

# Australian Centre for Health Law Research



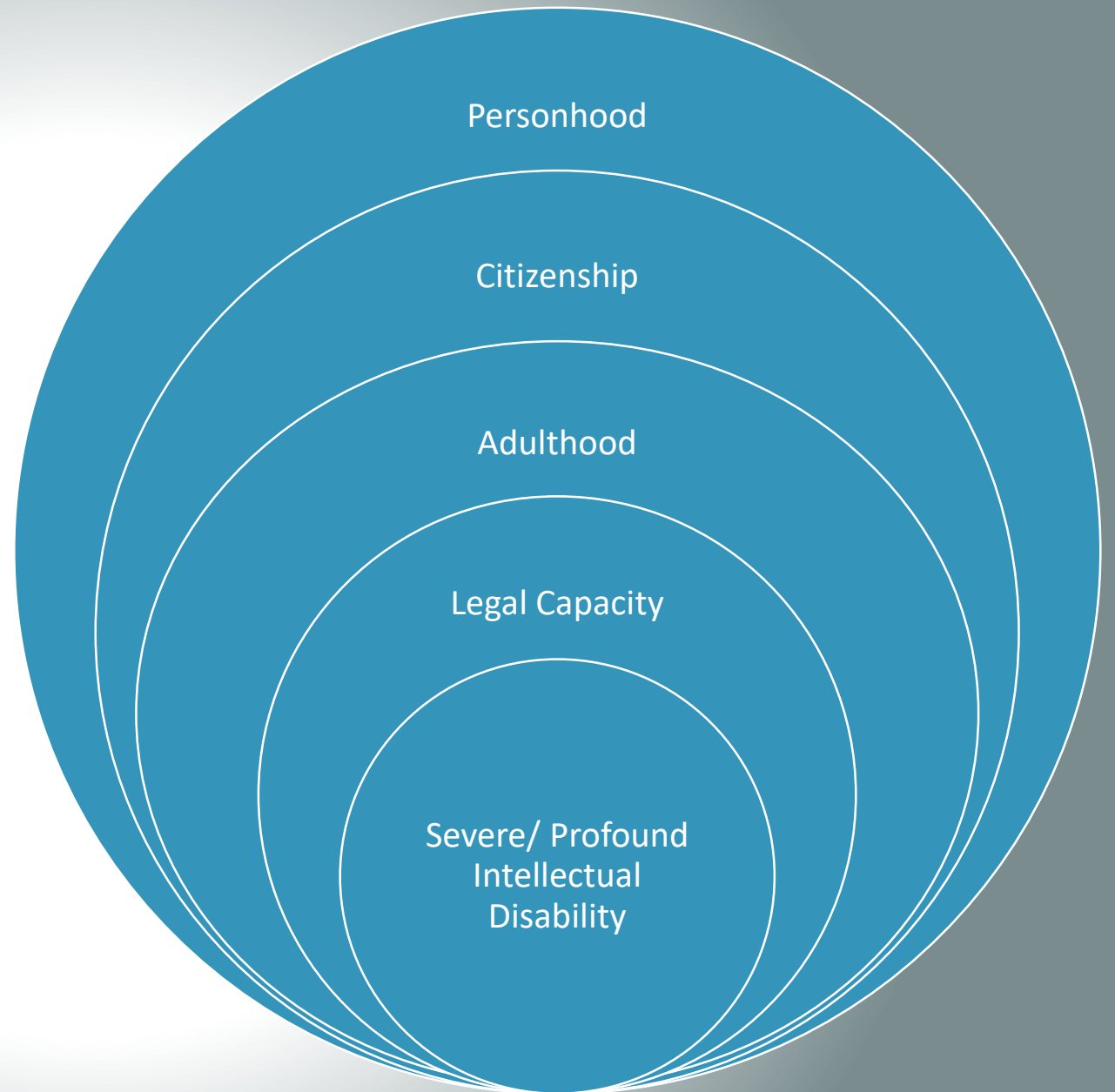
## The Transition to Adulthood Project: Adventures in Becoming a Legal Adult - Personal and Research Perspectives

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The Transition to Adulthood of People with Severe Intellectual Disabilities in Australia: A Socio-Legal Examination  
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# Boundary Conditions of Citizenship



Adulthood



Capacity

# Adulthood in Socio/Legal Contexts

- Beginning and end of life **boundary conditions**
- Adulthood is defined within **social contexts**
- Hard to define, but we “know it when we see it”
- These definitions are reflected in and shaped by **law**
- They are enacted in our social **systems**
- In Australia legal adulthood is at **18 years** of age
- Being an adult is the point where **legal capacity** is presumed
- A variety of earlier points at which capacity is granted in Australian law, but this is **exception** based
- After the age of 18, lack of legal capacity must be **proven**
- Adulthood reveals **realities** of legally recognised decision-making and the operation of **capacity** in law and regulation
- Illustrates the essence of the problem with **dedifferentiation** for those with severe/profound intellectual disabilities
- Helps reveal the **embodied realities of difference** in a space where difference must be dealt with in practice



## HOW TO ADULT



SHOP FOR A NEW TIE.



