Supported decision-making
What is it and how can we do more of it?

Dr Craig Sinclair, UNSW School of Psychology

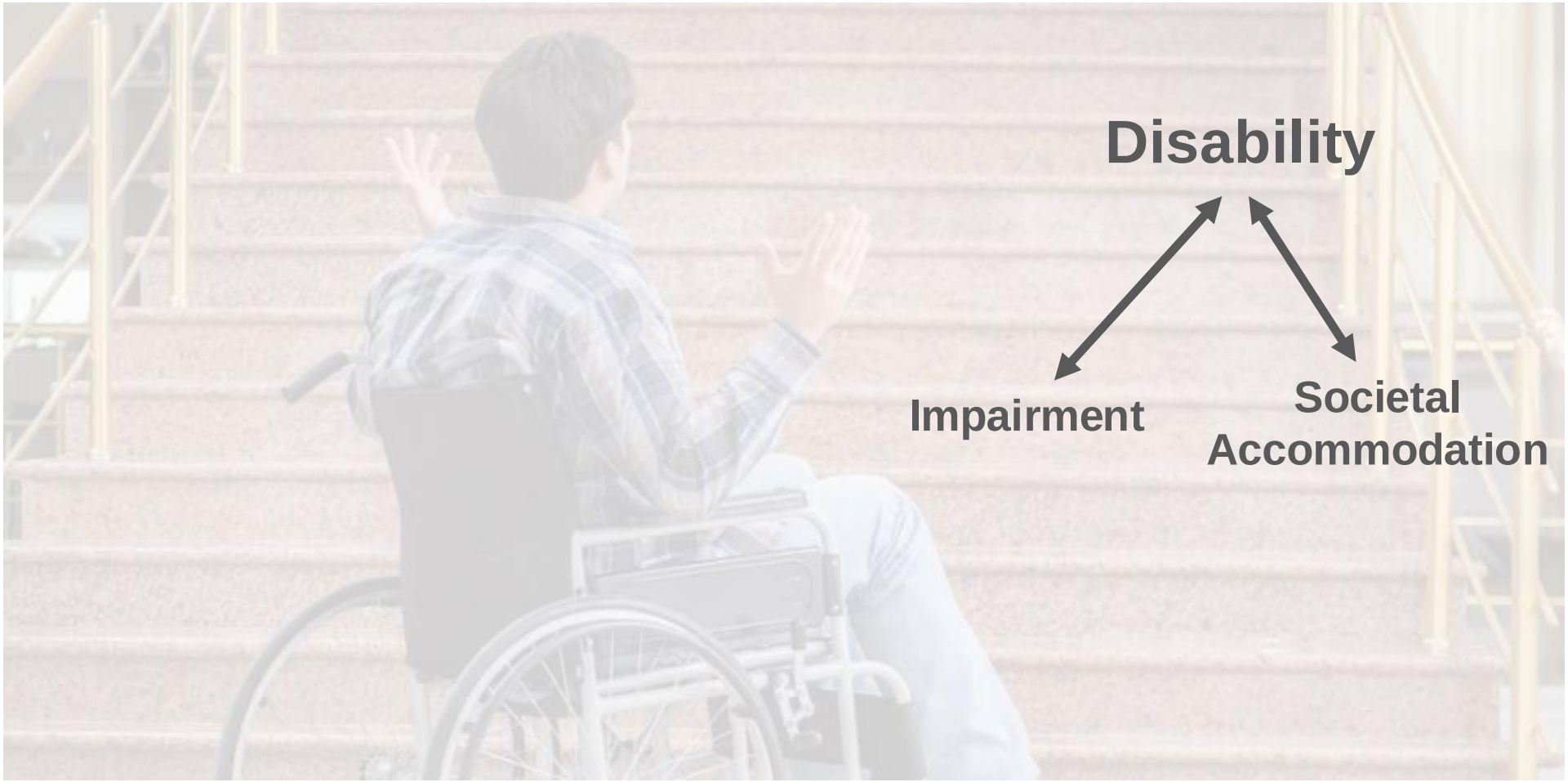
New Zealand Dementia Foundation
Dementia Mate Wareware Network Hui
13 June 2024

Overview & Objectives

- Human Rights Basis
- Supported Decision-Making in Practice
- Policy & Law Reform
- Future Directions?

