



Delivering decision-making support to people with intellectual disabilities in Australia: Assessing the impact.

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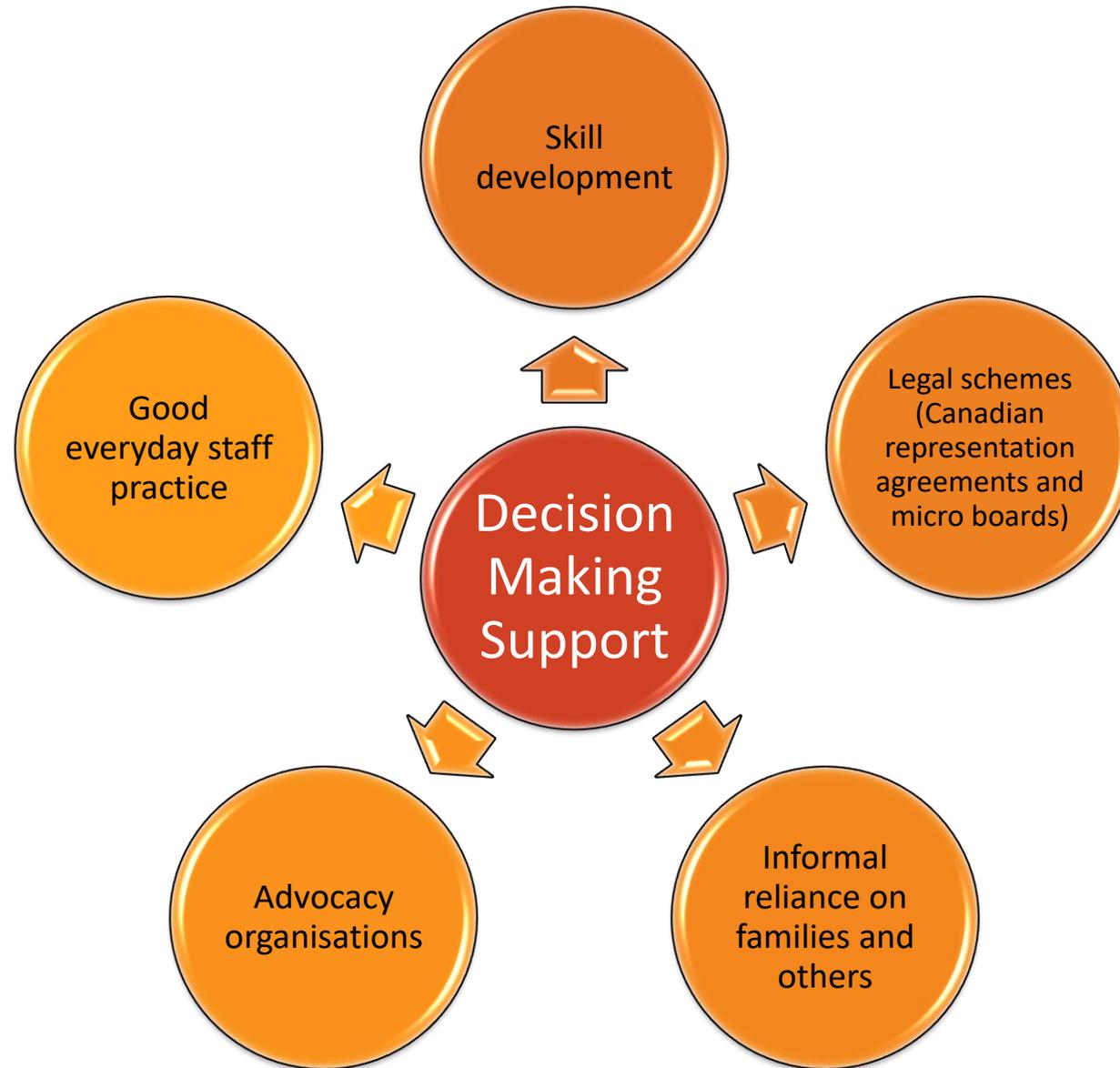
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New Paradigm of Supported Decision Making



- Premise: everyone has the right to participate in decision making
- Sufficient and effective support tailored to the individual to participate through:
 - changed expectations of others
 - development of skills and experience
 - support to express will and preferences
 - interpretation of the person's will and preferences.

