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LIVING WITH DISABILITY
RESEARCH CENTRE

“Glossing over issues in the rush to have everybody under the Disability banner”. A case study of a differentiated reform the Australian National Disability Insurance Scheme.

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Background - Dedifferentiation

- “...dismantling of special arrangements for vulnerable groups, dissolution of categories and growing individualism” (Sandvin & Soder, 1996, p117)
- People with intellectual disability not differentiated as a group distinct from others with disabilities- clear trend in Australian disability policy since late 90s (Bigby, 1999)
- Shift from solidarity – collective voice, diagnosis, specialist knowledge or services to functional capacity genericism, individualism and choice
- Coincides with neo-liberal changes to welfare states – individualism, choice and markets
- But also aligns disability rights movement aspirations –accommodating difference, equal rights, citizenship, individual choice and control
- Debates about risks and benefits – in principle and empirical evidence (Bigby & Ozanne 2001; Clegg & Bigby, 2018)
‘Treat people with intellectual disability as members of the broad disability group wherever possible, and protect and develop differentiated opportunities, services and research whenever necessary.... Ensure that all services recognise and respond appropriately to the unique needs of people with intellectual disability and staff have the necessary knowledge and skills to do so’. (ASID Position statement 2017)
- For whom in what circumstances might differentiation be important? Or dedifferentiation beneficial?

Aims and method

- Case study of Australian National Disability Insurance Scheme (NDIS)
- Single largest group of adults participants are people with intellectual disability 60-65%
- What did dedifferentiation and differentiation look like – in the design and implementation ?
- What have been the benefits and negative impact of dedifferentiation for adults with intellectual disabilities?
- What changes are occurring and why?
- If there are problems are they inherent or open to remediation? And how?

Methods

- Analysis of sources
 - Academic literature NDIS – policy, adult participants [excluding children] from 2014
 - Grey literature – government and third sector reports from 2014 & earlier reports re design
 - Mainstream media 12 months July 2018 – 2019
 - Semi structured interviews with 11 key informants, including, senior public servants, policy makers, academics, and personnel in disability support organisations involved in development of the NDIS or advocacy

What is the NDIS?

- Replaced system 'underfunded, unfair, fragmented, and inefficient...little choice and no certainty of access' (PC 2011, p. 2).
- Doubled funding—\$22b a year by 2020 – approx. 1.1% GDP

Purpose

- Enable exercise choice and control to pursue goals, and planning and delivery of supports (S.3e).
- Enact disability rights - give effect to Australia's obligations under the CRPD (s. 3(1)(a)).

Approx. 460, 000 people individual funding packages

- Permanent and significant impairment(s) that substantially reduces their functional capacity or psychological functioning (NDIS Act s. 24). [only 10% of people with disability]