CC: Jonathon Kos-Read

1. Human Rights Basis



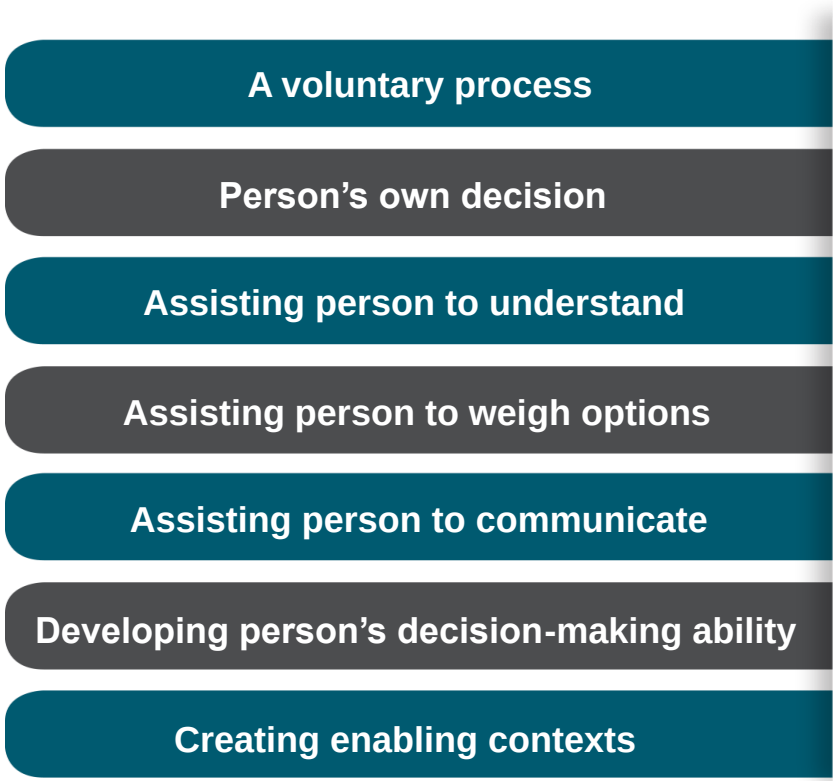
Shakespeare, T., Zeilig, H., & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia, 1471301217701506. doi:10.1177/1471301217701506*

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Defining Supported Decision-Making

“…the process whereby a person with a disability is enabled to make and communicate decisions with respect to personal or legal matters.”

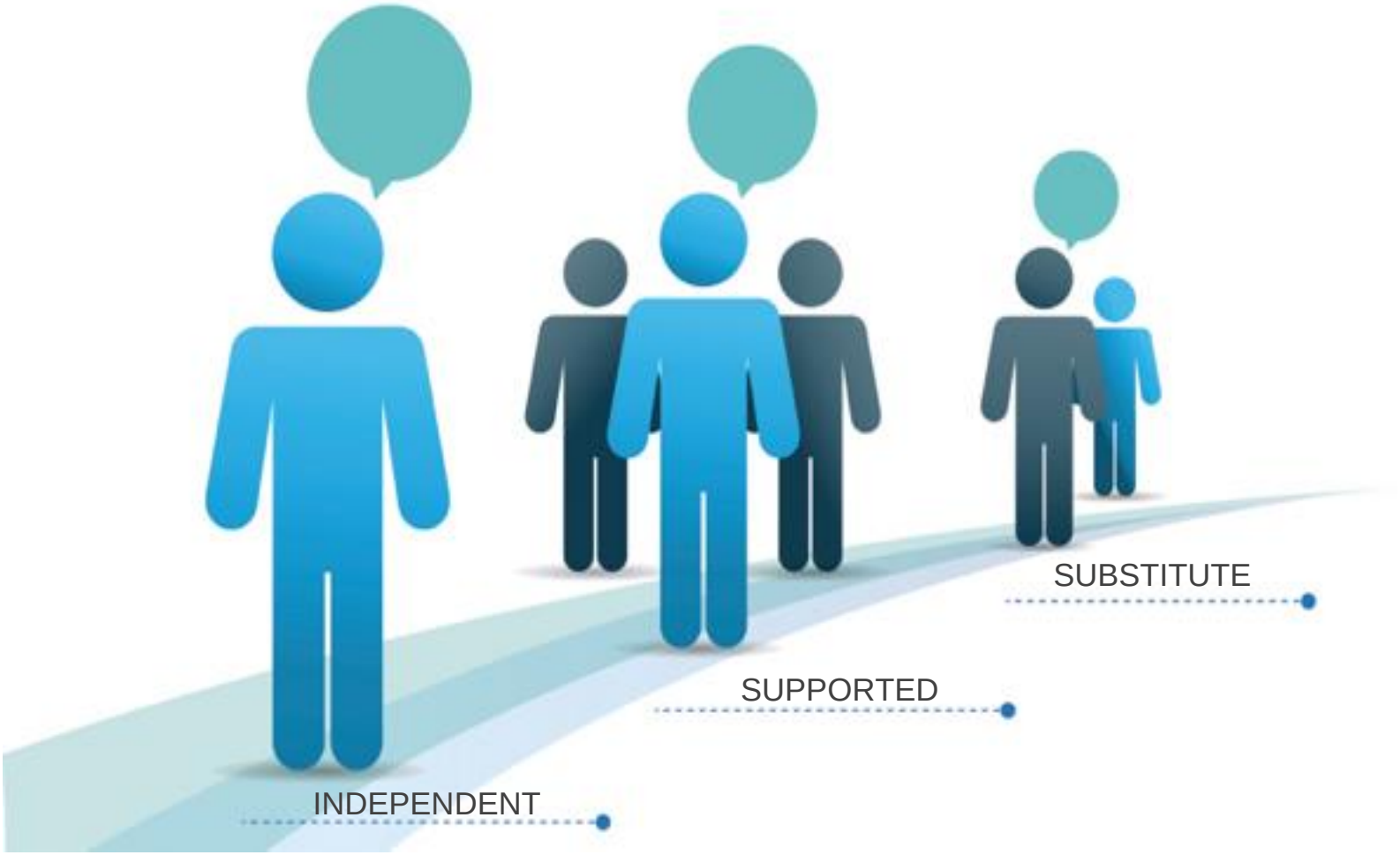
(United Nations, 2006)



