


Acknowledging, interpreting and acting on the will and preference of people rarely heard

Dr Jo Watson
School of Health and Social Development
Deakin University
Melbourne, Australia


Twitter: @Jowat




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 decision making incompetence.






Signatory nations shall:
"take appropriate measures to provide access to persons with disabilities to the support they may require in exercising their legal capacity"

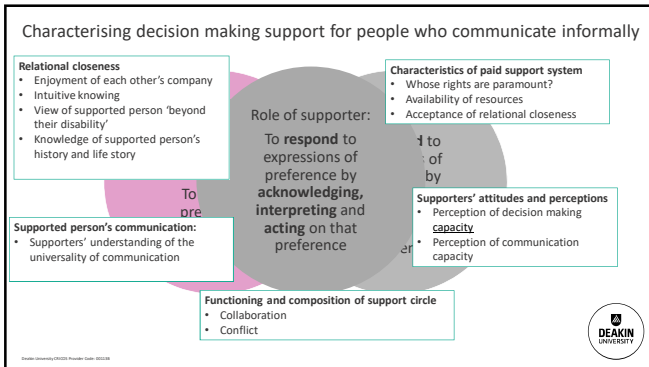
"Persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life"

UNCRPD
Article 12:
Equal recognition before the law

Legal capacity is the right to make one's own decisions

Personhood





The role of a person who communicates informally 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)

DEAKIN UNIVERSITY

The role of supporters is:

to respond to expressions of preference by: acknowledging, interpreting and acting on this expression in some way

DEAKIN UNIVERSITY



Understanding the universality of communication






Supporters demonstrate greater levels of responsiveness when they understand that communication is universal

Image used with permission for educational purposes




The Human Communication Continuum



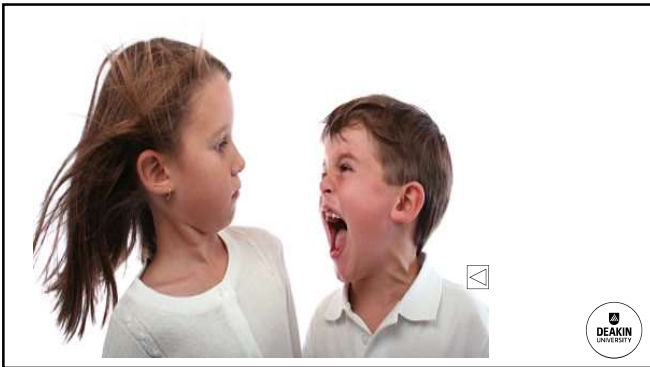
Unintentional Formal

Intentional informal

Watson and Joseph, 2015





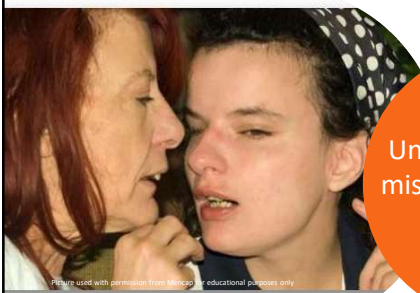




“all people, no matter how severe their level of disability, can and do attempt to communicate”

(Mirenda, Iacono, Williams, 1990 p.3)





Understanding our misconceptions and biases



“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)


“Because, you know he can’t communicate. He has a lot of brain damage you know”
(Paid support worker)



“So, like with Kev [intentional communicator], 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”

Paid support worker






“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?”

(Paid support worker)




The Human Communication Continuum



Unintentional Formal

Intentional informal

Watson and Joseph, 2015





Building decisions from expressions of preference



'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)



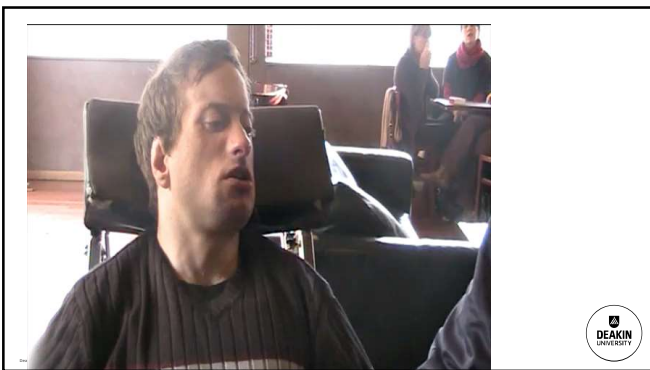
Understanding a person's will and preference

Preferred activity analysis (Watson, 2017)


Exploration of options worksheet (Watson, 2017)











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

Knowing a person's life story




Our stories allow us to share our humanity with one another



Story telling strategies

- Multi-sensory story telling
- Multimedia profiling
- Communication dictionaries
- Books about me



Seeing a person beyond their disability

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".



We need to challenge the system around relational closeness





Collaborate, collaborate, collaborate





