



Developing an evidence-based support for decision making practice framework

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Legal Reform and Changed Expectations Founded on the 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)

See: Then, Carney, Bigby & Douglas (2018)

Translating rights into practice

- Considerable attention to legal concepts and schemes for supported decision making
- Early adopters Canada and Sweden generated little evidence on processes, outcomes or practice of support.
- Doubts about delivery of intended benefits for all people with cognitive **disabilities** (Carney & Beaupert, 2013, Kohn & Blumenthal, 2014, Law Commission of Ontario 2014)
- Growing attention to practice – and models for delivering support
- For example 6 pilot projects in Australia between 2010- 2015
 - Similar designs, dyads decision maker and supporter – with external support
 - Primarily people with mild intellectual disabilities and pre-existing relationships with supporters.
- Insights into models for delivering support but little evidence about practice
- Training programs based on ideology rather than evidence (Bigby et al., 2017)

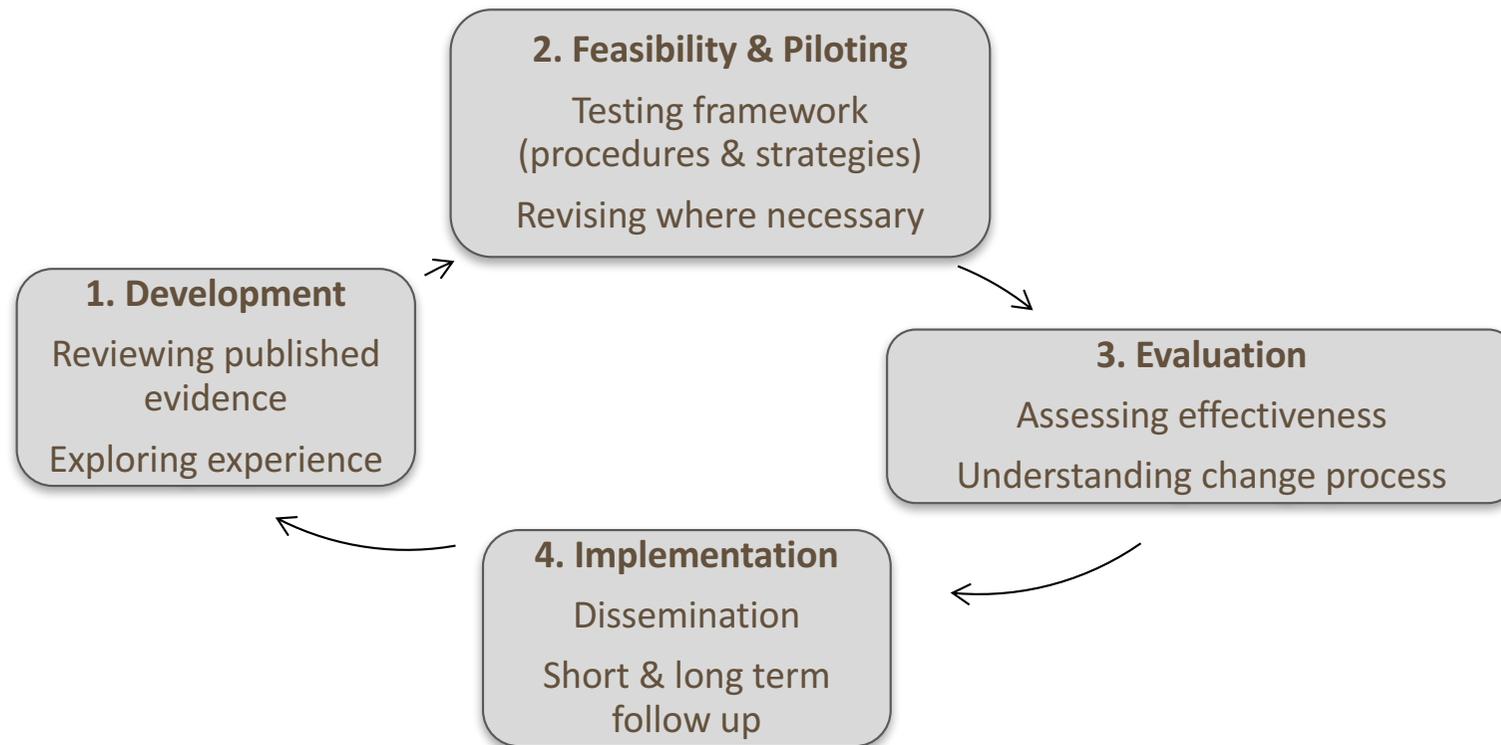
Our Focus - Building the Capacity of Supporters

