"CHOICE AND CONTROL" WITHIN AUSTRALIA'S NATIONAL DISABILITY INSURANCE SCHEME (NDIS): CAN IT BE ACHIEVED FOR PEOPLE WITH SEVERE OR PROFOUND INTELLECTUAL DISABILITY?
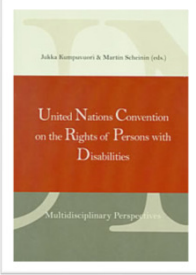
LESSONS FROM SUPPORTED DECISION-MAKING PRACTICE AND RESEARCH

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Deakin University CRICOS Provider Code: 001138

CHOICE AND CONTROL:
A PARADIGM SHIFT IN PUBLIC POLICY

Aukka Kumpuvuori & Martin Scheinin (eds.)

United Nations Convention on the Rights of Persons with Disabilities

Multidisciplinary Perspectives

"Recognizing the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices.

Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them"

(UNCRPD, 2006 Preamble)

ARTICLE 12

"…States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life".

"…States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity"

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CHOICE AND CONTROL

"**Choice and control** is about people with disability, their families and carers having control over the course of their lives, including the flexibility to make decisions about the disability services and supports they use"
(National Disability Insurance Agency, retrieved May 2017 from

"The scheme is a new way of funding individualized support for people with disability that involves more **choice and control** and a lifetime approach to a person's support needs"
(National Disability Insurance Agency, 2013 , p. 2)

"On the whole, participants want more **choice and control** in their life"
(COAG, 2017, p.21)

Choice

+

Control

→

NDIS

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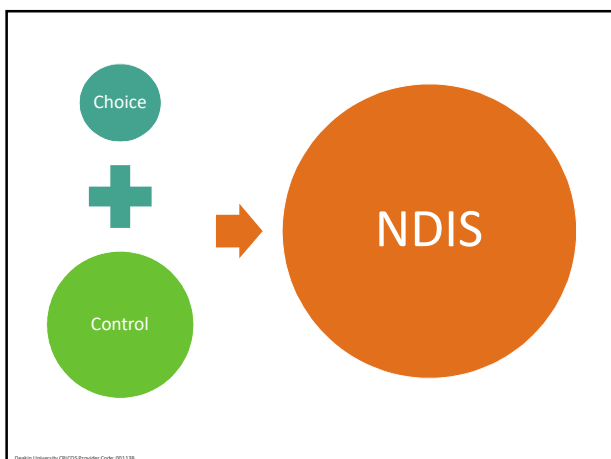
RESTRICTION OF DECISION MAKING SUPPORT WITHIN NDIS

Individualised approaches often present the act of preference expression as unproblematic
(Finlay, Walton & Antaki, 2008);

The expression of preference for people who communicate informally is rarely straightforward and demands dedicated time and attention
(Finlay et al., 2008; Grove, Bunning, Porter, Olsson, 1999).

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The more severe someone's cognitive disability the fewer opportunities they have to exercise "choice and control"

(Wehmeyer & Garner, 2003; Agran, Storey, & Krupp, 2010; Burton-Smith, Morgan, & Davidson, 2005)

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ESTIMATED USERS OF THE NDIS
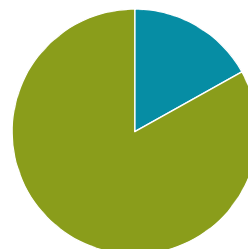
- People with Intellectual Disability
- Other

Cited in Bigby (2014)

"If we are to ensure that the NDIS delivers on its promise of choice and control, and social and economic participation for people with intellectual disabilities:

- How can the voices and perspectives of people with intellectual disabilities be built into the very fabric of the NDIA and the NDIS?

- How will support for choice and choice and decision-making be mediated by the NDIA to ensure that the desires of people with intellectual disabilities are at the heart of decisions about support?"

Bigby (2014)

METHOD

Design: An action research iterative research design;

Participants: 5 people with severe or profound intellectual disability and their circles of support (33 in total);

Procedure: A supported decision-making intervention over a period of 3-6 months for each case study;

Data collection: Interview, facilitated group discussion, questionnaire, and observation;

Analysis: Interpretative phenomenological analysis.