Supported decision-making vs **support *for* decision-making**

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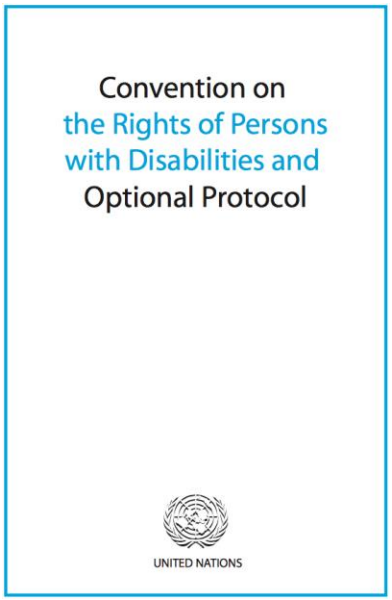
Locating ‘support for decision-making’



Cognitive Decline Partnership Centre. (2018). Supported decision-making resources. Retrieved from https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/

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CRPD Article 12



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

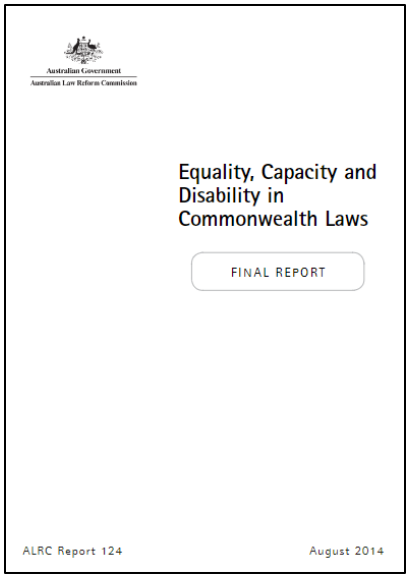
Article 12 – Equal Recognition Before the Law

1. People with disabilities are recognised as **persons** before the law
2. People with disabilities have **legal capacity** on an equal basis with others
3. People with disabilities **have a right to access support**
4. There must be **safeguards to prevent abuse**

- No new rights, but a new framework for law reform and advocacy
- De-coupling of mental capacity and legal capacity
- Positive wording of a ‘right to access/receive support’
- Articles should not be read ‘independently’

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

Response in Australia



Australian Law Reform Commission – National Decision-Making Principles

1. **The equal right to make decisions:** All adults have an equal right to make decisions that affect their lives and to have those decisions respected
2. **Support:** Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives
3. **Will, preferences and rights:** The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives
4. **Safeguards:** Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence

- Commonwealth legislation
- Law Reform Reports in Queensland, New South Wales and Victoria
- Legislation in Victoria, acknowledgement of CRPD principles in QLD, ACT and SA legislation
- Pending law reform in New South Wales?

Australian Law Reform Commission (2014). Equality, Capacity and Disability in Commonwealth Laws. Sydney: ALRC. https://www.alrc.gov.au/publications/equality-capacity-disability-report-124

Aged Care and Disability Royal Commissions



Aged Care Royal Commission

- High level comments acknowledging importance of supported decision-making, but no specific recommendations
- Acknowledged previous calls (e.g. ALRC) to embed 'National Decision Making Principles' in the Aged Care Act
- Broad recommendations about a rights-based Aged Care Act – mostly in economic terms (e.g. access to care) and restrictive practices
- Conflicting recommendations from the two Commissioners