“With its rejection of the idea of incapacity and its enunciation of an entitlement to receive assistance, supported decision-making essentially shifts the focus from the capacity of the person being assisted to the adequacy or otherwise of the capacity of those providing assistance” (Carney, 2017, p. 48)

- Law reform will provide legal framework for SDM
- Government, professions and the disability sector also needs to pay attention to the practice needed to enact SDM effectively
- And mechanisms/criteria to guide, monitor or regulate practice, other than professional codes of ethics or practice frameworks (Bigby & Frawley, 2010; Carney & Beapert, 2013).
- Longstanding and parallel interests of authors in decision making – people with intellectual disabilities and acquired brain injury
- Program of research on supporting decision making

Aims

- Develop an evidence based practice framework to guide decision making support for people with cognitive disabilities – intellectual disability and acquired brain injury
- Four phase approach modelled on Medical Research Council guidance for developing and evaluating complex interventions (Craig et al., 2008)



Phase 1 – Development

1. Development
1.1 Reviewing
published evidence

Systematic literature search and review - from 2000

- Processes of supporting decision making - people with intellectual disability or ABI
- Weak evidence base
 - small scale studies
 - confounding choice and decision making
 - often one of number of factors investigated
- Identified knowledge underpinning aspects of decision support
 - choice making, communication, and the impact of cognitive impairment on capacity.
- Reflected in practical strategies identified in research about effective decision support.
 - simple adapted communication strategies like color-coded buttons on a TV
 - ‘cognitive scaffolding’ to break down a big decision into smaller steps
 - active support practice, based on concepts such as task analysis, to enable choice and control about everyday matters
 - training programs to improve decision making skills - topics such as sexuality, later life options, avoiding abuse and navigating health care systems

1.2 Empirical studies exploring the experience of people with cognitive disabilities and their supporters.

1. Development
1.2 Exploring
experience

- 7 exploratory studies
- Experiences of 52 adults and 75 supporters.
- Constructivist framework - interviews - observational methods - analysed using Grounded Theory principles
- 13 published papers
- Positive experience if -
 - “...support is provided by one or more individuals with whom they have a **trusting relationship**; who have a **knowledge of their history and goals**, and the **nature of their impairment and level of functioning**; who are **flexible and use variable strategies to tailor their support to the unique needs** and characteristics of each individual; and who **collaborate with the individual** to reach their desired outcome”. (Douglas, et al., 2015 p. 40).
- Uncertainty about role of family – potential for their exclusion
- Unclear processes to take account of perspective of person themselves
- Absence of mediation processes to resolve competing perspectives

Features of Decision Support

- A complex process with discernible, interacting and overlapping components
- Iterative rather than linear process
- Involves multiple players, the person with cognitive disability, supporters, and others involved in influencing or impacted by the decision
- Participation and support needs change with every decision
- Each part of the process requires ongoing tailoring to the individual
- Shaped by the context in which it takes place
- Implementing the decision may not rest with decision supporters
- **Enabling factors - characteristics of supporters**
 - positive attitude towards exercise of choice and control
 - creating decision making opportunities
 - ability to adopt a neutral and non-judgmental stance
 - positive relationship based on trust and understanding
 - knowing about a person's cognitive impairment
 - ability to adjust support and communication to the strengths and weaknesses of the individual. (Bigby et al., 2015)

Problematic aspects of decision making support

- Common patterns of limited involvement in major or minor decisions that affect their lives
- Paternalistic, controlling or risk averse nature of decision support;
 - Reflects the values of others rather than their own or driven by perceptions of risk or resource constraints
 - Negatively affected by supporters' lack of communication skills, poor knowledge about cognitive disability, and unawareness of the influence of their own preferences and values
 - Disempowering meetings conducted by professionals that obstruct rather than facilitate involvement in decision making
- Onerous complex tasks of decision making support “twirling plates on a stick” as supporters simultaneously draw on ideas about rights, practicalities and risks

Video



Jerry – who is making the decision?