MAKE MACARONI



DO CARDIO.



DON'T LET THE EXISTENTIAL DREAD SET IN.

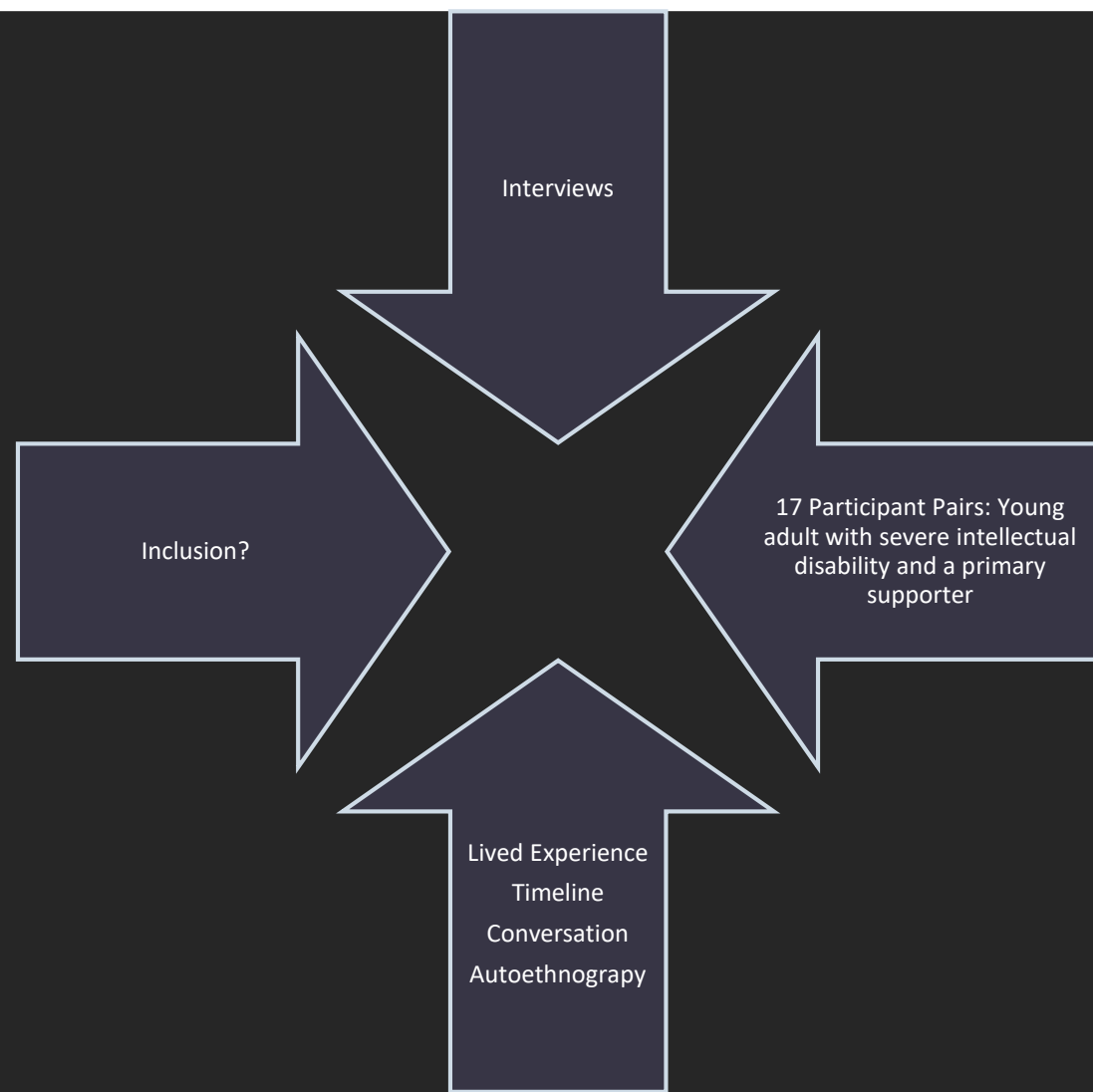


DON'T LET IT SET IN.



VACUUM THE RUG.