Disability Royal Commission

- Drawing directly on the Convention on the Rights of Persons Disabilities
- Longer history of research and practice in supported decision-making in the disability sector
- Dementia and aged care settings included in the terms of reference

Department of Health and Aged Care

- "The new [Aged Care] Act will … include rules on supported decision-making to ensure older people have choice and control."

https://www.agedcarequality.gov.au/about-us/legislation-and-policies/new-aged-care-act

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A national framework for supported decision-making



Nine Principles

1. **The equal right to make decisions**
2. **Support**
3. **Will, preferences and rights**
4. **Safeguards**
5. **Principled approach to supported decision-making:** "…that keeps an individual's stated or perceived will and preferences at the centre of decision-making."
6. **Best interpretation of will and preferences**
7. **Dignity and risk**
8. **Distributional equity:** "Those experiencing disadvantage in access to support for decision-making should be given priority…"
9. **Co-leadership of people with cognitive disabilities**

Bigby, C. et al (2022). Dignity, diversity, equity and best practice: A framework for supported decision-making. The Living with Disability Research Centre, La Trobe University. https://disability.royalcommission.gov.au/publications/diversity-dignity-equity-and-best-practice-framework-supported-decision-making

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Binary and Principled Approaches to supported decision-making

Binary Approach:

The person is the decision-maker, and they are supported to be actively involved, as far as possible.

Decisions are based on the person's stated will and preference, not the supporter's interpretation.

If this is not possible, then substitute decision-making is used (e.g. based on person's 'best interests').

Principled Approach:

Centring will and preference in decision-making

The person is supported to be actively involved, as far as possible.

Decisions based on the person's stated will and preference, or if this cannot be ascertained, the supporters' ***best interpretation*** of the person's will and preference.

Dignity of risk is acknowledged and supported. In very limited circumstances where will and preference involves risk of serious, imminent physical or financial harm, last resort substitute decision-making can be used, with '***personal and social wellbeing***' guiding decision-making.

Bigby, C. et al (2022). Dignity, diversity, equity and best practice: A framework for supported decision-making. The Living with Disability Research Centre, La Trobe University. https://disability.royalcommission.gov.au/publications/diversity-dignity-equity-and-best-practice-framework-supported-decision-making

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Will and Preference

'Will': "…founded on a person's deeply held, reasonably stable and reasonably coherent personal values."

- Reflecting higher-order process of deliberation and reasoning within a values system
- Generally coherent with a person's other "beliefs, intentions and general temperament"

'Preference': "…[momentary] desire, inclination or preference – even when strongly expressed."

While will and preferences may, by and large, run together…
(i.e. *will-and-preference*) – the CRPD, and supported decision-making practice, raise questions about how to respond when these diverge.

The CRPD calls for a 'best interpretation of will and preference', when the person is not able to be supported to express their will and preference.

Szmukler (2017). The UN Convention on the Rights of Persons with Disabilities: 'Rights, will and preferences' in relation to mental health disabilities. *International Journal of Law and Psychiatry*, 54, 90-97
Carney, T., Then, S.-N., Bigby, C., Wiesel, I., Douglas, J., & Smith, E. (2019). Realising 'will, preferences and rights': Reconciling differences on best practice support for decision-making? *Griffith Law Review, 28(4), 357-379. doi:10.1080/10383441.2019.1690741*

2. Supported Decision Making in Practice



Key Components

- Identifying supporter/s
- Identifying decision points
- Resourcing support

- Supporter/s:
  - have access to information
  - provide assistance communicating with others
  - provide ongoing help in implementing decisions
  - act with due diligence

- Decision-Maker:
  - ‘owns’ the decision
  - has access to independent advocacy

- The supporter/s act to assist the person, keeping their will and preference at the centre of the process

Community Experiences

Relational experience of dementia

"…what we are faced with here is a problem that you and I have and you and I have to deal with it. So, it's not the individual. It's at least the individual and their carer. To take it further, it's the family, the friends, the associates… all those people are somehow affected." (Tony, person living with dementia)

Impact of societal responses

"I've always been very confident and sure of myself but I'm not anymore… it's just not there anymore. Probably because of other peoples' reactions…" (Josie, person living with dementia)

Sinclair, C., *et al.* (2019) Journal of Bioethical Inquiry https://doi.org/10.1007/s11673-019-09945-x

