



Queensland  
**Aphasia**  
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# Profound intellectual disability and decision-making: Lived experience from the margins

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# Acknowledgment of Country

The University of Queensland (UQ) acknowledges the Traditional Owners and their custodianship of the lands on which we meet.

We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We recognise their valuable contributions to Australian and global society.



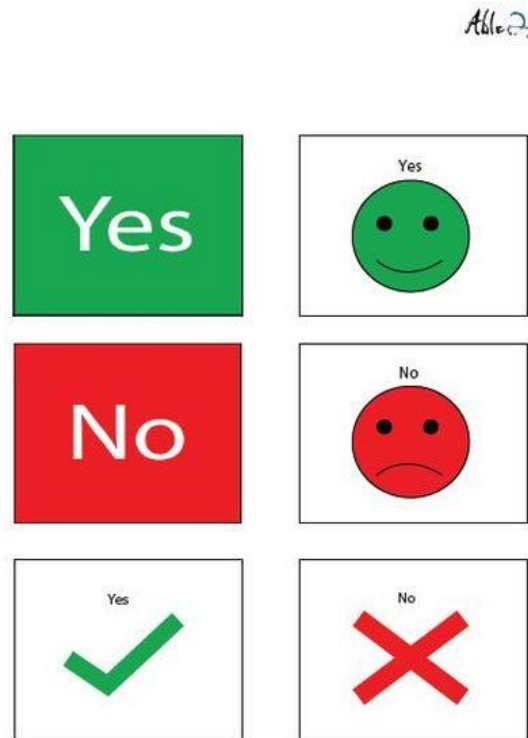
# Decision-making in practice

## The Problem:

- Nothing about us, without us: People with profound intellectual disabilities?
- Is decision-making really supported?: Practical Examples
  - Our experience: Deciding to do this Keynote
  - An example from my research: Banking and Finance
  - ‘Will and Preferences’?

## Better Understanding the Problem:

- Profound Difference
- Radical Dependence
- What might **Inclusion** based on this understanding look like?



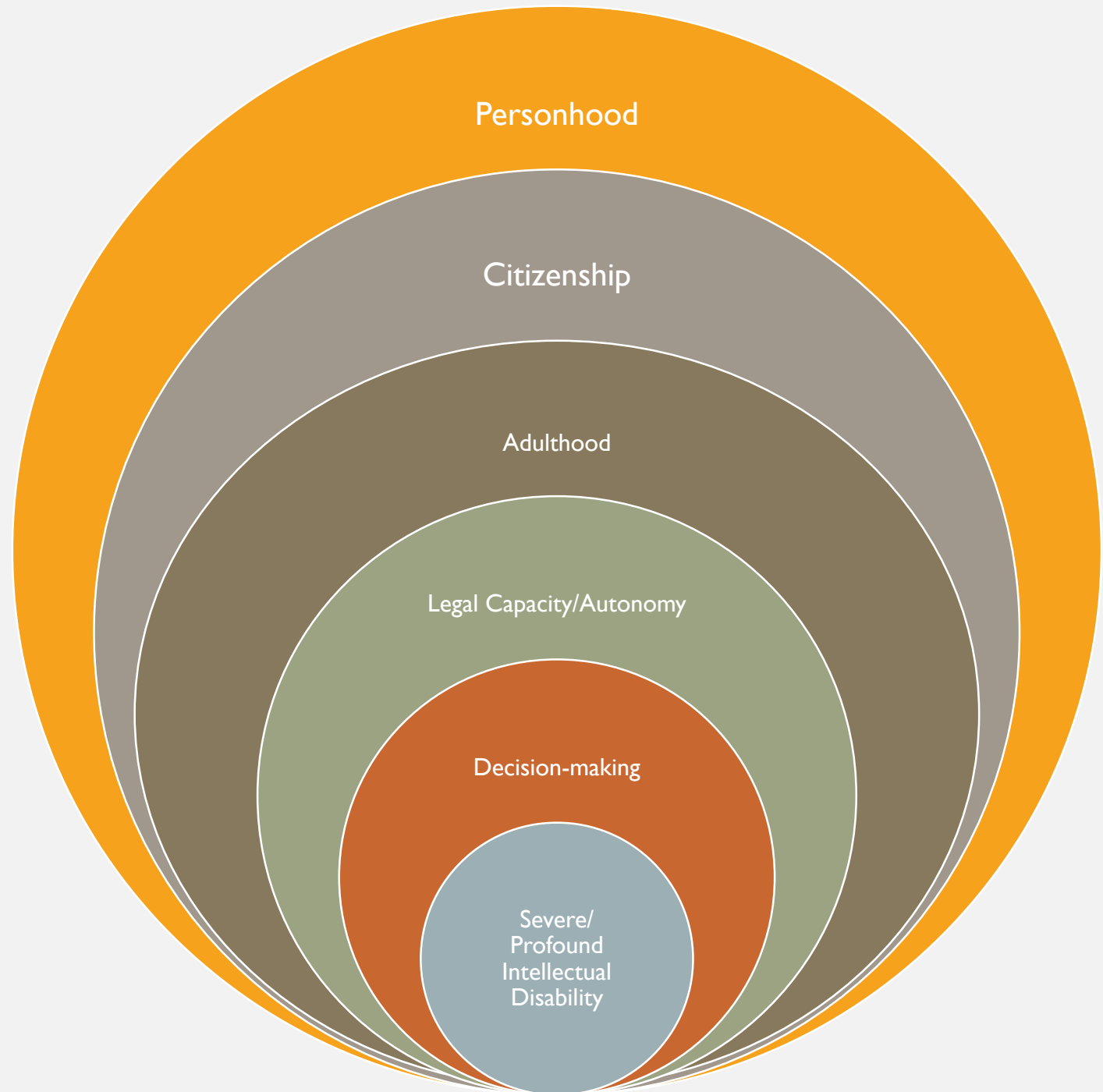


# Our Story

RESEARCHING THE PERSONAL

The Transition to Adulthood of  
People with Severe and Profound  
Intellectual Disabilities in Australia:  
A Socio-Legal Examination (2023)