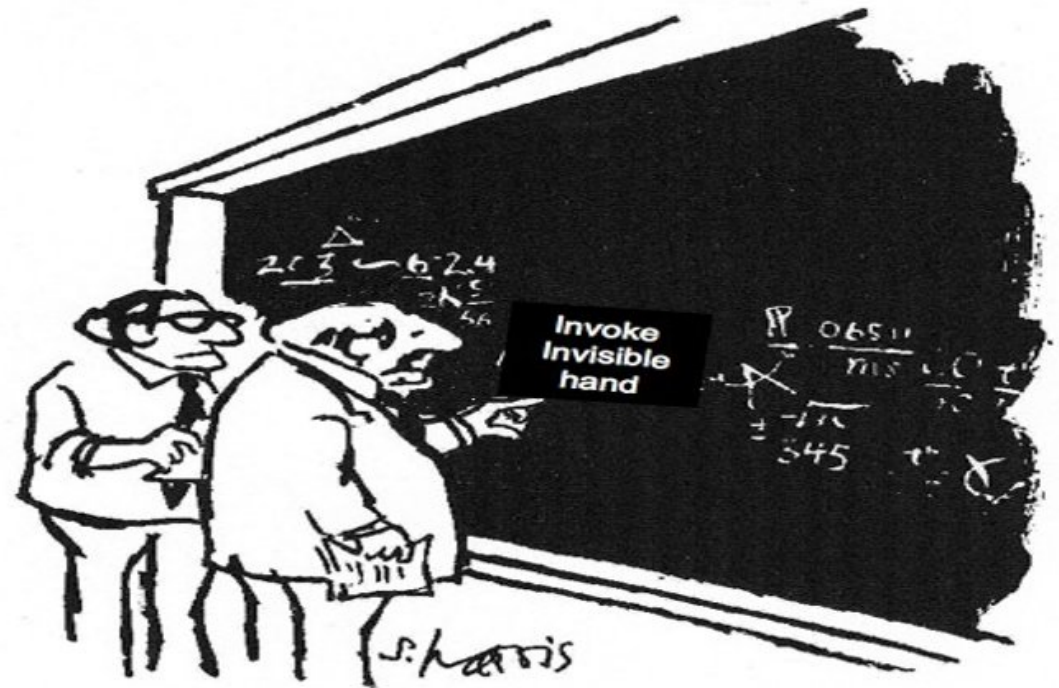
Strengthen mainstream capacity for inclusion - ILC projects and Local areas coordinators

Features – differentiated –no specific provisions for people with intellectual disability

- Individual choice and control – rather than professionally driven planning and service identification
- Enforceable rights - merits review some decisions AAT
- Total marketisation of disability services delivery – no block funding – no commissioning – no opting out
- Fund 'reasonable and necessary disability supports' - cost effective, articulated in plan
- Not duplicate but rely on mainstream for non disability related needs – housing – health – etc
- Implementation likened to 'building a plane while flying it' (Whalan, Acton, Harmer 2014)

Insurance based - Integrated social and economic purposes

- Goals of increased economic participation by people and carers [+ generating employment?] (Millar & Hayward, 2017)
- Individual choice through the Market more cost effective
- Investment rationale - reduce future costs by investment in the present.
- Actuarial approach - plans and funding of supports calculated for present and future claims
- 'Claims management' - active monitoring and reporting
- Inherent tensions - Human rights & relational autonomy v efficiency, economic imperatives and scheme viability



"I think you should be more explicit here in step two."

Dedifferentiated Policy Advocacy

- Origins of an insurance based scheme lie in evolution of Australian workers welfare state and neo-liberalism
- Reinserted onto reform agenda in 2008 via 2020 Summit held by Rudd Labour govt
- Powerful group – parent of 2 young men cerebral palsy /financier, person with physical disability/actuary, past deputy prime minister/social policy specialist
- Harnessed significant political capital, social capital and philanthropic funds through this group (Thill 2014)
- Public Campaign with wide appeal led by ex politician. ‘Every Australian Australian Counts’
- United and Cross Disability – carers, people with disabilities, service providers (Manne, 2011; Bigby, 2015)
- Remarkable consensus – little debate about implementation – don’t rock the boat
- Labor and then bipartisan support - political maneuvering – but led to implementation a year early July 2013
- Very different from previous campaigns – ‘minus children’ ‘forgotten people’ ‘when needs go begging’ (Age various, Disability Council WA)
- Won on economic rather than welfare grounds
- More dedifferentiated and more successful than previous campaigns

Design – people with intellectual disabilities and their issues underrepresented at the table

