



# Supporting people with cognitive disabilities in decision making: processes and dilemmas.

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# Background

- **The right to make one's own decisions** is central premise of the UN Convention on the Rights of Person's with Disability.
- Law Reform Commissions in Australia and internationally have focussed on new structures to enable people with CD to access support with decision making.
- NDIS legislation provides for the support of a plan nominee; a mix of substitute, supported and informal decision making (Carney, 2015).
- Much of the support with decision making occurs in the informal sector with family, service providers and, on occasions, lawyers.
- Supporters may not always be fully informed or convinced by the supported decision making philosophy. Research suggests it is not done well (Antaki et al., 2009; Bowey & McGlaughlin, 2005).
- Whilst some research is now being undertaken there remains a weak evidence base about processes of effective support for decision making for people with CD.

# Study aims

The study is part of a larger project “Supporting decision making and guardianship: building capacity within Victoria” being undertaken by Scope and funded by the Legal Services Branch to develop and test resources to enhance capacity of lawyers, workers and families to provide good support for decision making.

**Aim: To explore the experiences of people supporting people with cognitive disability (CD) to make decisions:**

- How do people provide support?
- What are some of the dilemmas they face?

Note: We make a distinction made between support for decision making and supported decision making.

# Methods

- Ethics: Obtained from LTU and Scope.
- Recruitment: the study was advertised through disability service providers newsletters, mailing lists and forums.
- Participants (n=35): 22 family members; 12 workers in disability services; 5 lawyers.
- Data collection: semi structured one on one interviews (lawyers and two family members); focus groups (4 x family members in carer support groups and 3 x disability workers).
- Data analysis: inductive thematic approach (Braun & Clarke, 2006).
- Findings presented within 3 major themes: 1) understandings of support for decision making for people with CD; 2) processes for supporting people with CD to make decisions; 3) dilemmas and tensions.

# FINDINGS

## Understandings of Support for Decision Making

### ***Making Sense of Support with Decision Making***

- Not all were aware of UNCRPD imperatives but **understood is as a human right to be accorded respect and dignity:**

*... [a person with CD should] decide what they want, get what they want and to have people listening to them and making sure they get it" (lawyer).*

*These people are human beings and deserve as much respect and dignity as anybody (family member)*

- A difficult and, dynamic and chaotic process;
- A break from the past where people were not perceived to have rights or the capacity to make or be involved in decision making. Some of these attitudes were seen to still linger:

*There are still people out there, working in the field who... have the same mentality as 20 or 50 years ago working in the institutions which is 'you come over here and sit down here and... wipe that off your mouth, everyone get into your pyjamas now, it's time for bed' (lawyer).*

# Understandings (cont.)

## *Differing types of decisions*

- Wide range of decisions – what to eat or wear through, whether to take up offers to participate in activities, planning personal goals, where to work, whether to get engaged or married, have a baby, move out of home.
- Lawyers more likely to mention ‘one off’ life changing decisions with legal dimensions, eg. whether to plead guilty in a criminal case, to apply for increased access to children in kinship care.

# Processes and Strategies of Support with Decision Making

## ***Supportive Relationships as the context***

- A relationship between the supporter and the person with CD.
- Support also often involved collaborations with different supporters.

*Families are involved in how people ultimately make their decision, other services and stakeholders can be involved... So it is sort of ensuring that the person has the benefit of all the people that they believe help them to make a decision (worker).*

Supporters themselves needed support:

- Family members valued speaking to other families through carer support groups.
- Lawyers sought support from disability support services if they felt they didn't have enough understanding of an issue or how to support someone with CD:

*...if we don't understand fully how to work with someone who uses a particular form of communication, we'll get advice and support from somebody who does before we meet with them and when we meet with them (lawyer).*

- Workers spoke of needing support from supervisors or managers to talk through issues, including moral dilemmas. (This support was not always sufficiently available).

# Processes and Strategies of Support (cont.)

## *Person-centred – tailoring support to the individual*

- This involved 1) supporters having a relationship of trust; and 2) knowing the person well - their cognitive capacity, life experiences, personality and modes of communication.
- Family members were more likely to have this knowledge; workers and lawyers had strategies for building trust and rapport, for example:

*He had footy posters all over the place so after I explained who I was and what I was doing, I said how could you possibly barrack for Essendon, the Cats are the people we need to barrack for so I tried to build a bit of a rapport up, a bit of a banter (lawyer)*

# Processes and Strategies of Support (cont.)

## *Person-centred – tailoring support to the individual*

Common strategies for tailoring support to the individual involved:

- **Engaging and building trust.**
- **Attention to Communication:** listening; awareness of verbal and behavioural cues; checking back for understanding; attentiveness to will and preference.
- **Education about Options, Consequences and Practicalities:** doing the research, making information understandable; presenting the options and pros and cons; explaining the consequences.
- **Creating opportunities** that encourage participation and build confidence.

# Processes and Strategies of Support (cont.)

## ***Aiming for neutrality***

- Workers and lawyers highlighted the importance of neutrality, rather than a stance of 'best interests'. This involved respecting decisions made by the person with CD whether or not they were perceived as good or sensible.