Supervisors: Professor Shih-Ning Then  
& Dr Elizabeth Dickson  
*Queensland University of Technology*





## Deciding to come to this Conference



# Banking



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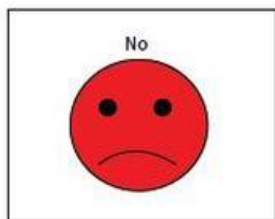
**Fran:** ‘Oh, she has to come in and fill out this paperwork.’ Well, she’s not able to read or write. ‘Oh, you just fill it out and she just signs it!’ Well, she can’t hold a pencil. ‘Oh, she just has to make a mark’. Well, she can’t. **She physically doesn’t even know what she is doing.** I said, ‘can’t I sign on her behalf?’ And they said, ‘no, you can’t.’  
[laughs] *Interview 15: Fran, mother of Susan (age 17)*

**Belinda:** Oh, the bank account! Well, because he had to have his own bank account for the post-school funding to go into, the bank says he has to have his own account. I said, ‘well, he can’t sign!’ ‘No, he has to come in and he has to sign his own name.’

So, we went to the bank, and it was all ready for us. And Andrew loves pens, he’s swiped quite a few pens in his time [laughs], and, well, I managed to get him to put a dot on their piece of paper. They were happy with that. Apparently, that’s all we needed was a dot on a piece of paper and Andrew got his own bank account  
[laughs] *Interview 20: Belinda and Andrew (age 23).*

# The Problem...

Able2L



## Supported Decision-making

- UNCRPD Article 12
- Merges legal *standing* with legal *agency*
- Implementation in Australia?

## The Hard Cases?

- Realities of *profound difference* and *radical dependence*

## Substituted decision-making

- (Best interpretation of) will and preferences?
- Realities of practice in systems/jurisdictions
- Good alternatives?



## PROFOUND DIFFERENCE

**Catherine:** So, a week later, she's still not back to normal so we went back, and she actually had a compression fracture of her spine. But what I'm trying to get at is, **she can't communicate that.** That's the hard part. She can't tell me if she's hot or cold, she couldn't even tell us she had a broken back.

*Interview 19: Catherine, mother of Molly (age 21)*

**Millie:** I can ask her about banking as much as I like, she has no way of understanding that. I might ask, but **she can't answer those questions.**

*Interview 6: Millie, mother of Sarah (age 26)*

**Alison:** Yes, I wish! I wish I could put her on the phone! Mary can't hear, she can't speak, **she can't make any decisions on behalf of herself, and she doesn't fit into their system.**

*Interview 1: Alison, mother of Mary (age 18)*



## RADICAL DEPENDENCE

**Angela:** There's this assumption that it all gets done somehow. And you know, there are people who are like us doing it, and there's no recognition of **how much time that takes** or **how difficult agencies make it**. *Interview 11: Angela, mother of William (age 19)*

**Eleanor:** Administration, **somebody has to do it, because if you don't**, then [...] nobody gives a shit. Yeah, so it needs to be kept on top of until they die, basically. *Interview 4: Eleanor, mother of Drew (age 22)*

**Michelle:** There's no advocacy group for people with profound disabilities, is there.

**Jade:** No, there isn't. And I do quite a lot of work with advocacy agencies and I think, well... none of the clients they've brought to me have been severely intellectually impaired. They have all been people who could be helped with an assisted decision-making process. **There's no advocacy out there for people like us**, though, there's no help. *Interview 16: Jade, mother of Kim (age 20).*

# Systems: where ideals meets reality

**Jennifer:** The banks are discriminating against both those people with that kind of disability, AND their families by making it so hard to open up a bank account. We went to multiple banks. I don't remember which ones, but it was several, including our own, which is Suncorp. **Not one of them would open a bank account** unless Tom had signed an enduring Power of Attorney, which of course he couldn't do, or if we had guardianship or QCAT administration. *Interview 12: Jennifer and Tom (age 23).*

**Alison:** And, oh, that's right! The points! [both laugh] Yes! You had to have so many points for “proof of identity” [makes air quotes]. Mary doesn't have a driver's license [laughs] and Special Schools don't normally do a photo ID. She had a Companion Card and a Medicare card, but it wasn't enough, didn't give you the “points”. She had no passport, she'd never been overseas, well, because she can't go on a plane! So, that's just another hurdle. I had to prove her identity several times, **that she did exist even though she's sitting right in front of you.**

**Lydia:** Emily turns 18 in November, and when I went for the [NDIS Plan] Review, they said, “have you got a nomination in place for when she turns 18 that you will continue to act on her behalf”. And I said, “I didn't know I had to do that, I assumed I would continue to act on her behalf, because **her capacity isn't going to change based on what age she is.** She can't do it now, so why can she do it when she turns 18?” “Oh, well, legally at 18, she's allowed to come in and do her own reviews” [laughs] Well, good luck with that!

*Interview 15: Lydia, mother of Emily (age 17)*

# INCLUSION?

- Supported decision-making **doesn't work** for everyone
- How do we **include** people who can't be supported to make some complex decisions?
- Systems don't always **recognise** supported decision-making
- Substituted decision-making is **inflexible** – we need better ways to do this
- We need **better solutions** for people who have severe and profound intellectual disabilities that recognise profound difference and radical dependence



If you have experience supporting someone who receives aged care services in Australia and want to do an interview with me about all things aged care, fill in the EOI at the link!



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