

Listening to people rarely heard:  
*Supporting decision making for people who communicate informally*

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sjáumst í Rússlandi



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Það er rúsinan í pylsuendanum



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We live in a time and place where freedom and autonomy are valued above all else

(Schwartz, 2000)



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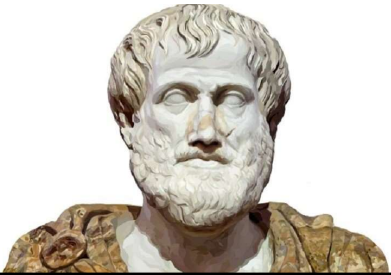
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Autonomy



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Is autonomy a universal right?



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Photograph used with permission and returned from Listening to those rarely heard DVD (Watson & Joseph, 2011)



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The less formal a person's communication the fewer opportunities they have to exercise "choice and control"

(Wehmeyer & Garner, 2003; Agran, Storey, & Krupp, 2010; Burton-Smith, Morgan, & Davidson, 2005, Watson, 2016, 2017)



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**United Nations Convention on the Rights of Persons with Disabilities**



“...promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”

(UN General Assembly, 2006 Article 1)




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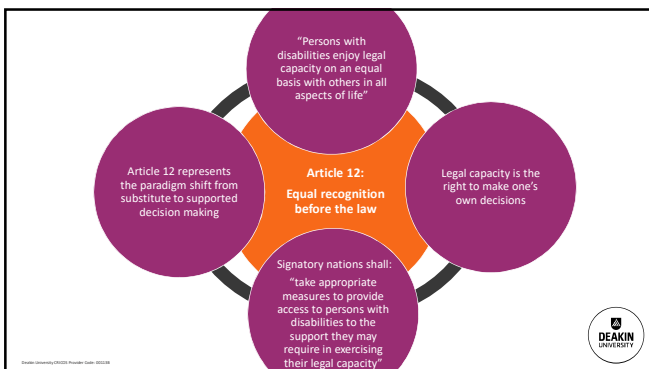
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“Such people it is argued, lack the capacity of reason, of self-awareness, and of self-determination. These attributes define personhood, and consequently their absence means that an individual lacking them is therefore not a person. From this perspective, euthanasia for such nonpersons is acceptable and indeed should be actively pursued”

(Singer 1993)

“..it [the enlightenment] probably had the largely accidental effect of narrowing down our understanding of the essence of personhood – an essence that telescoped narrowly into cognitive ability”




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### Supported decision making

Supported Decision Making explicitly recognizes that choices are made within a social context, and therefore it is likely to benefit those who require support from people who know and love them to make decisions.

Supported Decision Making makes the assumption that everyone can guide their own decisions with support, and therefore challenges the notion of individual decision making incompetence.

(Watson, 2016)



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Does Article 12 and supported decision making have the potential to resolve this inequality?



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'The starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices'

(Beamer, 2001)



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### Re-conceptualising decision-making capacity

The ability of a person to make or participate in a decision either independently or through a collaborative process of support from a group of people in the concerned person's life who know them well.

This definition embraces the interdependent and collaborative nature of decision-making particularly for people who communicate informally and sometimes unintentionally, rejecting the notion of individual decision-making capacity.

(Watson, 2016)

Watson 2017



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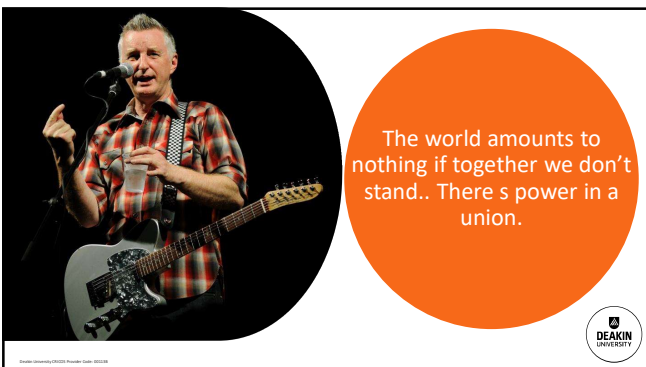
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**Relational autonomy**

“The traditional notion of autonomy as involving self-sufficient independence and boundaries against others is unhelpful...

... Instead of rejecting it, autonomy can and ought to be reframed around the idea that self determination is consonant with the importance of the role of others in relation to that self”

(Reconceiving Autonomy: Sources, Thoughts and Possibilities by Nedelsky, 1989)

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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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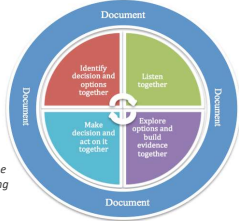
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## A Decision Making Framework

A tool for people supporting those who communicate informally to live lives they prefer



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



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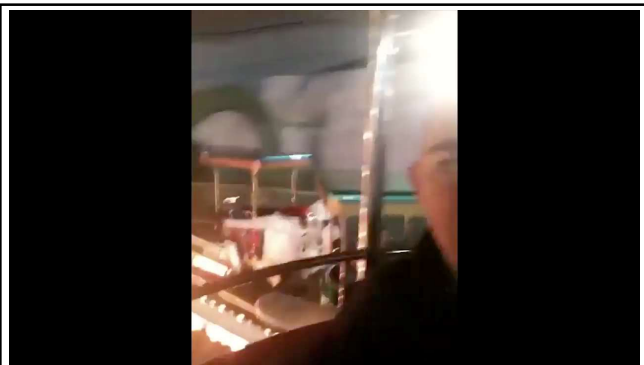
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## Research questions

