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

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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

- Skill development
- Legal schemes (Canadian representation agreements and micro boards)
- Informal reliance on families and others
- Advocacy organisations
- Good everyday staff practice
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)

Methods and findings from evaluations (5)
Rationale, model, scope participants of each pilot
Data extracted and compared across programs
Checked for accuracy and progressively synthesised
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
  - Trail 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-Tk74kJiRqGxRU24QTw45mO-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
References and Resources

Virtual Special Issue of Research and Practice in Intellectual and Developmental Disabilities on support for decision making – free access to 10 papers

http://explore.tandfonline.com/page/med/rapidd-supported-decision-making

http://hdl.handle.net/1959.9/556872


Knox, L., J. Douglas & C. Bigby (2016). "I won’t be around forever” : Understanding the decision-making experiences of adults with severe TBI and their parents." Neuropsychological rehabilitation, 26,2, 236-260
http://dx.doi.org/10.1080/09602011.2015.1019519


**Pilot project evaluations**

Wallace M. Evaluation of the Supported Decision-Making Project. Office of the Public Advocate (South Australia), 2012.


Carers NSW. Supported Decision Making workshops for 14-18 year olds with disability, their families and/or carers. Sydney: The Department of Family and Community Services (FACS) and Ageing, Disability and Home Care (ADHC), 2016.


Other resources


Thank you

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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