ☐ environmental cues ☐ Other (please explain)
Decision carried through or implemented?	☐ Yes, straight away ☐ No, but a date is planned and has been added to a calendar or visual schedule or planner ☐ No, but it is planned as a task for somebody in the team ☐ No, and no plan made
Comments	

Gorman, A. (2020). *Individualised supported Decision Making booklet*. Developmental Disability WA. https://ddwa.org.au/resources/

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References

1. ACT Disability, Aged and Carer Advocacy Service. (2013). Spectrums of Support, A Report on a project Exploring Supported Decision Making for People with Disability in the ACT. Canberra: ADACAS. http://www.adacas.org.au/media/1083/spectrums-of-support-final-20130911.pdf

2. ALRC. (2014). *Equality, Capacity and Disability in Commonwealth Laws: Final Report.* Sydney. Australian Law Reform Commission.

3. Bach, M. & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity*. Law Commission of Ontario.

4. Beamer, S., & Brookes, M. (2001). *Making decisions: Best practice and new ideas for supporting people with high support needs to make decisions*. Values into Action.

5. Bigby, C. & Douglas, J. (2020). Supported Decision Making. In R.J. Stancliffe, M. Wehmeyer, K. Shogren, B. H. Abery (Eds.), *Choice, preference, and disability. Promoting self-determination across the lifespan (pp. 45-66).* Springer. https://doi.org/10.1007/978-3-030-35683-5_3

6. Carney, T., & Beaupert, F. (2013) Public and private Bricolage – Challenges balancing law, services and civil society in advancing CRPD supporting Decision Making. *UNSW Law Journal*, 175, 175-201.

7. Chartres, D., & Brayley, J. (2010). *Office of the Public Advocate South Australia: Submission to the productivity commission inquiry into disability care and support*. Office of the Public Advocate.

8. Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O.Clift-Matthews, V. & Martin, A. (2015). Supported Decision Making: A review of the international literature. *International Journal of Law and Psychiatry*. 29,61-67.

9. Department of Foreign Affairs and Trade. (2008). *Convention on the rights of persons with disabilities* (Australian Treaty Series Number: [2008] ATS 12). Government of Australia. https://www.info.dfat.gov.au/Info/Treaties/treaties.nsf/AllDocIDs/636560118784755BCA25726C0007D2AC

10. Kohn, N., Blumenhal, J. & Campbell, A. (2012). *Supported Decision Making: A Viable Alternative to Guardianship*. Penn State Law Review. 117:4

11. Johnson, Hilary, Watson, Jo, Iacono, Teresa, Bloomberg, Karen and West, Denise 2012, Assessing communication in people with severe-profound disabilities: co-constructing competence*, Journal of clinical practice in speech-language pathology*, *14,* (2), 64-68.

12. *National Disability Insurance Scheme Act 2013* (Cth). https://www.legislation.gov.au/Details/C2013A00020

13. Nota, L., Ferrari, L. Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research, 51*, 850-865. http://doi.org/10.1111/j.1365-2788.2006.00939.x

14. United Nations (2006). *Convention on the Rights of Persons with Disabilities.* United Nations. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html

15. *Mental Capacity Act*. (2005). https://www.legislation.gov.uk/ukpga/2005/9/contents

16. Watson, J. (2016). Assumptions of Decision Making capacity: The role supporter attitudes play in the realisation of article 12 for people with severe or profound intellectual disability, *Laws*, *5*(6), 6. https://doi.org/10.3390/laws5010006

17. Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life Decision Making: Case studies of relational closeness in supported Decision Making for people with severe or profound disability. *Journal of Applied Research in Intellectual Disabil*ity, 30,1022-1034. https://doi.org/10.1111/jar.12393

18. Webb, P., Davidson, G., Edge, R., Falls, D., Keenan, F., Kelly, B., . . . Shea Irvine, R. (2020). Service users' experiences and views of support for Decision Making. *Health & Social Care in the Community, 28*(4), 1282-1291. https://onlinelibrary.wiley.com/doi/abs/10.1111/hsc.12961. doi:10.1111/hsc.12961