Delivering Decision Making Support



Decision Making Support in Australia



Legal reform for supported decision making is pending in Australia

- Reform would give, for example, legal standing to supporters
- Use of term support for decision making to avoid confusion
- Many elements are not new and have begun to be put into practice

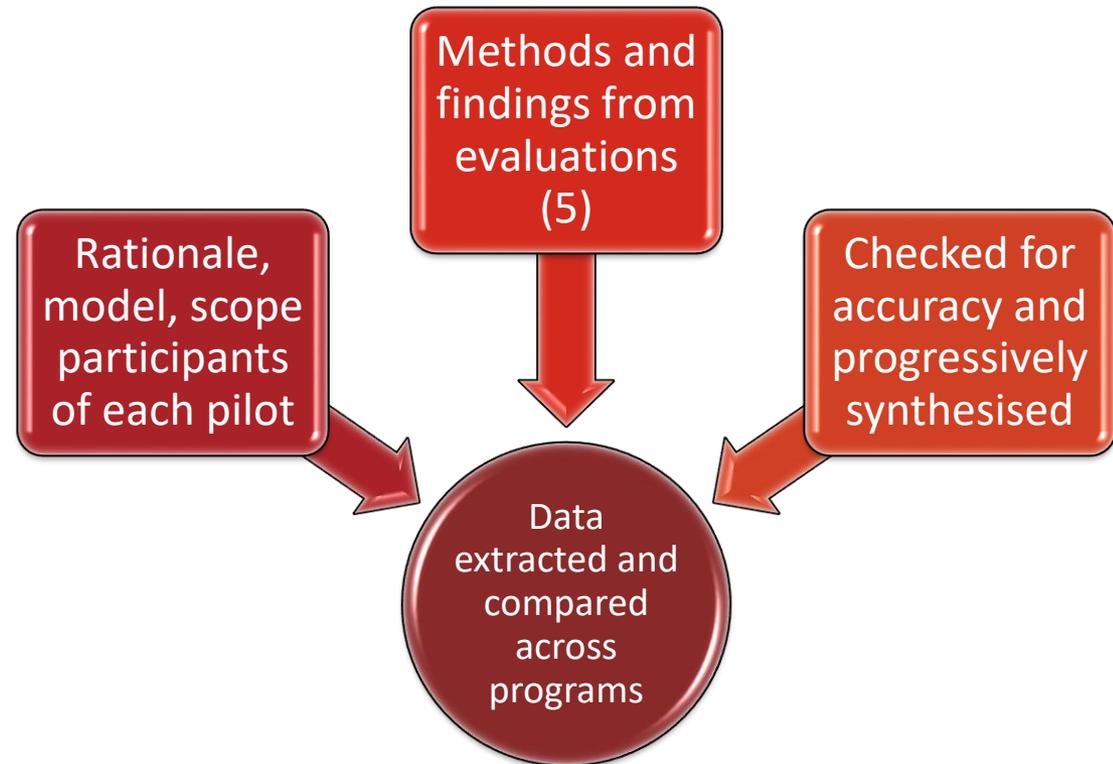
- Six Pilot projects between 2010- 2015 potential insights into:
 - Practice
 - Program models
 - Costs & benefits and effectiveness of varying models

Method

- From the large body of grey literature about the pilots
 - What can be learned
 - Implications for future development
- Critical review of descriptive and evaluative documents and resources developed



- SA1 Office of Public Advocate
- ACT, ADACAS, advocacy organisation
- VIC, Office of the Public Advocate
- NSW, Dept of Family and community services
- SA 2, Office of the Health & Community Services Complaints Commissioner
- WA Individualised Services (Waid)