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Community Experiences

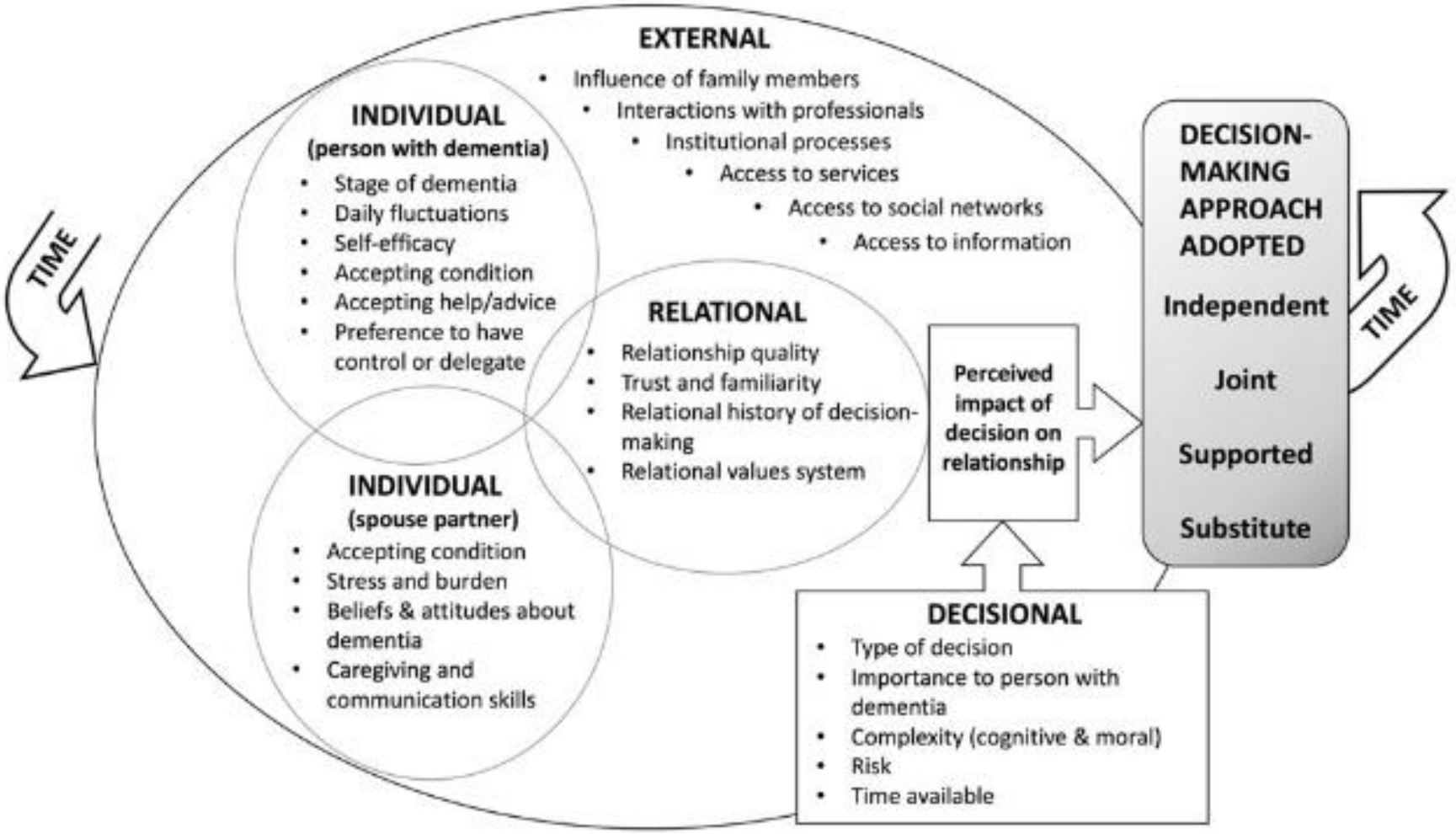
Roles and identity

"…when he's doing his banking on the computer he loses some finances from whichever account and I can't understand what he's doing, but we work through you know, 'let me sit down and I'll see where you're going and what you're doing'… instead of taking the whole lot off him at this moment because he likes to be the husband and the protector…" (Carmen, partner of person with dementia)

Sinclair, C., *et al*. (2019) Journal of Bioethical Inquiry https://doi.org/10.1007/s11673-019-09945-x

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Contextual factors in decision-making



Sinclair, C. et al (2018). How couples with dementia experience healthcare, lifestyle and everyday decision-making. *Int Psychoger.* 30(11): 1639-1647.

