



Support for decision making: Development of an evidence-based practice framework for supporters

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Right to participate



CONVENTION on the RIGHTS of PERSONS with DISABILITIES

2006

- Persons with disabilities enjoy **legal capacity on an equal basis** with others in all aspects of life.
- Signatory nations agree to develop “appropriate measures to **provide access** by persons with disabilities **to the support** they may require in exercising their legal capacity.”



Australian Government

Australian Law Reform Commission

2014

- 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 (principle 2)
- The **will, preferences and rights of persons who may require decision-making support** must direct decisions that affect their lives. (principle 3)

Support for decision making

- Sufficient and effective support
 - is tailored to the individual and the situation
 - varies in type and intensity depending on the decision
 - compensates for the person's difficulties with decision making through
 - changed expectations of others
 - development of their skills and experience
 - support to express their will and preferences
 - sometimes interpretation of their will and preferences
 - is dependent on the skills of the decision-making supporter

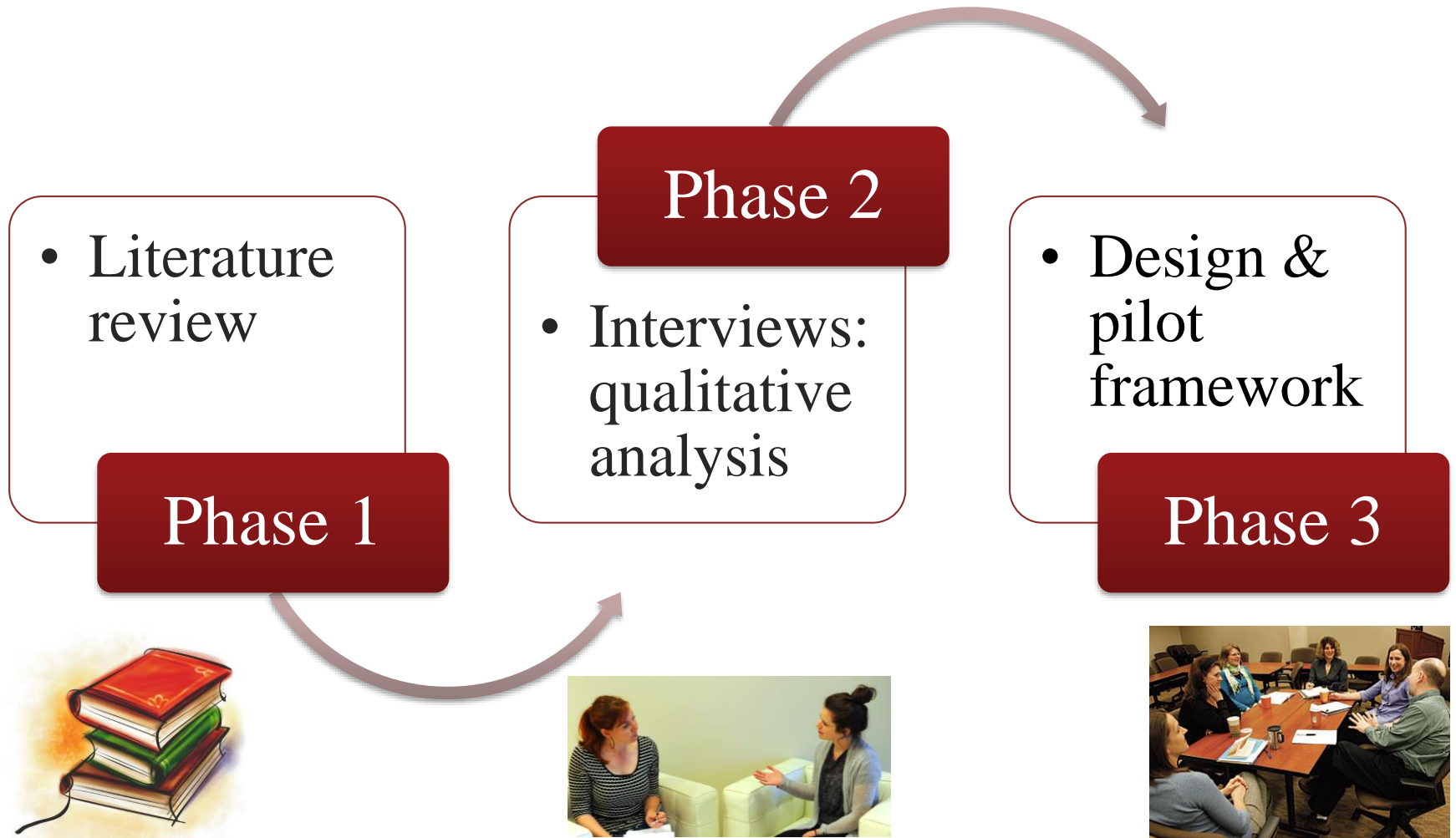
Supporters

- Relatives
- Friends
- Volunteers
- Paid/professional supporters
- Formal agreements (Canada: representation agreements & microboards)