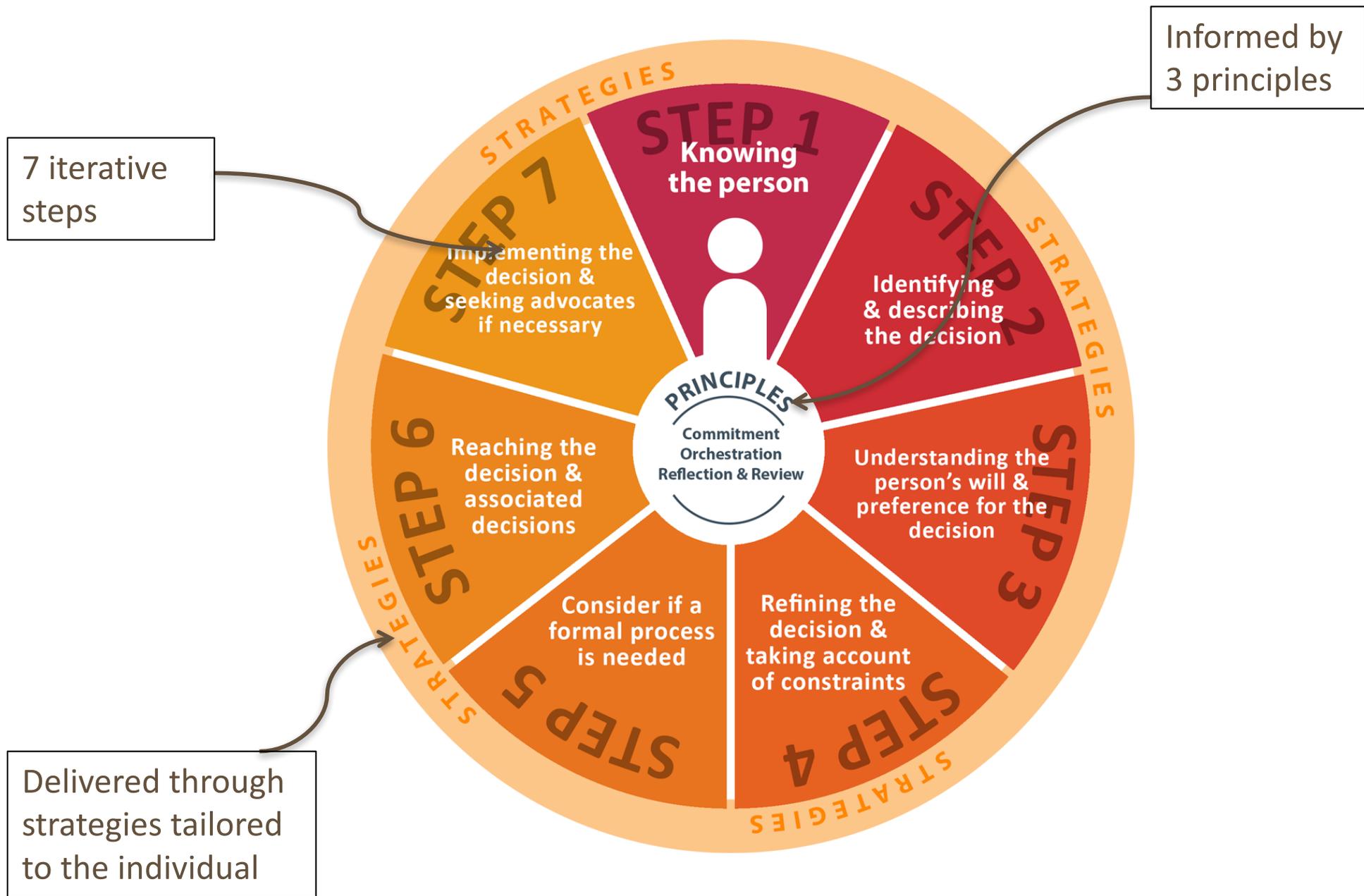
Phase 2 - Feasibility and piloting

La Trobe Support for Decision Making Practice Framework

2. Feasibility & Piloting
Testing framework
(procedures & strategies)
Revising where necessary

- Draft framework based on stage 1 applicable to people with intellectual disability or ABI
- To be used flexibly across the continuum of self-generated, through informal shared and substitute decisions. (Bigby & Douglas, 2015; Douglas & Bigby, 2018)
- Developed training procedures and strategies
- Piloted with support workers and health professionals working with 45 people with intellectual disabilities in a large residential setting.
- Revisions made and a training manual developed.
- Tools and Checklists
- Further small pilots with other groups
 - iCare workers in NSW
 - Ability Linkers and LAC's
 - Leadership plus program - Queensland Public Trustee

La Trobe Support for Decision Making Practice Framework



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

Commitment to support necessary for the person to **make, communicate and participate in decisions that affect their lives and that their will, preferences and rights direct decisions that affect their lives** (ALRC, 2014 principles 2 & 3)

If will and preferences in conflict resource to rights

Framework provides criteria for reflection, review and accountability of supporters could be used where informal intersects with formal such as NDIS planning



Knowing the person



In different ways – from different perspectives

A major challenge for new supporters – when the person can't tell you

Time and Creativity - different issues for different people

Attributes and style: including their personal characteristics (*Who I am, how I feel about myself*)

Level of functioning: specific impairments, skills, and abilities

Social Connections: with others and how they are seen by others in their network. Their network may include family, friends, support workers and other professional 'experts' who have been involved in their life.

Experiences: their past experiences and the experiences you have had with the person

Preferences: their likes and dislikes



Identifying and describing the decision





Understanding the person's will and preferences

- 'blue sky' step
 - think as widely as possible
 - consider all the possible options and their consequences
 - explore the person's preferences about all the things that will be encompassed in the decision
 - 'going to moon' – what is embedded in this preference
 - differences between will and preferences

Strategies to Understand the Person's Will and Preference

Attention to Communication

- Pitching information and communication at the right level.
- Awareness of verbal and behavioural clues.
- Checking back for understanding.

Orchestration

- Finding out what other supporters understand to be the person's will and preference.