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Supported Decision-Making Strategies

Cognitive Impairment	Strategies
Difficulty retaining information	• Repeating information in different ways • Alternative approaches to storing / accessing memories (e.g. multi-sensory)
Difficulty understanding or weighing up multiple options	• Translating jargon • Simplifying concepts • Reducing the number of options • One topic at a time
Vulnerability to suggestion	• Safeguarding decision-making process by knowing the person well • Transparent communication
Impulsivity	• Managing risks, negotiating, revisiting
Difficulty communicating choices	• Assistive technologies • Alternate media (e.g. visual, tactile) • Photographs and cards

Sinclair, C., *et al*. (2019) Journal of Bioethical Inquiry https://doi.org/10.1007/s11673-019-09945-x

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Strategies for addressing social contextual barriers

Cognitive Impairment	Strategies
Social isolation	• Local support groups • 'Circles of support'
Lack of suitable options	• Negotiating / tailoring individualised approaches to traditional service models
Attitudes of service providers	• Advocacy
Opposition from other family members	• Independent and credible professionals • Independent 'ombudsman'

Sinclair, C., *et al*. (2019) Journal of Bioethical Inquiry https://doi.org/10.1007/s11673-019-09945-x

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Professional Perspectives

Establishing the basis for decision-making

"I think part of people being a healthcare clinician is to focus on big milestone healthcare decisions, which are decisions 'that are important'… because they're the most important things to us… but actually the more important decisions are the decisions that are really important to [the person]. The first step to that process is finding out what is important to them and then fitting everything else that we do around that." (Palliative care consultant)

Sinclair, C., *et al*. (2019) Dementia https://doi.org/10.1177/1471301219864849

Professional Perspectives

The supportive toolbox

"So we generally go through a scaffold in helping them answer… obviously starting with open ended questions and working all the way down to a binary choice." (Speech pathologist)

"…I err on the approach of [using] as many communicative domains as possible. So I write it down. I have a picture. I say it. I gesture it. I reiterate it in every possible way." (Speech pathologist)

Sinclair, C., *et al*. (2019) Dementia https://doi.org/10.1177/1471301219864849

Professional Perspectives

Managing professional boundaries

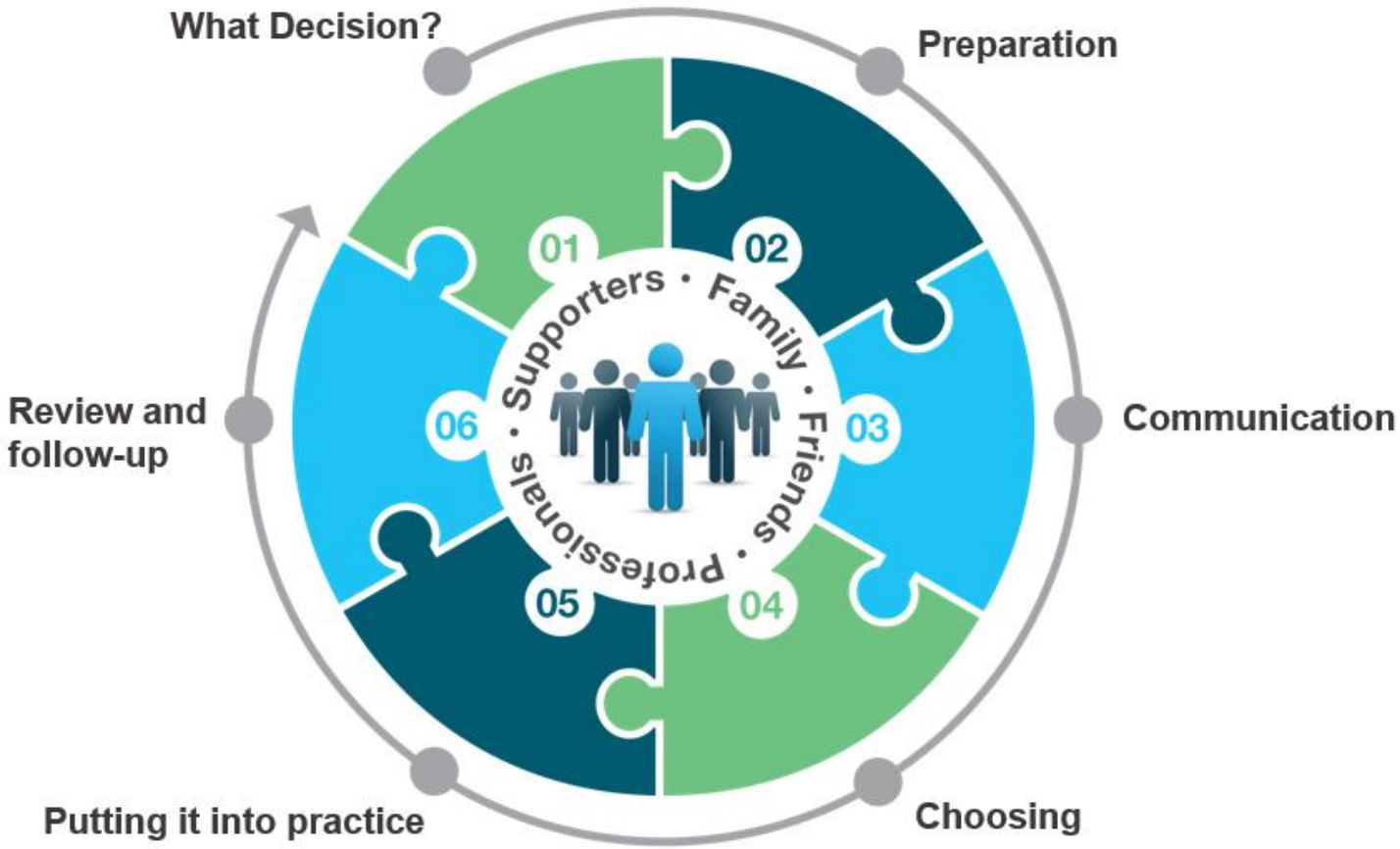
"It's scary to think that you could accidentally influence someone's decision or accidentally plant an idea in their head or do something that's detrimental to their case." (Speech pathologist)