Our Aims

- Develop an evidence based framework to guide the practice of decision-making supporters
 - Understand the experience
 - people who receive support
 - people who provide support
 - Identify factors that underpin the delivery of effective decision-making support
 - Design a framework with associated resources
 - pilot, review and revise
 - Evaluate the framework and associated resources
 - rigorous trial

Method



Results

Phases 1 & 2 ^{a,b}

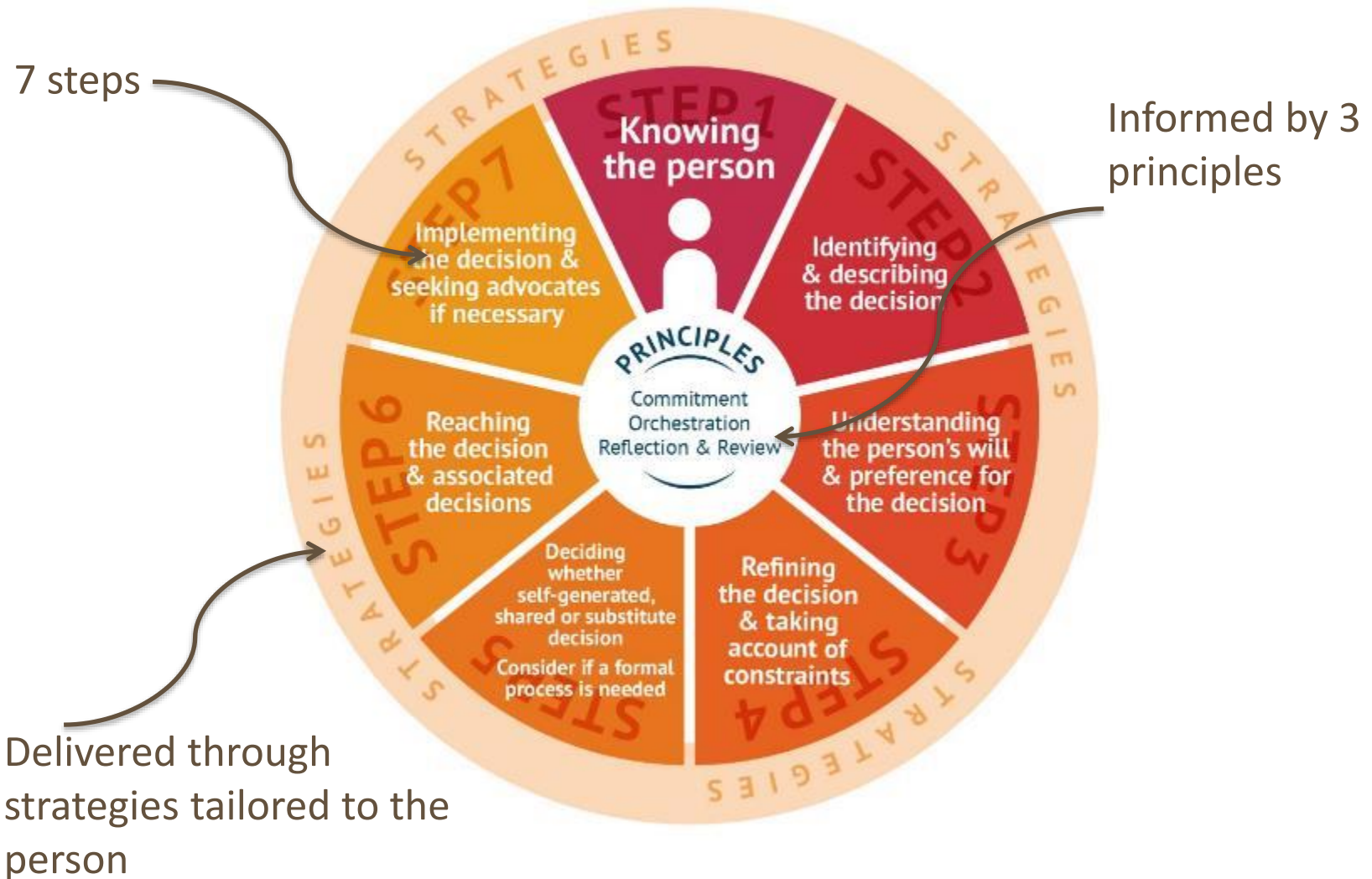
- Douglas et al. (2015). Factors that Underpin the Delivery of Effective Decision-Making Support for People with Cognitive Disability. *RAPIDD*, 2(1), 37-44.
- Bigby et al. (2015). Supporting People with Cognitive Disabilities in Decision Making – Processes and Dilemmas. Melbourne: Living with Disability Research Centre, La Trobe University.

Phase 3 ^c

- Bigby & Douglas (2016). Support for decision making: A practice framework. Melbourne: Living with Disability Research Centre, La Trobe University.

