LA TROBE UNIVERSITY

Living with Disability
Research Centre

Developing an evidence-based support for decision making practice framework

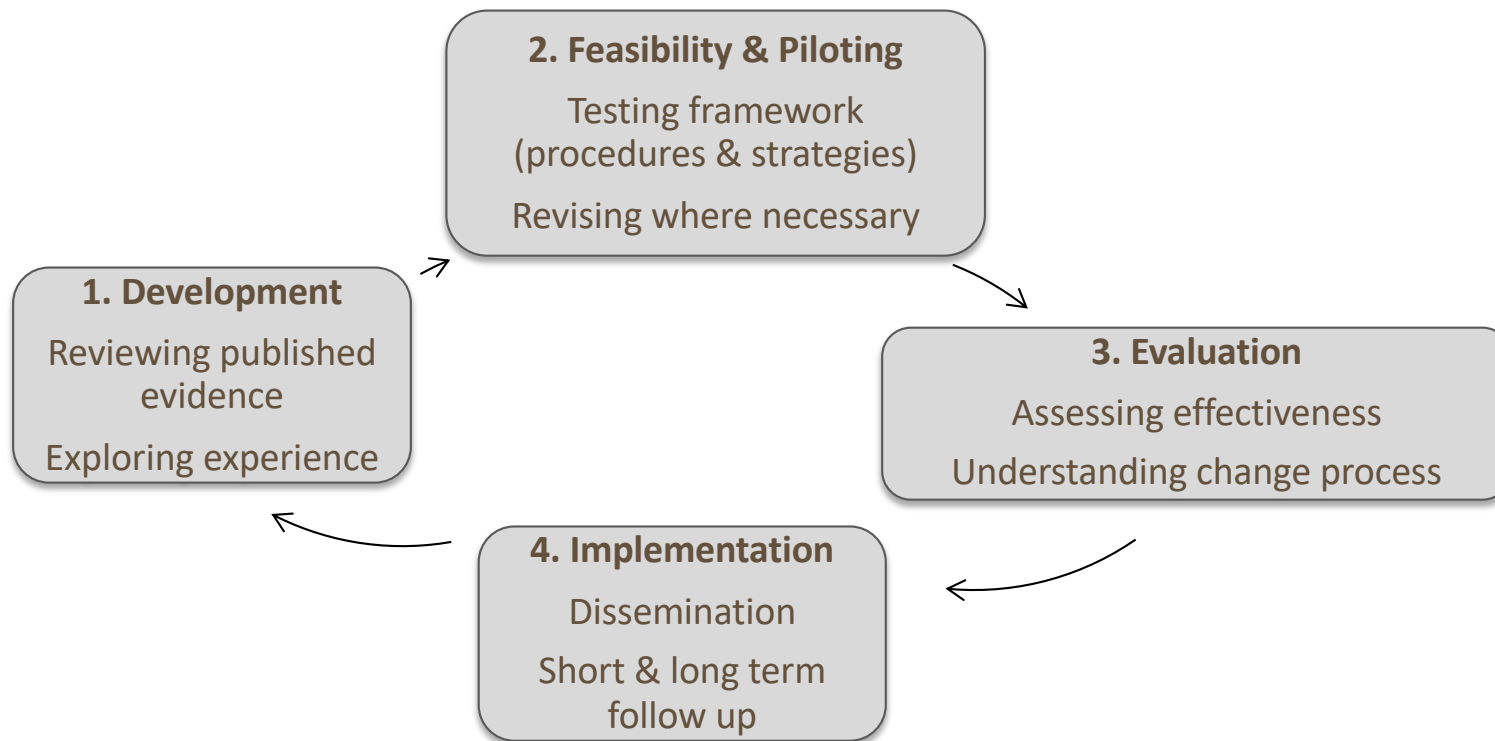## Professors Christine Bigby & Jacinta Douglas

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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)

2. Feasibility & Piloting

Testing framework
(procedures & strategies)

Revising where necessary

1. Development

Reviewing published evidence

Exploring experience

3. Evaluation

Assessing effectiveness

Understanding change process

4. Implementation

Dissemination

Short & long term follow up

Phase 1 – Development

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

- **Enabling factors - characteristics of supporters**

  - positive attitude towards exercise of choice and control

  - creating decision making opportunities

  - aware awareness

  - 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)

Knowledge underpinning aspects of decision support

- At level of individual

    - skill development, 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 of people with cognitive disability - topics such as sexuality, later life options, avoiding abuse and navigating health care systems

Negative aspect 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

  – Paternalistic

  – Unduly influenced by risk averse organizational management

  – 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

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

- 7 exploratory studies

- Experiences of 52 adults and 75 supporters.

- Constructivist framework - interviews - observational methods - analysed using Grounded Theory principles

- 13 published papers – similar to the literature

- 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, - not necessarily proceed in a fixed order and may be recursive

- 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   .