# Method





# Areas of Regulation

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- NDIS
- Finance and Banking
- Contract for services
- Therapy, equipment, support work
- Housing/Accommodation
- Centrelink (Disability Support Pension)
- Medicare
- Consent to medical treatment
- Voting

**“When Billy left school, it was like we’d been put out in a tiny boat in the middle of a lake. We were on our own now.”**

*Marla, mother of Billy (age 23)*



## **“When you leave school, you’re on your own”: Transitions**

It was such a shock really, we’d had this great Special School experience, when we left I only had 3 days a week school hours at a program, with no transport, 4:1, and I worked 5 days a week, so that’s not going to work, is it! *Rose, mother of Andrew, age 23*

[The Special School] had a program for some Year 13s where they meet and they do more. But it's really for those, I would say Jim is more “too disabled,” if you could call it that in a school for people with disabilities. He was “too disabled” [air quote]. So he couldn't go into that in Year 13 cause they were focusing more on maybe getting some sort of employment. And that's not gonna happen for Jim. *Carol, mother of Jim, age 24.*

Because he missed so much school [due to seizures] I probably could have fought and said I want you there for another year. But they said that they virtually thought it was like a babysitting service. It's not gonna help him. We didn’t do that extra year. *Rhonda, mother of Barry, age 19.*

The last school senior year is huge for any parent who's had a child five days a week going, now I'm with her 24/7, with the care she requires, 24/7, without a doubt. The panic, the dread for her, and me, crept in more, more for me as a mum thinking, my God, I know how much she loves being out and about. Can I continue to do this? What are we going to do? But then we fought and got the NDIS early. Thank God. *Sara, mother of Rachel, age 19.*



## Core Themes: The Severity of Intellectual Disability

- That's what I mean, it is exactly this kind of thing that Jane can't do. No I can't put her on the phone, no I can't ask her which account she'd like! I'd get off the phone and cry. *Patricia, mother of Jane, age 20*
- And I said, well Paul can't sign. And he [bank manager] goes, Paul has to understand what he's signing. [laughs] Well of course that's never gonna happen. I said, 'well that's just ridiculous! You can see him right here, he can't sign, so now what are we going to do?' *Ann, mother of Paul, age 27*
- And you've got to vote now, Rachel, or you've got to go pick up your keycard, Rachel, get your pin number for the bank, Rachel. Oh my God, *that's* never going to happen. So the battle began... *Sara, mother of Rachel, age 18*
- People think...see Jim says "hello." But from that, he doesn't know what to say next, that's as far as he gets. We get a lot of "hello", and that's what we get, and that's it. And then we don't really know what to say after that. And so people think he'll answer but he can't. *Carol, mother of Jim, age 24*

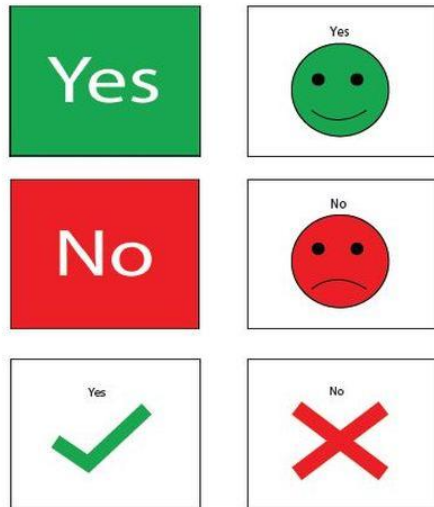
# “Red Tape”



- You have to say it over and over to everyone, nothing links up. And you have to say how bad it is. You can't be positive. So you go around to everyone talking about how terrible your life is and how terrible their life is. It's soul destroying. Why can't they talk to each other?" *Ann, mother of Paul, age 27*
- I think it's the fact that no government department speaks to each other. None. And you constantly have to do paperwork. It's just huge. And it's never ending. *Carol, mother of Jim, age 24.*
- It's just dreadful. Oh, you can't think of a positive, there's no positive about anything in life. Absolutely. And you do, you get sick of writing that. And you get sick of writing like "daily routines" and what he needs and what he *can't* do, because there are so many things. You know, the whole functional ability tests, like, do you really have to continue doing that? I mean, he's never getting better. *Cath, mother of John, age 23.*
- [at Centrelink] I had to prove her identity several times, that she did exist, even though she's sitting right in front of you. *Sara, mother of Rachel, age 18*
- I should take him with me [to Centrelink] all the time they were so helpful [laughs]. But it's so hard to take him with me, because my daughters become the carers, when you have to do the business side of stuff, and nothing worse than he loses it there and he's just yelling. *Harriet, mother of Zach, age 19*