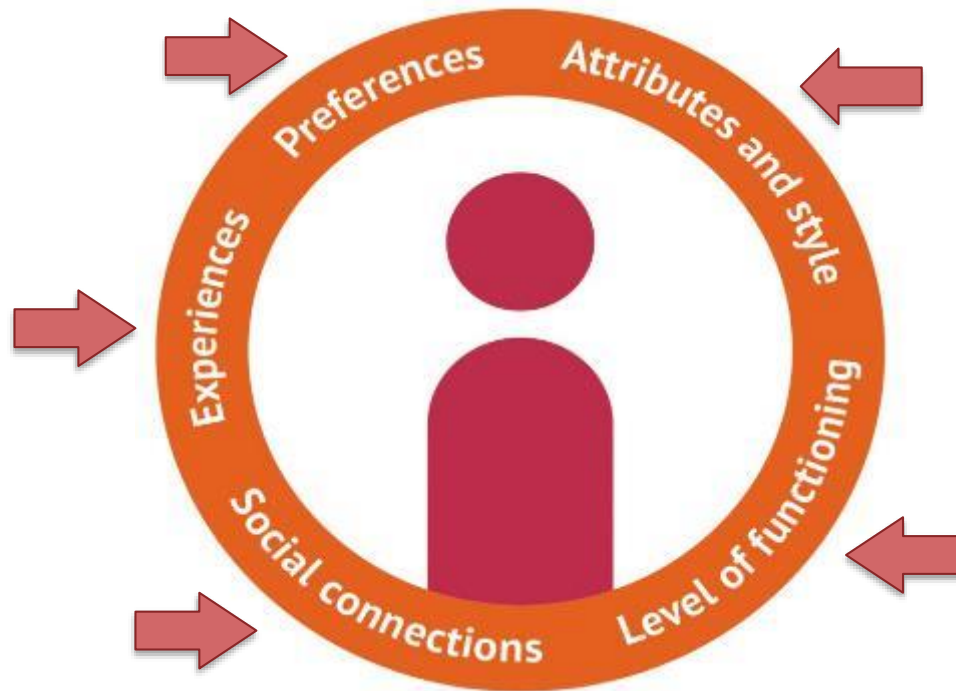
^aLa Trobe University Faculty Research Grant, ^bVictorian Legal Services Board, ^cFamily and Community Services, NSW.

The Process of Support for Decision Making





Know the Person





Identifying and Describing the Decision





Understanding the persons will and preference

‘blue sky’ step

- think as widely as possible
- consider all the possible options that need to be explored and their consequences
- explore the person’s preferences about all the things that will be encompassed in the decision



Refining the decision and taking account of constraints

- Preferences are prioritized, refined and shaped by constraints
 - time
 - money
 - impact on other people
 - safety.
- Ways are found to ensure the decision will be implemented
 - potential constraints might be questioned or creatively managed



Deciding the type of decision – is there a need for a formal process

- Support for
 - self-generated decision
 - shared decision
 - may resemble an informal substitute decision
 - a more formal process of making a substitute decision
 - due to the anticipated harm to themselves or others
- The same person may participate at different times in making self-generated, shared or substitute decisions with support.



Reaching the decision and associated decisions

- Reflect prioritised preferences as closely as possible
 - Identify consequential decisions that will flow from a major decision
 - In supporting each of these smaller decisions the support for decision making cycle loops back to step 1 and is repeated
- Depending on the decision
 - it may be formally recorded and communicated to others involved in the person's life who will support its implementation.



Implementing the decision & seeking advocates if necessary

- Implementation may not rest with the decision making supporter
 - May need advocates to support implementation of the decision
 - Others in a person's circle may shift into an advocacy role
- The processes of support do not stop here
 - consequential decisions
 - unrelated decisions as their life unfolds.

Strategies: general considerations



Attention to communication

Pitching information and communication at the right level – awareness of verbal and behavioral clues – checking back for understanding



Education about consequences and practicalities

Making it understandable, doing the research – presenting the options and pros and cons – explaining consequences of decisions and that priorities can be undermined by small decisions



Listening and engaging to ensure all options are considered

Attentiveness to will and preference – taking the time – using others as sounding boards



Creating opportunities

Active reframing that invites participation – providing a sounding board – acknowledging low expectations and building confidence – testing options – introducing and nurturing the seeds of ideas – bringing in others to trial a situation – creating distance to enable greater autonomy



Breaking things down

Breaking into smaller components that are shared across the person and supporter – teaching and shaping skills

The Process of Support for Decision Making

PRINCIPLES

Commitment

to the person and their rights

Orchestration

of others involved in the person's life

Reflection & Review

on your own values, influence
and support

Back to our aims

- ✓ Develop an evidence based framework to guide the practice of decision-making supporters
 - ✓ Understand the experience
 - ✓ Identify factors that underpin the delivery of effective decision-making support
 - ✓ Design a framework with associated resources
 - ✓ pilot, review and revise

Evaluate the framework and associated resources

- rigorous trial
- **ARC Linkage Grant (in progress)** (Bigby, Douglas, Carney, Wiesel, Shih-Ning, Chesterman, & Cook)

Thank you

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