Descriptive Overview

- Small: 6 - 36 decision makers
- Time limited: 1-2 years
- Non-statutory
- Similar aims
 - Enabling people to have more control over own decisions
 - Trial models of supported decision making with specific groups – socially isolated, people with more complex needs
 - Developing resources for supporters
- Opaque program logic – support to dyad of decision maker/supporter by coordinator and training
- Design slightly different
 - Support to dyad by coordinator or facilitator
 - Two step process – support for decision readiness – support to dyad
 - Dispersed – coordinator support to facilitators who support one or two dyads

Descriptive Overview

- Little information about inputs – staff time or skills
- Or about outputs, decisions made
- Decision-makers
 - Majority people with mild intellectual disability but also people with acquired brain injury
 - Targeted sub groups
 - At risk of guardianship (SA)
 - Complex support needs (ACT)
 - Socially isolated with informal support (VIC)
- Supporters
 - Recruited through existing networks, freely given and paid relationships
 - Volunteers with no prior relationship
- Development of resources – values and ideologically based



Images from, Supported Decision Making Project Resources, https://www.youtube.com/watch?v=Zqv7_J3SAAQ&index=2&list=PLC-Tk74kPjiRqGxRU24QTW45mO-PstVtu

Findings from the Evaluations

- 5 of 6 programs some evaluative report – very small sample sizes, primarily descriptive.
- Main themes:

Positive outcomes

- For decision makers – confidence, skills,
- For supporters – change of approach
- Feasibility for people under guardianship

Uncertain boundaries of decision support

- Difficulty getting decisions acted on
- Opposition and conflict from others in persons network
- Where do decision makers stand vis a vis others
- Does support extend to advocacy? Or case management?

Difficulty securing supporters

- Most supporters known to the person already but hard to engage
- Significant time to recruit
- Pre-existing volunteers in Vic but high drop out at first stage

Findings for the Evaluations

Positive value of program staff and support

- Supporters valued assistance to negotiate relationships, expectations, clarify aspects of role
- Staff provided advocacy, helped resolve conflict
- Staff helped continuity

Limited experience and low expectations of decision making

- Difficult to think of decisions want to make
- ACT identified decision readiness as initial step
- Need for broader cultural change to raise expectations of others
- More experience and opportunities for decision making

Varying value of written resources

- Conflicting views, some found them more useful than others
- Some preferred face to face individual support

What can be learned from these Programs?

- Positive outcomes can be achieved – even for people with guardians
- Demonstrates potential of decision support for people who are socially isolated – need for more knowledge about recruitment, retention and mentoring
- Identified some key issues for future – rather than resolved - practice
- Operating in the informal sphere of civil society can be difficult
- Moving to a formal or quasi legal scheme may help to more clearly define role and standing with others and be more inclusive
- Value of programmatic approach – embeds training, support, back up for decision making supporters
- Demonstrate support for decision making is an ongoing, lengthy, and time consuming process and not something that can be done alone

Last words... Implications for NDIS

- Decision making support is part of reasonable and necessary disability related needs – over long term, rather than one off short term event
- If decision making support is different from short term advocacy - case management - planning – needs teasing out more
- Everyone (planners and case managers) need to recognise when support for decision making is happening – is it working well or is there a need to look further for good support
- Need to tackle wider community/staff/family expectations and understanding about support for decision making
- Big gap in understanding how to deliver support about program logic, costs and benefits -some indication high resource intensity required
- But finding ways to support and resource decision making supporters is important
- There is a need to focus on the practice of How if the benefits are going to be realised – too often good policy fails at the practice stage

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Thank you

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Supporting Inclusion of people
with cognitive disability



Implications

- Regard as part of reasonable and necessary disability related needs – over long term, rather than one off short term event
- No clarity re success of short term capacity building programs such as WA - new study will test this and evidence based resources
- Need to tackle wider community/staff/family expectations and understanding about support for decision making
- No real progress in understanding practice or what resources work
- Exposed gap about program logic, costs and benefits
- Some indication high resource intensity required