RESEARCH QUESTIONS

1. What role do people who communicate informally play within a supported decision-making process?

2. What role do supporters of someone who communicates informally play within a supported decision-making process?

3. What factors underlie supporters' role of responsiveness in supported decision-making for people who communicate informally?

A model of decision making support for people with severe or profound intellectual disability

Watson, 2016
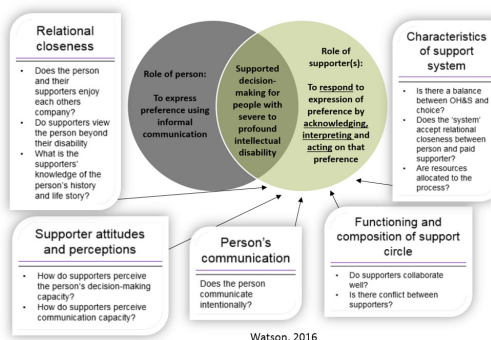
CHARACTERISING SUPPORTED DECISION-MAKING FOR PEOPLE WITH SEVERE OR PROFOUND INTELLECTUAL DISABILITY

Role of person:
To express preference using informal communication

Supported decision-making for people with severe to profound intellectual disability

Role of supporter(s):
To respond to expression of preference by acknowledging, interpreting and acting on that preference
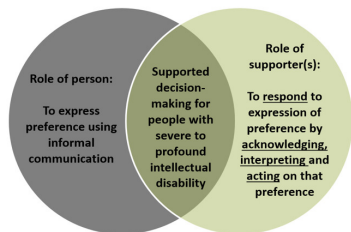
1. What role do people with severe or profound intellectual disability play within a supported decision-making process?

2. What role does a supporter of someone with severe or profound intellectual disability play within a supported decision-making process?

## THE ROLE OF A PERSON WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY IN DECISION-MAKING

To express will and preference, intentionally and unintentionally using a range of modalities

(e.g. behaviour, vocalisation, vocal pitch, muscle tone, facial expression, eye movement, self-harm, breath, unintentional physiological functions)

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THE ROLE OF SUPPORTERS IN DECISION-MAKING FOR PEOPLE WITH SEVERE TO PROFOUND INTELLECTUAL DISABILITY

The role of supporters is to **respond to expressions of preference** by **acknowledging, interpreting** and **acting on** this expression in some way.
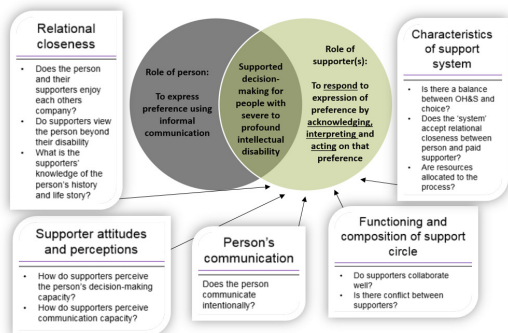

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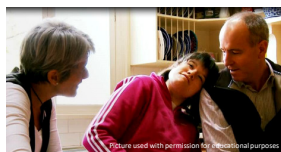
"See, look at him, when he's hovering around the kitchen like that [acknowledging expression of preference], he's usually hungry. He's saying give me my dinner now [interpreting expression of preference]… so we know we have to get our skates on [acting on expression of preference]"

"He's helped us come to a decision about whether or not he gets an Ipad [acting on expression of preference]. If we hadn't seen him staring at that video [interpreting expression of preference], I mean, did you see his face? [acknowledging expression of preference]"

"head back like that, that certainly tells us stuff, oh yeah and the chair rocking [acknowledging expression of preference]. It usually means, get me out of here, or do something [interpreting expression of preference]. Come on mate let's go outside [acting on expression of preference]"

A model of decision making support for people with severe or profound intellectual disability

Relational closeness
- Does the person and their supporters enjoy each others company?
- Do supporters view the person beyond their disability
- What is the supporters' knowledge of the person's history and life story?

Role of person:
To express preference using informal communication

Supported decision-making for people with severe to profound intellectual disability

Role of supporter(s):
To respond to expression of preference by acknowledging, interpreting and acting on that preference

Characteristics of support system
- Is there a balance between OH&S and choice?
- Does the 'system' accept relational closeness between person and paid supporter?
- Are resources allocated to the process?