Early design and consultative processes dominated by others

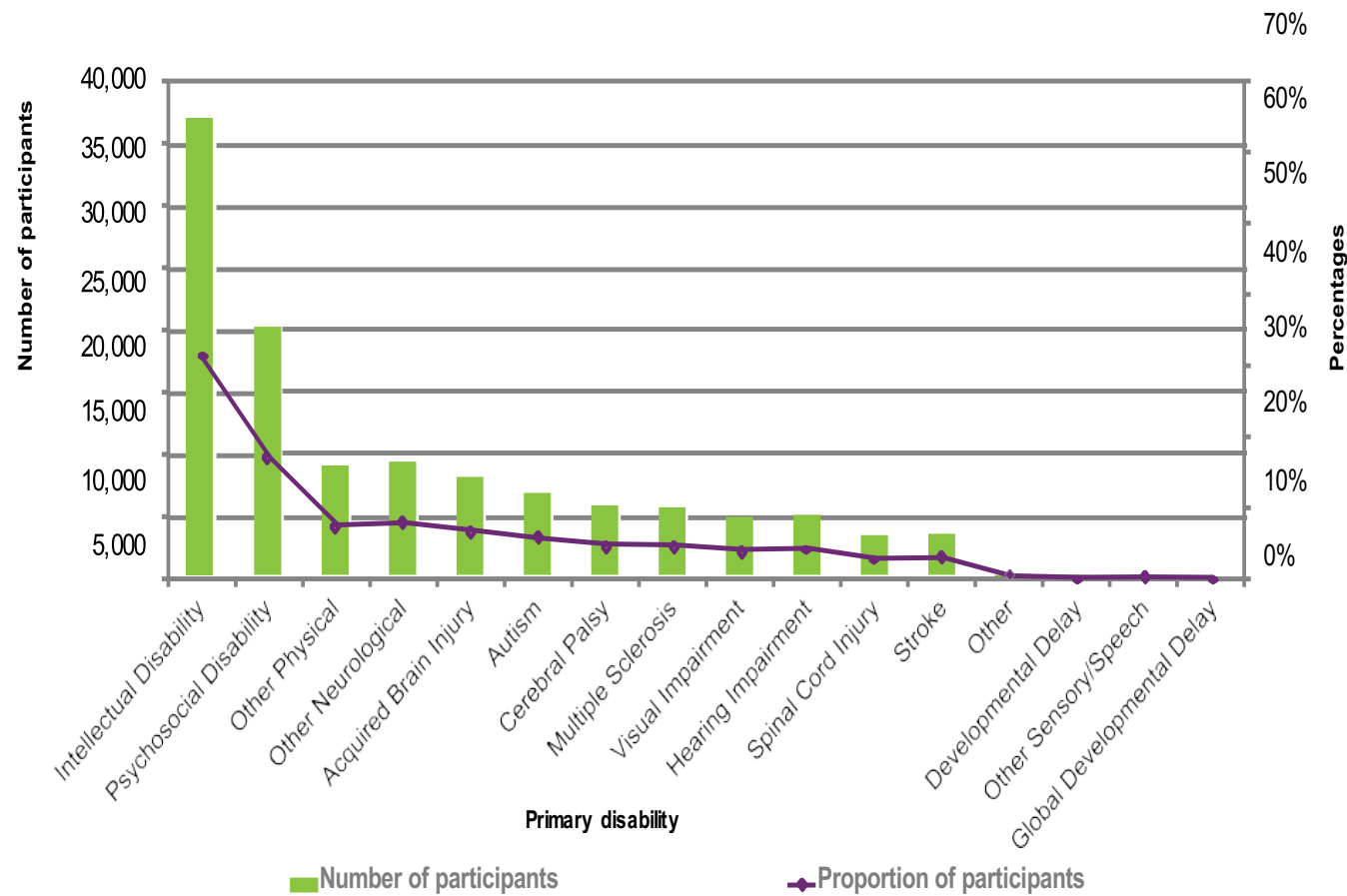
...probably over-represented and disproportionately represented were people in wheelchairs with physical disabilities who were resourceful, well resourced, articulate, brought to the table a whole set of life experiences, the capabilities and capacities that in fact people with intellectual disability don't bring.... [people with intellectual disabilities] weren't represented in proportionate numbers ...things that were part of original scheme design and quality and practice definitely didn't resonate and weren't sufficiently nuanced. [Senior federal bureaucrat]

Sixty percent of people on the NDIS will be people with intellectual disability but the scheme itself is designed with a very different idea of who a disabled person is in mind. [Professor 1]