- Decision must be implementable, and this may not rest with decision-making supporters who may need to engage advocates to support implementation
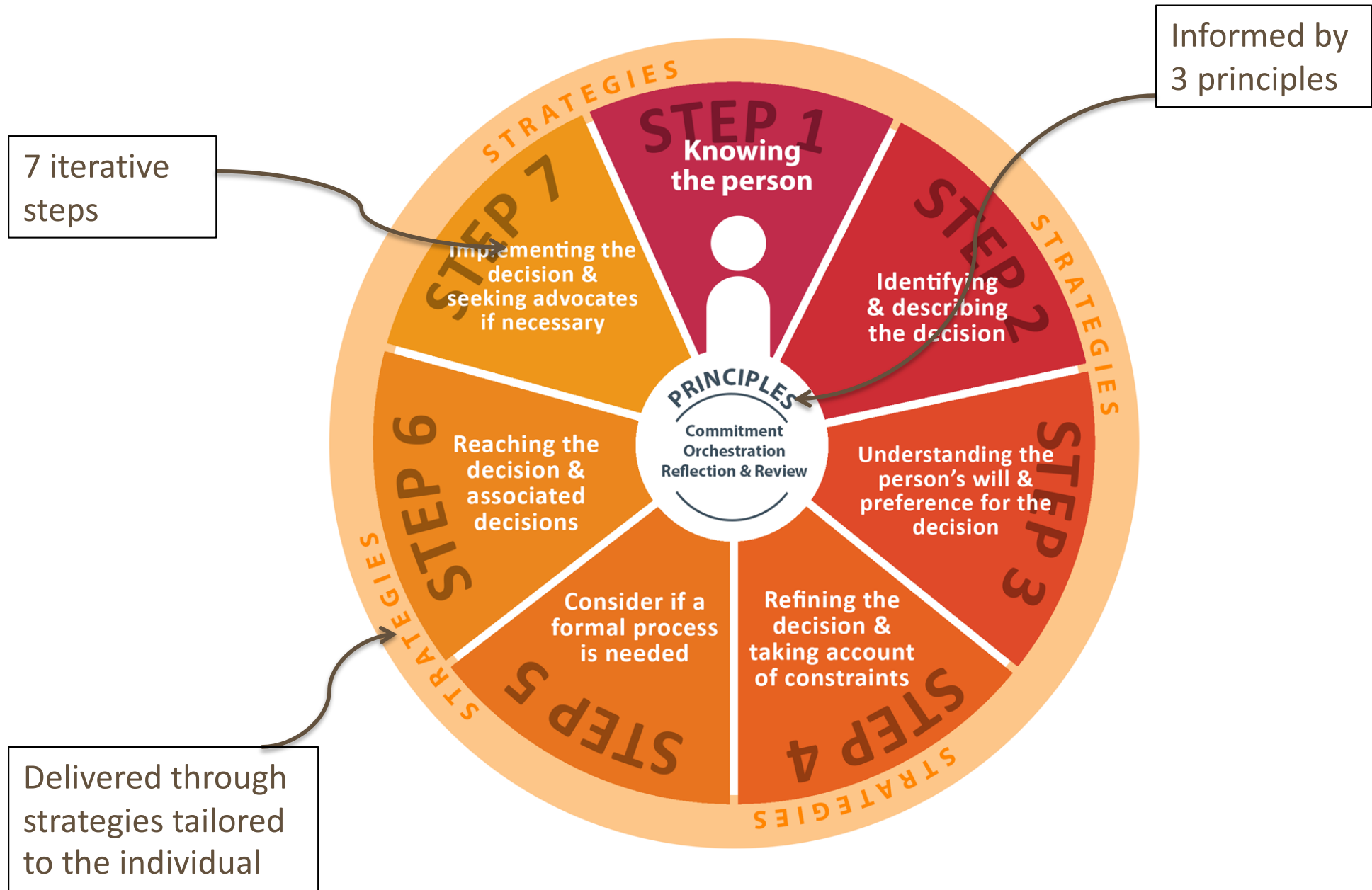
Phase 2 - Feasibility and piloting
La Trobe Support for Decision Making Practice Framework

- 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

La Trobe Support for Decision Making Practice Framework

Informed by 3 principles

7 iterative steps

Delivered through strategies tailored to the individual

STRATEGIES

STEP 1
Knowing the person

STEP 2
Identifying & describing the decision

STEP 3
Understanding the person's will & preference for the decision

STEP 4
Refining the decision & taking account of constraints

STEP 5
Consider if a formal process is needed

STEP 6
Reaching the decision & associated decisions

STEP 7
Implementing the decision & seeking advocates if necessary

PRINCIPLES
Commitment
Orchestration
Reflection & Review

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

Tools

Support for Decision Making Checklist	
I HAVE….. (tick box that applies)	I DID THIS BY…..(insert explanation)
☐ Found ways to know the person	
☐ Identified the decision	
☐ Described the features of the decision	
☐ Explored the person's preferences	
☐ Identified constraints	
☐ Refined the decision with constraints considered	
☐ Identified whether conflict existed	
☐ Identified whether a formal process was needed	
☐ Reached a final decision	
☐ Identified associated decisions	
☐ Selected advocates to implement the decision	
☐ Checked the person's preferences were maintained during implementation	
Applied the Principles: ☐ Commitment ☐ Orchestration ☐ Reflection & Review	
Used the Strategies: ☐ Attention to communication ☐ Educated about consequences and practicalities ☐ Listened and engaged ☐ Created opportunities	

