



LIVING WITH DISABILITY
RESEARCH CENTRE

Stories from the Wild West Frontier

The NDIS Experiences of People with Severe and Profound Intellectual Disabilities

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The Wild West and the NDIS

- My mind always goes to the wild west, which was sort of displayed on TV and everything as being fairly lawless, but also a place of great opportunity.
- Not everything is perfect, and not everything is working and people promise more than they deliver, but it's worth kind of ignoring all that and just pushing ahead and taking advantage in a way of how the sort of regulatory framework is still evolving and still developing.
- It's sort of not a time to stop and worry about whether you're doing the right thing. It's more time to - the sort of forward-looking and if there's opportunities that arise that broadly fall under that heading of meeting the reasonable needs of the person involved, then sort of just back your judgment and go for it and see what happens.



NDIS

- A new era in disability service delivery.
- A historical shift in allocation principles in disability policy.
- The scheme is expected to favourably influence the health and wellbeing of many people with disability in Australia.
- The actuarial model, and the principle of “reasonable and necessary” disability support that underpins the scheme’s objective to provide lifelong, individualised support to people with disabilities.

Project Aim

- By exploring the personal stories of two participants who have accessed and navigated the NDIS, this presentation asks if the scheme is living up to those celebrated ideals.
- Methodology draws on techniques of oral history and live story interview.
- The presentation is an exploration of two individual stories of the NDIS experiences of people with severe and profound intellectual disability.
- Based on a chapter that I have written.

Participant: Bethany (Damian Palmer, Father)



Participant: Nick (Jane Tracy, Mother)



Pre NDIS

Damian:

“I follow federal politics reasonably closely and have for a long time, but I can’t really remember, I don’t have a clear memory of the NDIS, the steps that it went through.”

“I remember thinking it was there and that what I was hearing this could be really good, just thinking about in terms of decent funding for disability services and a more coherent overall service provision.”

Pre NDIS

Jane:

“I thought it was a fantastic idea, first of all to remove the inequity that was around how you got your disability.”

“I was excited about the opportunities for that, for demanding of education and health - two services that I know a lot about - and transport and justice, that they become more inclusive for the community overall.”

Planning – Goal Setting

Damian:

“So her goals are all in there – supposedly from her perspective. But again I have this question about is that actually fully respecting the person that she is, or is that still expecting her to be a particular way, or pretend that she is and should be? Just kind of how – almost whether it’s a denial of the reality that Christine and I live with, that we have to pretend, play some kind of pretend game or voice it or word it in a way, present it in a way that’s not actually a true representation of Bethany and our life together as a family.”

Planning – Goal Setting

Jane:

“It helped me crystallise my knowledge of Nick into a written document that I found very - I took a long time to do it, and it was really good because then I kind of felt ‘well, I can die now, I’ve put all this stuff down, my vision for Nick is now written down’, and other people could take it and run with it, instead of it all being in my head. So that was really helpful.”

Strong Advocates

Jane:

I'm in a privileged position: English is my first language, I've got education, I can advocate - it doesn't do any good, but I can advocate - and obviously people who don't have any of that are much worse off. And so people must just give up, and people don't get the stuff that they need. And that's why there's so much money that's not being spent. It's exhausting, jumping through all these hoops.

Approved Plans

- The mistakes in Nick's plan were minor but frustrating.
- Jane more concerned about administrative burden of managing the NDIS
- Mistakes in Bethany's plan more serious.
- Mistakes could not be easily rectified because neither got to review a draft of the plan.

Outcomes

- Nevertheless. Some positive outcomes for each participant.
- Damian: “People with Dravet Syndrome can deteriorate to the point where they can no longer walk. If someone can no longer walk there are additional support needs. That’s just an example, if the scheme properly funds her needs in that area through hydrotherapy and her AFOs, well then longer term that does have a financial payoff for the scheme.”

Conclusion

- Julia Gillard, on the NDIS in 2012: “a transformational approach” to the provision of disability services in Australia that “will respond to each individual’s goals and aspirations for their lifetime, affording certainty and peace of mind for people with disability and their carers alike”.
- Yet. A more nuanced understanding of people with severe and profound intellectual disabilities and what the exercise of rights looks like for them, is integral if the NDIS is to properly accommodate them in the scheme.
- And a concern about equity; about what happens for those people with severe and profound intellectual disabilities whose parents are not around, or not well educated, or not particularly articulate advocates.

References:

- Antaki, C., Finlay, W., & Walton, C. (2009). Choices for people with intellectual disabilities: Official discourse and everyday practice. *Journal of Policy and Practice in Intellectual Disabilities*, 6(4), 260-266.
- Bigby, C. (2014). Is the National Disability Insurance Scheme taking account of people with intellectual disabilities? *Research and Practice in Intellectual and Developmental Disabilities*, 1(2), 93-94.
- Bigby, C., Whiteside, M., & Douglas, J. (2019). Supporting Decision making of adults with intellectual disabilities: perspectives of family members and workers in disability supported services. *Journal of Intellectual and Developmental Disabilities*, 44(4), 396-409.
- Bigby, C. (2020a). "Glossing over issues in the rush to have everybody under the disability banner": Dedifferentiation and people with intellectual disabilities in Australian National Disability Insurance Scheme. *Journal of Intellectual and Developmental Disabilities*.
- Bonyhady, B. (2014). Tides of change: The NDIS and its journey to transform disability support. *Australian Journal of Psychosocial Rehabilitation*, 7(1), 7-9.
- Carey, G., Kay, A., & Nevil, A. (2019). Institutional legacies and sticky layers: What happens in the cases of transformative policy change. *Administration and Society*, 51(3), 491-509.

- Clegg, J., & Bigby, C. (2017). Debates about dedifferentiation: Twenty-first century thinking about people with intellectual disabilities as distinct members of the disability group. *Research and Practice in Intellectual and Developmental Disabilities*, 4(1), 80–97.
- Collings, S., Dew, A., & Dowse, L. (2019). “They need to be able to have walked in our shoes”: What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual & Developmental Disability*, 44(1), 1-12.
- Henderson, D., & Bigby, C. (2017a). Whose lie story is it? Self-reflexive life story research with people with intellectual disabilities. *Oral History Review*, 44(1), 39-55.
- Palmer, D. (2016). ‘Can’t I just be me?’ When the embrace of goals is an act of exclusion. Paper presented at *Exclusion and embrace: Disability, justice and spirituality Conference*. Melbourne: 21-23 August.
- Perry, E., Waters, R., & Buchanan, A. (2019). Experiences of National Disability Insurance Scheme planning from the perspective of adults with intellectual disability. *Australian Journal of Social Issues*, 54(3), 210-223.
- Parliamentary Debates. (2012). *House of Representatives*. Canberra: Commonwealth of Australia.
- Productivity Commission. (2011). *Disability care and support: Productivity Commission Inquiry Report – Volume 1*. Canberra: Commonwealth of Australia.
- Productivity Commission. (2017). *National Disability Insurance Scheme Costs: Productivity Commission Study Report*. Canberra, Commonwealth of Australia.