'Individualist' verus 'relational practice'

"I quite adamantly stick to the policy that the client is the client – the old[er] person is the client and no other client should have input, although I may request or ask certain questions of the family members to verity what I'm searching for… but I generally don't let a client have a support person in with me." (Solicitor)

Sinclair, C., *et al*. (2019) Dementia https://doi.org/10.1177/1471301219864849

A Supported Decision-Making process

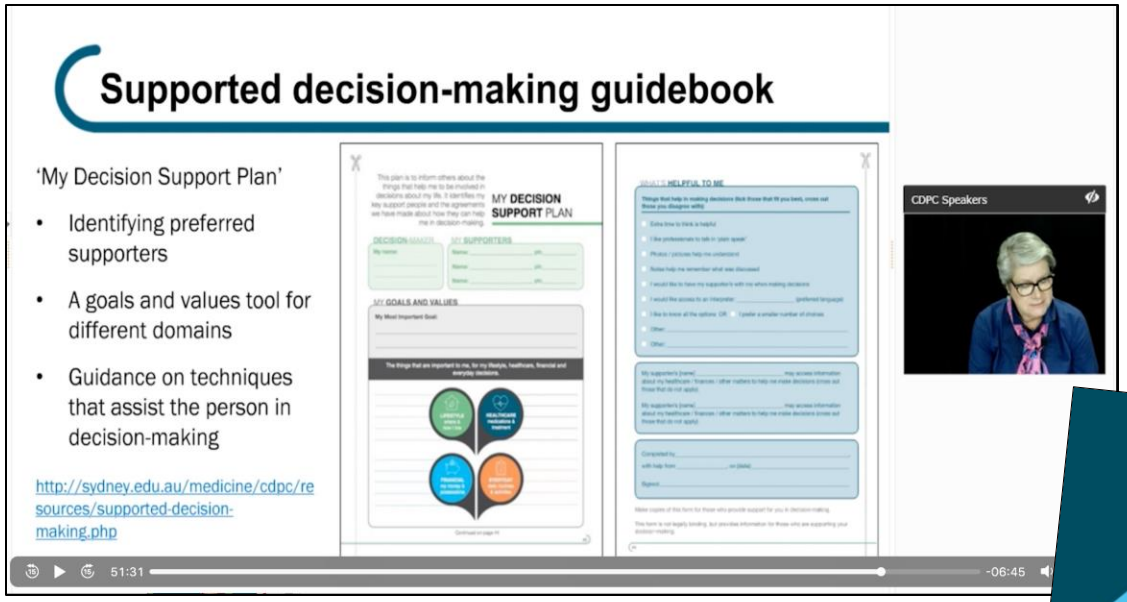




https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/

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Supported Decision-Making in dementia care







https://cdpc.sydney.edu.au/research/planning-decision-making-and-risk/supported-decision-making/

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The La Trobe Support for Decision-Making Framework