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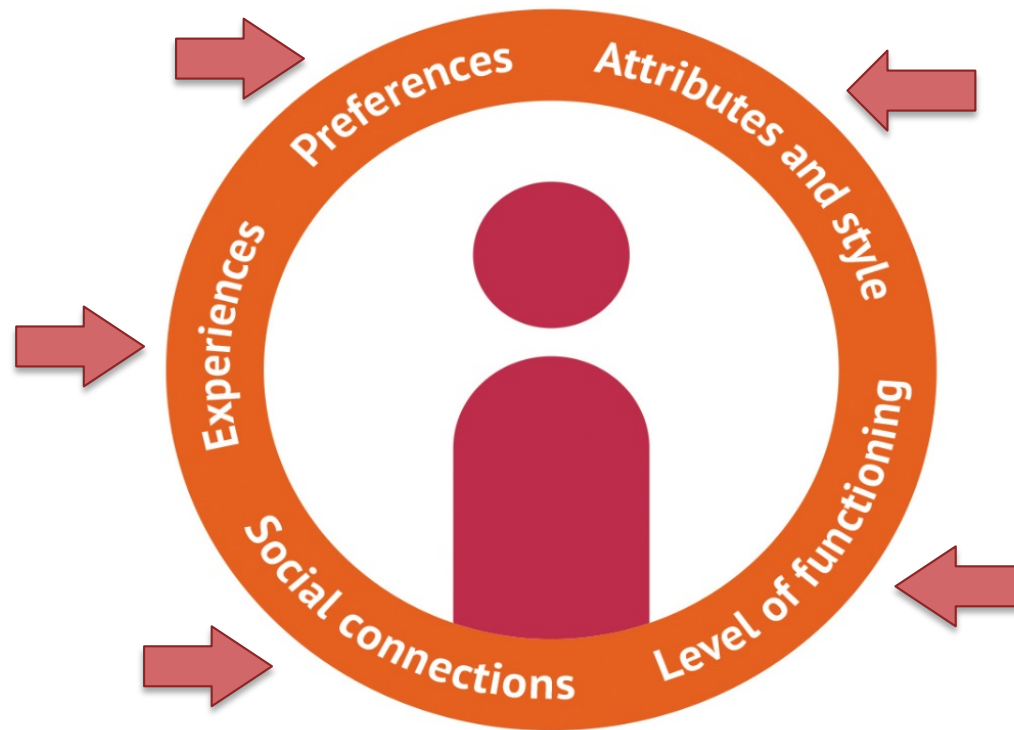
Breaking things down
Breaking into smaller components that are shared across the person and supporter – teaching and shaping skills

Knowing the person

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
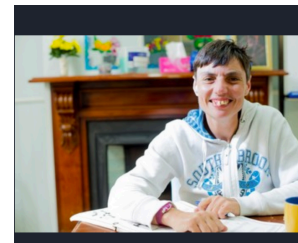
Refining the decision and taking account of constraints

- Preferences are prioritized, refined and shaped by constraints

  - time

  - money

  - impact on other people

  - safety - risk enablement process

- Finding ways to ensure the decision will be implemented

  - Questioning or managing potential constraints

Enabling Risk resources

About this resource.

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

Think about a risky choice			
List some positive outcomes that might come from this choice	Tick the box that best fits the category your positive outcome relates to		
	Physical Health & Safety	Psychosocial Well-Being	Financial
List some negative outcomes that might come from taking the risk	Tick the box that best fits the category your negative outcome relates to		
	Physical Health & Safety	Psychosocial Well-Being	Financial
List some of the negative outcomes from not taking the risk			
Explain how you might enable the risk to be taken			

Refining the decision and taking account of constraints

- Preferences are prioritized, refined and shaped by constraints
  - time
  - money
  - impact on other people
  - safety - risk enablement process

- Ways are found to ensure the decision will be implemented
  - potential constraints might be questioned or creatively managed

Is there a need for a formal process?

- Support for

    - self-generated decision

    - shared decision

        o may resemble an informal substitute decision

    - a more formal process of making a substitute decision

        o due to conflict or 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

    o 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

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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RESEARCH CENTRE
Supporting inclusion of people
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