Supporter attitudes and perceptions
- How do supporters perceive the person's decision-making capacity?
- How do supporters perceive communication capacity?

Person's communication
- Does the person communicate intentionally?

Functioning and composition of support circle
- Do supporters collaborate well?
- Is there conflict between supporters?

Watson, 2016

What does this mean for practice within the context of the NDIS?

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BUILDING CAPACITY WITHIN THE SYSTEM TO INCREASE UNDERSTANDING OF:

- The UNCRPD and the relationship of Article 12 and supported decision making to individualised planning;

- What supported decision making can look like for people who communicate informally;

- The role of communication partners to respond to will and preference (acknowledge, interpret and act);

- The factors that impact on responsiveness.

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A FOCUS ON ENHANCING RESPONSIVENESS THROUGH DEVELOPING UNDERSTANDINGS OF:

1. Communication
   Valuing all communication;

2. Attitudes and perceptions
   Perceptions of communication and decision making;

3. The importance of relational closeness
   Knowledge of a focus person's history and life story;
   Knowledge of the focus person "beyond their disability;
   Enjoyment of one another's company.

4. The value of collaborative decision making support;

5. The value of a coordinating role.

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COMMUNICATION:
AN UNDERLYING FACTOR IN SUPPORTERS' RESPONSIVENESS

Supporters demonstrated greater levels of responsiveness when those they supported communicated intentionally rather than unintentionally

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VALUING ALL COMMUNICATION

Well he was aspirating all the time. It was just too risky. We had no choice. He was always in hospital with pneumonia. Na, even if he could participate in the decision he would have had no say, it had to go in, you know, it was a matter of life and death. Ask Tina the speechie. That's just the way it had to be.

Well it was hard. Kev loves his food. I mean he really loves his food, hey guys. So, we knew what he would prefer. But he had so many bouts of pneumonia, and he gets so sick. Remember that Christmas he was in hospital, poor love. But we weighed things up and it was clear that he wanted to eat orally, so even though he now has the peg, we let him take risks and eat most days. It's just really important to him, so it's worth the risk. That's what we reckon anyway.

"So, like with Kev, he is much clearer, we know what he wants more, so we tend to respond to him you know. He will bang the cup on the table, saying, I want breakfast. I want it now! Not like Yuri, he is so quiet, and we don't know what he wants, it's so much harder to work it out, you know. So you know, I guess you could say we ignore him a lot of the time"

"I feel bad, he gets ignored a lot, because he can't tell us stuff. I guess we don't respond to him, like, as much as the others. There's nothing to respond to. Does that make sense?"

SUPPORTER ATTITUDES AND PERCEPTIONS:
AN UNDERLYING FACTOR IN SUPPORTERS' RESPONSIVENESS

Supporters demonstrated greater levels of responsiveness to a person when they had:

- A positive belief regarding that person's ability to communicate;

- A positive perception of that person's decision-making capacity.

POSITIVE BELIEF IN ABILITY TO COMMUNICATE AND MAKE DECISIONS

Supporters classified as responsive:

"Yeah, he's communicating, he communicates all the time, you know, whether it's spitting, crying, you know so many things".

"Well, he is telling us things all the time you know. You know, what he wants to eat or doesn't want to eat"

Supporters classified as unresponsive:

"They can't, they can't really tell us things, you know. They can't tell us; they haven't got a voice to speak"

"…At the end of the day, people don't know what we're dealing with here. They just can't communicate. It's different for them, they can't tell us what they want"

"Because, you know he can't communicate. He has a lot of brain damage you know

RELATIONAL CLOSENESS:
AN UNDERLYING FACTOR IN SUPPORTERS' RESPONSIVENESS

Supporters who reported having an intimate or very close relationship with a person they support demonstrated greater levels of responsiveness to that supporter's expression of will and preference.