- Preferences can change over time. What they liked a few years ago might not be their preference now.

Need for interpretation

- By supporters based on their knowledge of the person, or acquired from the perspectives of others who know the person well or in different contexts.



Refining the decision & taking account of constraints

- Preferences are prioritised, refined and shaped by constraints
 - time
 - resources (money, people or items to carry out a decision)
 - impact on other people
 - safety
 - geographical
 - physical space and design
 - policy and procedures
- Ways are found to ensure decision can be implemented
 - potential constraints might be questioned or creatively managed
 - [enabling risk](#): respecting preferences and minimising potential harm
 - consequences of not taking the risk



About this resource.

Enabling Risk: Putting Positives First is an online learning resource developed specifically for disability support workers.

Tom 1



Tom 2





Consider if a formal process is needed

- Is there conflict among supporters or between the person and supporters.
- Is a danger that supporters may override the person's preferences to avoid risks.
- Is mediation required for the decision.
- Important to bring conflict to the surface and name it so that you can find ways of dealing with it.
- Decision types
 - self-generated decision with support
 - 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

- Making sure the decision reflects prioritised preferences as closely as possible
 - identify consequential decisions that flow from a major decision
- Depending on the decision
 - it may be formally recorded and communicated to others involved in the person's life who will support its implementation



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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 tailored to the individual and each step



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

Phase 3. Evaluation Work in Progress

- Two parallel impairment-specific randomised controlled trials (supporters of people with intellectual disability or ABI)
- Blinded randomised assignment to the education program and waitlist control conditions within each of the impairment groups.
- Contrasting the groups on pre-intervention, post-intervention, 3-month, 6-month and 12-month follow-up measures.
- Mixed method design with both quantitative and qualitative measures.
- Development of customized measures of change in approach to decision support and satisfaction with support
- Process-related outcomes evaluated through interviews at each time point, to build further understanding of the change process
- To date 50 dyads with intellectual disability & 18 with acquired brain injury

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Thank you

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Living with
Disability
RESEARCH CENTRE
Supporting inclusion of people
with cognitive disability