The La Trobe Support for Decision Making
Practice Framework Learning Resource

ABOUT | MODULE 1 | MODULE 2 | MODULE 3 | MODULE 4 | MODULE 5 | MODULE 6 | RESOURCES | CONTACT

LA TROBE UNIVERSITY



Module 1

The Context of Support for Decision Making

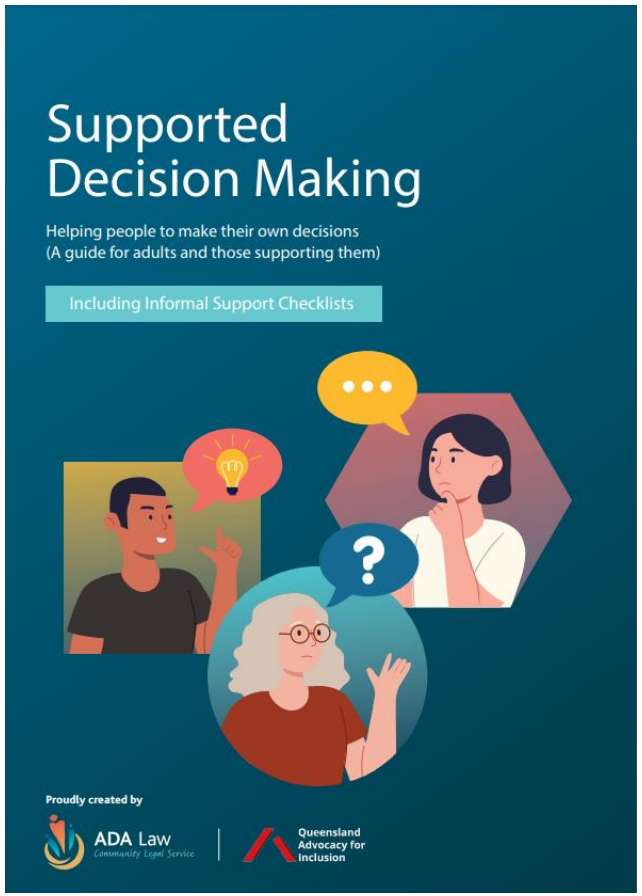
In this module you will be introduced to the ideas about supported decision making, and the changes taking place in expectations of how people with disabilities are supported to make decisions.

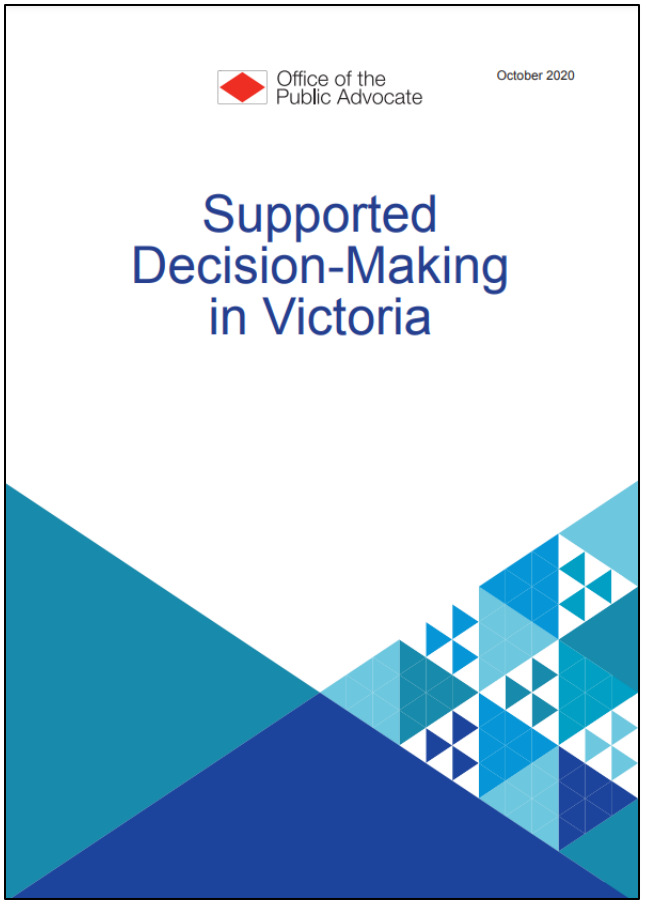
https://www.supportfordecisionmakingresource.com.au/

The EARLI Project

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Further Resources





https://adalaw.com.au/wp-content/uploads/2024/02/Supported-Decision-Making-Guide-v6-WEB.pdf
https://www.publicadvocate.vic.gov.au/your-rights/your-supported-personal-and-financial-decisions

3. Policy and Law Reform



3. Policy & Law Reform

- Supported decision-making needs to be understood in the context of a rights-based approach

- Dignity, diversity and equity
  - Culture
  - Resourcing

- Supported decision-making occurs along a spectrum
  - Avoid binaries of ‘supported’ and ‘substitute’ decisions
  - Keep will and preference central

- Incoming aged care legislation will require supported decision-making
  - Commonwealth and state/territory legislation
  - ‘Best interests’ and ‘will and preference’ jurisdictions
  - Principle of subsidiarity in tribunal processes
  - Regulation and aged care standards?

Sinclair, C., *et al*. (2019) Journal of Bioethical Inquiry https://doi.org/10.1007/s11673-019-09945-x

4. Future Directions

EARLI Project

- Life story work and advance care planning
  - Building relationships
  - Reminiscence
  - Scaffold for current & future decision-making
  - Self-advocacy

- Australian home care clients
- People with progressive neurological conditions
- People with HIV
- Older adults experiencing frailty





Thank you

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