SUPPORTERS WHO REPORTED INTIMATE/VERY CLOSE RELATIONSHIPS
HISTORY AND LIFE STORY

"It was everything that we all know he wanted, coz you know, we know him love. We have known him all his life. And Dave reminded me, you know his cousin, you know the one with the hair, he reminded me about the jelly slice that he loved before the peg when he was teeny tiny. So we had to have that after didn't we, with a cuppa you know. He would have loved it"

"We used to take him up to Echuca. He liked to go for a ride in the speedboat. We used to sit him in the speedboat and he used to get excited with the water splashing and that sort of thing. He might be like me I'm a bit of a speed freak!"

SUPPORTERS WHO REPORTED INTIMATE/VERY CLOSE RELATIONSHIPS
SAW PERSON BEYOND DISABILITY

If Kevin had control over the stereo in the bus, what would he listen to?

"oh yeah… he likes some like rock type music, like ACDC. Yeah something with a bit of guts"

"Yeah, you're right, something with guts, loud loud loud! Yeah louder the better hey Kev. A deep heavy base line don't ya reckon, Nirvana or maybe even Primus"

If Nathan had control over his food, what would he eat?

"He'd be a foodie I reckon. You know creamy yummy cheese, flash wine, chocolate, the works"

If he/she had control over his life, what would it look like?

"He would be comfortable, but stylish. He wouldn't wear these trackie dacks. I think he would be quite social. He has that Scottish sense of humour. He would have to have a very fast car. I always thought he would be a courier or something like that"

"She just really loves interacting with other people, singing, dancing, you know. She would have made a great cheerleader".

ENJOYING COMPANY

Supporters who reported intimate or very close relationships

Hey Yuri, we love it here, don't we mate? [He placed his arm around Yuri and squeezed]. We love people-watching together. There's all sorts come here, we have a bit of a laugh, don't we mate?"

"So, we love it. We really look forward to our Thursdays. You know we just hangout. Ang hassles me all week long, you know 'in the car car'. It's so much fun, we spend the whole day laughing!"

Supporters who reported distant/not close relationships

I know this sounds awful, but I kind of was shocked when I met them. Is it awful that I dry retched! Yuri had a smell! Oh, I'm sorry I sound awful. It wasn't only me though, he didn't seem to care that I was there either… With Kevin and Yuri, I kind of get the feeling that they don't want me in their life. They give me very little back. D'ya know what I mean?

FUNCTIONING AND COMPOSITION OF CIRCLE OF SUPPORT:
AN UNDERLYING FACTOR IN SUPPORTERS' RESPONSIVENESS

Supporters demonstrated greater levels of responsiveness when they did so within the context of collaboration
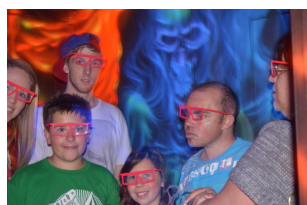
Interpreting individually	Interpreting collaboratively
Support worker 3: He's not saying anything [No acknowledgment of preference expression]. He's comfortable I guess. I know I should see something in this, it's a trick question may be [No acknowledgment of preference expression]. I can't see anything [No acknowledgment of preference expression]. I don't know what he is saying, with that noise [No interpretation of preference expression], I don't get what you're wanting me to do, may be I'm missing something? Na, I'd just keep him in the sling, I don't know [No action in response to preference expression].	Supporter 1: "Wow look at that. Look at his face? Can you stop the video? I want to show you" [acknowledgment of preference expression]. Supporter 2: "Ah, yeah, he looks a little stressed I reckon" [interpretation of preference expression]. "When you pause it like that, you see his little mouth change" [acknowledgment of preference expression]. Supporter 3: "Looking at that, he isn't happy. Not at all" [interpretation of preference expression]. "Listen, listen to that noise, that's a pissed off noise [interpretation of expression preference]. "Bloody hell, looking at this he wants to stay in his chair" [interpretation of expression preference]. "Why didn't she just leave him there?" [Identified action in response to preference expression].

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CONCLUSIONS

These findings further our understanding of what decision-making support looks like for people who communicate informally.

They give a focus for practice and policy efforts aimed at ensuring people who communicate informally can achieve choice and control within the context of the NDIS.

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ACKNOWLEDGMENTS

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This research is especially dedicated to two participants in this study, who died during. They along with their families and supporters taught me so much more than any seminar, workshop, textbook, or academic paper ever could about living with a severe or profound intellectual disability.

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