

THE RELEVANCE OF ARTICLE 12 FOR PEOPLE WITH SEVERE/PROFOUND INTELLECTUAL DISABILITY

IASSIDD 15TH WORLD CONGRESS

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THE ISSUE

People with intellectual disability generally do not have the same choices as those without cognitive disability.

The more severe someone's intellectual disability the fewer opportunities they have for self-determination

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



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”As has been the case with self-determination movements of the past, such as self-advocacy and person centred practice, opportunities for supported decision-making appear to be dominated by people with mild, as opposed to more severe intellectual disability, whose decision-making capability are less likely to be questioned”

(Watson, 2016 p.334)



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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

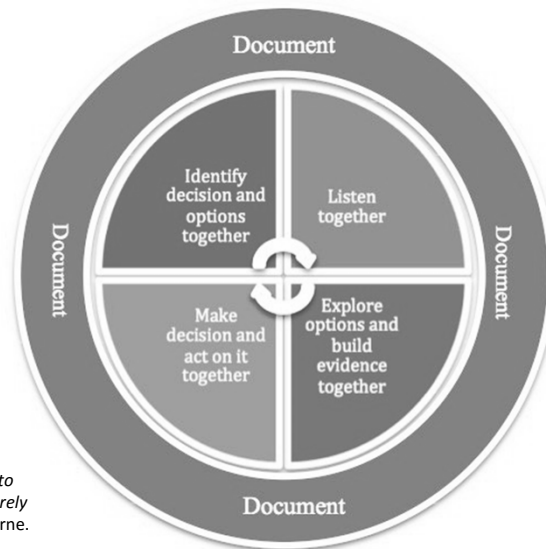
Data collection: Interview, facilitated group discussion, questionnaire, and observation

Analysis: Interpretative phenomenological analysis



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THE APPROACH: LISTENING TO PEOPLE RARELY HEARD



Watson, J. (2016). *PhD Thesis: The right to supported decision-making for people rarely heard.* (PhD), Deakin University, Melbourne.

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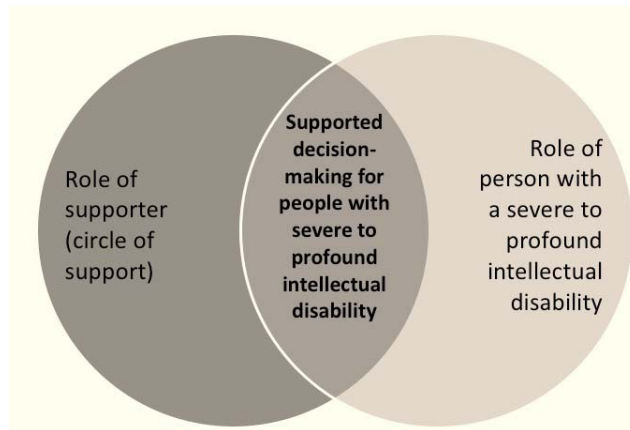
RESEARCH QUESTIONS

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?
3. What factors underlie supporters' role of responsiveness in supported decision-making for people with severe or profound intellectual disability?

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



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The role of a person with severe to profound intellectual disability in supported 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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“He screamed and splashed the shower water [expression of preference using body language and vocalisation]. I came into the shower cubicle thing and asked him if he had finished, He smacked me over the head [expression of preference using behaviour]” (support worker)

“Sometimes if he’s interested, his head is down but his eyes are up [expressing preference using head/eye movement] ...” (supporter worker)

“He communicated... that he was hungry and wanted a chest massage... with the humming and that [expression of preference using vocalization] ...there’s something about the pitch of that noise ... the pitch of hum [expression of preference using vocalization], the speed of his huffing and puffing [expression of preference using breath]” (support worker)

“He's communicating that he doesn't like change through that behaviour, you know the humming [expression of preference using vocalisation] and gauging [expression of preference using behaviour of concern]. Have you seen him put his hand in his mouth, you know the flapping [expression of preference using behaviour of concern]. That happens when we change something” (supporter)



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Characterising the role of supporters in supported 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]”