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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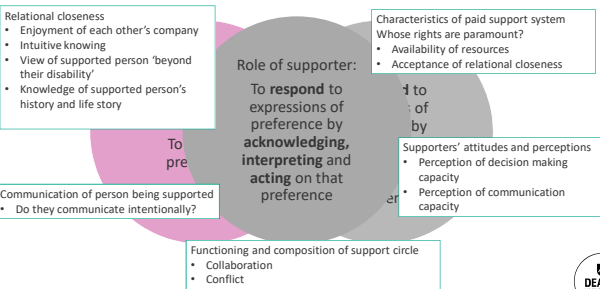
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## Characterising decision making support for people who communicate informally




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**".. there's something about the pitch of that noise he makes, I can't explain what it is, but I just know, that he is responding to the chaos in the room. It's the pitch of his hum, with the speed of his huffing and puffing or something. No, guess it's everything all put together. I don't know, I just know. Sounds a bit weird, doesn't it?"**

(Paid supporter)




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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]"*

*"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]"*




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"Ok, so you're saying he can make a decision? I get it, I get what you're saying, but I'm, I'm not sure you know him, do you? He can't tell us what he wants. We just decide shit for him. You know, no offence but we have all these programs and stuff, but at the end of the day, people don't know who we're dealing with here. They just can't communicate. It's different for them, they can't tell us what they want, so we just have to get on with it and make decisions that we think are best for the guys"

"...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"  
(Unpaid supporter)




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**Risk taking**

Well he was aspiring 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.  
(Paid support worker)

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..... 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.  
(Paid support worker)




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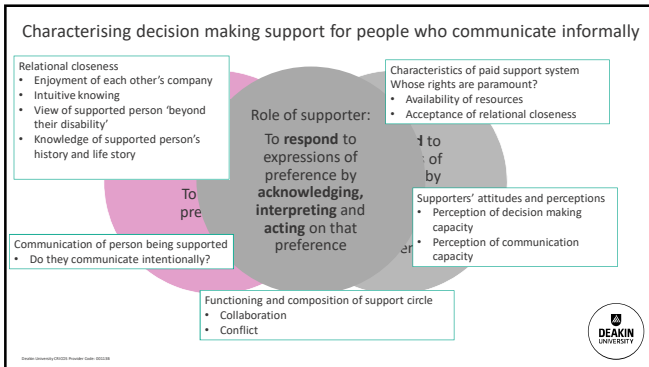
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**Relational closeness:**  
*An underlying factor in supporters' responsiveness*

Supporters reporting an intimate or very close relationship with a person they support demonstrated greater levels of responsiveness to their expression of will and preference

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**What does relational closeness look like?**  
Knowing a person's life story

Our stories allow us to share our humanity with one another

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**What does relational closeness look like?  
Knowing a person's life story**

*"It's just great to hear all the stories of what she got up to from her folks. You know she's already had such an amazing life. Thanks to them, I really feel like I know her. Just looking at the family photos, and talking to them, I feel really close to her you know, like I have known her all my life. Really though, I've only really worked with her this year"*

*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"*

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**What does relational closeness look like?  
Seeing a person beyond their 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"*

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**Enjoyment of each others company**

*"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!"*



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'I know this sounds awful, but I kind of was shocked when I met them. Is it awful that I dry retched? Gary had a smell, oh I'm sorry I sound awful.'

They weren't like Dave when I first met him. He made me laugh. He looked me in the eye and made me laugh. With Neil and Gary, I kind of get the feeling that they don't want me in their life. They give me very little back, you know what I mean'

"His challenging behaviour don't help, behaviours of concern, whatever we are calling it these days. The spitting, it's so not attractive. It's ok for us because we're used to it, but all that spitting and then playing in it. We were in Spotlight the other day, people were staring and moving away, it's just disgusting and I tell him that! I make him clean it up. Who's going to want to be his friend?"




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### Barriers to relational closeness



I've told her [paid support worker] that she shouldn't be dropping in there for a cuppa! She knows too much about Neil and his family. It's ok that she shares superficial things with Neil but she knows, she's seen it all these times she has seen and what she got up to on the weekend, stuff like that. But she also, you can't then over the line in terms of professional and personal stuff. I don't get it. It's impossible. I'm meant

"It was decided that the paid relationship was wrong, that such a friendship was 'unprofessional' and crossed the boundaries of what was acceptable. So it stopped. No more meals with the family. No more days out or festive fun (Paid supporters)




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'He is just not as lucky as some others guys in the house. The only people who really give a shit about him are us support workers. Imagine a life like that'

\* Support worker




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“Honum varð litið upp til hlíðarinnar og bæjarins að Hlíðarenda. Þá mælti hann: “Fögur er hlíðin svo að mér hefir hún aldrei jafnfögur sýnst, bleikir akrar en slegin tún, og mun eg ríða heim aftur og fara hvergi!”



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Thank you to all those who participated in this research.

The research is especially dedicated to two men who died during the study.

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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