*...everybody has the right to make a bad decision, people should be supported to make their own decisions....they can make the wrong decision, it's their decision, doesn't matter if you disagree with it" (lawyer).*

- Self awareness of one's own values was critical to being neutral:

*...trying not to impose your own values when people are making a decision (worker).*

# Processes and Strategies of Support (cont.)

## ***Actively shaping decisions***

- On a number of occasions, family members gave less emphasis to being neutral. They had their own stake in the decisions. They also tended to have an overarching vision for the person's life; day to day decisions should be congruent with this:

*You have to have a philosophy...my view, with or without [name of daughter with CD's] input, is very much the goal that ...she should be working within the community, living within the community, supported as appropriate (family member).*

- They often spoke about shaping decision by sowing the seeds of particular ideas:  
*[My daughter should eventually live] in her own flat, her own apartment. But I've got to provide seeds for that...she won't be living anywhere anytime soon, we're talking a five to eight year horizon before that happens but that's the process of making it a tangible visual experience as much as anything else so she can look and see and touch...and actually grasp (family member).*

# Dilemmas and Tensions

*“...it’s not black and white and it can’t be and yet most government policies want it to be black and white” (family member).*

## ***Remaining Neutral***

Dilemmas arose from the power and influence that supporters could potentially exercise in the lives of people with CD. There were often hidden assumptions about what is in a person’s best interests (the type of life they should lead/is best for them).

One mother spoke of a conversation with her daughter’s fiancé about the timing of their marriage,

*[Fiancé] said when could they get married and they were both there and I said well [daughter] was 32 at the time and he was 18 years older so he was 50 then. So I said ‘how about when [daughter] is 50, does that sound okay?’, ‘yeah that’s fine, that’s fine’. He said ‘I’ll wait, she’s worth it’.*

# Dilemmas and Tensions

## ***Balancing rights with risk and self interest***

- Where family members thought a person with CD made decisions that was too risky for their long term health/best interests, they might 'step in'. Eg. plans for life long goals, health issues, readiness for relationships, marriage and parenting.

*Like when she had to have a pacemaker replaced. She said 'no way...we have a sausage sizzle at work, I'm not going'. And I said you have to go, your battery will go flat and you'll drop dead...(family member)*

- Workers too had boundaries, and weighed up a person's right to self-determination with judgments about risk and duty of care.

*...at the back of your head that if something goes really wrong somewhere you're involved in any decision making are you going to end up in the coroner's court (worker).*

# Dilemmas and Tensions

## ***Tensions between different supporters***

Differing assumptions and perspectives could lead to conflict; eg.

- One worker supported people's rights to intimate relationships but found families had concerns about safety and would default to saying 'no'.
- Some family members felt undermined by workers they viewed placed too great an emphasis on choice and self-determination

*[staff] ...let her have a little treat and little treats only become an iced coffee which is full of ice cream and sugar and... [daughter] will gravitate to choices which are not going to help her from a health and weight point of view (family member).*

- Participants spoke of 'working around' those with whom they differed and not always in respectful ways:

*I don't pay a lot of heed to what she [mother] says (worker).*

*If we find someone...who is not meeting the goals, we ask [the organisation] we're employing with; we ask 'can we have a change'? (family member)*

# Dilemmas and Tensions

One worker was frustrated by his organisations 'risk adversity':

*if I hear that one more time; 'Oh no we can't do it because of the privacy legislation' or 'it is an OH&S issue', those have become the big excuses for 'we can't do what people want' (worker).*

Rights could be competing ; for example the rights of the person with CD versus the rights of family members:

*He came to respite and personally, I think it was wrong... He was screaming- kicking and screaming and it was just really sad and it's like no. That's not fair. On him, on us (worker).*

*He refuses to go in a taxi ...so now I have to get him there and get him home every day, five days a week...Their rights override our rights when it comes down to this (family member).*

# Dilemmas and Tensions

## ***Dilemmas posed by resource constraints***

- Financial resources and access to services placed limitations on the options and decisions open to people with CD.

*He needs sports programs and not all of the service providers have a lot of sports programs (family).*

*the waiting time [for supported housing] here in the eastern region is something like 18 years. (family).*

- Realism and pragmatism had to be part of the decision making process, for example what is reasonable, real or within a person's capacity.

*[he wants to] play full forward for the Western Bulldogs next year (family);*

*...And another thing that will happen is in a group situation, like five people that we work with, sometimes you've got to re-schedule their choice (worker);*

*...so it is about trying to be real about stuff too and just, this idea you've got is a really nice idea but to put it in place you need to think ahead (family).*

# Discussion

- The findings highlight the importance of relationships and the notion of a support system for decision making around the individual, both for the individual with CD and the supporters themselves.
- Underpinning principles: being person centered, tailoring support to the individual and neutrality.
- Support involves 4 broad strategies: Engaging and building trust; Attention to Communication; Education about Options, Consequences and Practicalities; Creating Opportunities.
- But there are real tensions and dilemmas associated with supporting people with CD to make decisions.
- It is important to have a network of supporters; though tensions can result.
- Self awareness and reflection are critical.

# Recommendations

- The issues identified in this study and previous literature highlight issues that should be taken into account in thinking about training and support for workers, family members and lawyers.

Training should:

- Inform people of the philosophy of supported decision making; ie the 4 key principles articulated by the Law Reform Commission;
- Build knowledge/skills re communication with people with CD; self awareness; conflict resolution; potential strategies for support with decision making;
- Explore the inherent tensions and dilemmas;
- Emphasise the importance of collaboration between supporters and build knowledge of differing supporter roles and issues;
- Be integrated into an ongoing program of support.