# Support as Invisible and Life-long

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- I'd have to say majority of parents or carers do everything. [...] I'm like, I wish that the government paid me as much as they pay a worker. That agency would take my kid overnight for what is it, \$1,400 a night or something? I do it for nothing, there's something there, something about that... *Sara, mother of Rachel, age 18*
- 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. *Angela, mother of John, age 19.*
- Administration, somebody has to do it, because if you don't, then the person just goes to a day program five days a week and nobody gives a shit. [...] Yeah, so it needs to be kept on top of until they die, basically. *Dee, mother of Cam, age 23.*
- I'm saving the government money by caring for Jim. I said you'd be forking out hundreds of thousands of dollars for someone 24/7 for him, and instead, I do that. And there's no appreciation at all for a carer. Not in the slightest. Not in the slightest. [...] And then when your kid's 25, 30 you're like, am I still supposed to be doing that? They've got no idea. *Carol, mother of Jim, age 24*

# The NIDS is great! ...but...

- Most people getting substantially more funding
- In most cases, NDIS had changed the young person AND the supporter's lives
- BUT...some not getting enough funding (levels/therapy/equipment)
- Issues with NDIA/LAC staff experience, attitudes, and responsiveness
- No draft plans!
- Being offered long plans with no chance to see them first (second plans)
- Concerns about underspent plans because of time for rollout and lack of services, especially overnights/accommodation
- Difficulty of Review processes
- Frustration with administrative requirements for access/ planning/ AT
- AT approval and supply a problem
- Thin Markets: due to severity and type of disability
- Algorithm issues – eg. not being classified as Complex Needs (or at wrong Level)
- Uncertainty and lack of knowledge about plans and how to use them
- Staff management and audit requirements



# The NIDS is great! ...but...



- I waited 8 weeks, trusted...trusted. But [when she turned 18] all of sudden she can now manage herself? I got locked out and even though we filled the [nominee] form out, because I gave it before she turned 18 but apparently it didn't take effect ...[laughs] So they went through her case because I'm bawling my eyes out, I've got all these invoices and how the hell am I going to pay them. I made them fix it while I stood there with her so that I could see I could log in and see her plan." *Maggie, mother of Judy, age 18*
- It was like, sometimes I was talking to a little bit of a brick wall. I don't know whether maybe [NDIA Planner] just wasn't experienced, but she didn't seem to be disability friendly. She said, he was tapping on a truck, and she said she found that annoying. Um, so she didn't have to say it like that did she? The idea was you take your young person in for half an hour to the meeting to show them what they're like, you know, in a physical, practical way, that this is the reason you're asking for all that stuff. So yeah, no experience with kids like John, and that's what she said to us, he was annoying. *Angela, mother of John, age 19.*
- Oh, yes. I just went, "whoa! I don't think we're going to use all that." It's ridiculous, I mean, if that's the amount of funding they're giving us, what did we do beforehand? It obviously came out of our own pockets. *Marla, mother of Billy, age 23*
- I went straight to the NDIA and asked for an employee who knows what they are doing. I screamed and yelled. [laughs] Lobbied, lobbied, lobbied. Then she got double the plan. [The first plan] had all the goals there but was priced incorrectly. I said, you've got to be kidding us! No way is Rachel going out there without one on one! I mean, if she's not getting one on one, who is, I guess is the question? *Sara, mother of Rachel, age 18*
- [NDIA] still don't understand that you must be on call in case something goes wrong and the support worker can't handle the situation, so you need to be on call all the time, really. *Harriet, mother of Zach, age 19.*
- We just don't have anywhere she can stay overnight. Most places that could take her, I just wouldn't leave her there. There's just nowhere so we don't spend that money we just keep her here. *Brian, father of Mary, age 28.*



## Why does this matter?



- Transition to adulthood is a **significant and difficult time** for supporters and the young person with S/PIMD, with change in all aspects of their lives
- This transition is **not well supported** by legal and administrative systems
- Severe/profound intellectual disability itself is **not well understood or supported**
- Adult children are “**supposed to**” be independent and handle things themselves BUT parents are also “**supposed to**” continue to care for their profoundly disabled children indefinitely
- Supporting a young person’s transition to adulthood is **complex** and takes a **significant amount of work**
- Legal and administrative systems are **siloed**
- Administrative work is **duplicated, inflexible**, and often **unnecessary**
- Advice within current systems is **inconsistent, fragmented**, and often **incorrect**
- This work **continues** throughout the person’s **lifetime**
- This represents the **struggle** between inclusion and difference; support and substitution; social and medical models of disability
- Reluctance to engage with **lived realities** of PIMD in social/legal systems AND in disability activism/human rights models/theories
- Transition to adulthood and legal/administrative decision-making shows the importance of the recognising **difference** for those living with severe intellectual disabilities and their supporters
- Our systems of decision-making and administration have to be able to account for everyone, **including** people who cannot be supported to actively make complex legal and administrative decisions for themselves

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