..the original membership of the Independent Advisory Council ...I would have had an expectation that there was some degree of commensurate representation ...but there wasn't... There was one woman, a fantastic woman...she was a mother, a carer, a provider and her son had a significant intellectual disability. But that was a sole voice (Senior federal bureaucrat)

- Arguably ignored international research on pre requisites for individualised funding and early warnings by academics and practitioners (Williams & Dickenson, 2016; O'Connor, 2014, Cliff, 2014; Bigby, 2015)

6.30 Distribution of active participants with an approved plan by primary disability for age 25+ yrs



Design and implementation assumptions

Participants will have:

- Capacity to claim, articulate their needs and provide evidence about these
- Capacity and experience to make decisions and exercise choice and control over supports
- Families or other sources of social capital to support and negotiate their claims
- Support that aligns with and prioritises individual's preferences and rights
- There would be a market for disability support services across Australia
- No role for govt as provider of last resort – or need for flexibility to fund providers for emergencies or change
- Disability related needs easily identified and separated from other needs
- Mainstream services accessible and responsive to people with disabilities
- Processes should be transactional rather than relational
- Planning an administrative rather than professional task
- For example, planners were unskilled, lacked knowledge of disability – often done by phone - tight time frames e.g. June 2017 Qtr. 1500 plans or 165 a day in final year of transition need to do 500 plans a day plus reviews (PC 2017)

Design

Slight nod towards differentiation and potential issues for people with intellectual disabilities in legislation

- People should be supported to exercise choice
- People will be supported in their dealings and communications with NDIA
- Assumed, **‘so far as is reasonable’** capacity to determine own best interests and make decisions
- Plans and funding **‘should so far as reasonably practicable’** be individualised directed by the participant
- Provisions for nominees as substitute decision makers to invoke best interests –‘guardianship light’
- Capacity / risk test for self management

But

- No funding for advocacy or independent brokers – no expectation of intensive case management
- No embedded supported decision making policy – or safeguards vis informal decision support such as criteria for judging quality of informal or formal sources
- Tends to conflate mental and legal capacity and run contrary to interpretations of UNCPRD article 12 as full and equal legal capacity not recognised in the legislation (Cukalevski, 2019)
- Advocates – ‘agree with the presumption of capacity. However, people with intellectual disability need access to very considerable support and skills training to make this presumption and choice and control real’ (NSW CID, 2015, p 12).

Dedifferentiated implementation in practice

NDIS at this point in its development, it **does not really understand the unique issues associated with people who have an intellectual disability.** [Senior NSW bureaucrat 2 2018]

Processes complex, difficult to navigate or comprehend

“ If they could explain planning to you a little bit more because I couldn’t understand it and its complicated for my mum too” (NSW CID 2014 p 25)

“ too much red tape, too many steps, too many papers, too many workers who don’t know what they are doing” (NSW CID, 2014)

- “.. it's incredible, but it has taken all of our minds and resources to access it. It's a question; how are people who aren't supported accessing the resources?” (sister of man with intellectual disability Sydney Morning Herald 2 March 2018)

Underspending on plans

- “Molly, 17, who has an intellectual disability, lived without any support for the first six months because she didn’t fully understand the plan or the choices. “I had no idea where to go or what to do next” (Advertiser, 26 March, 2019)
- Sue’s plan well over \$1 million in ‘core supports’, breakdown broken into “Funding for low risk daily adaptive equipment [A]ssistance in individual living arrangement for person with complex needs (x 1) Funding for recreational, social and community activities of your choice.” (OPA, 2018)

Short term 12 month grant funded community development projects

Reduced support

Failure to acknowledge relational practice necessary for planning

“The very notion of choice and control that drives the NDIS has created a discriminatory process for so many of our clients...**goals and plans are usually developed via a long process...** staff developing a close working relationship with the client... By spending time together workers are able to identify certain things over time that clients might bring up in a conversation. We can then reflect that back to them in terms of a goal or strategy. It’s a process that takes time ...if we were to sit with them and ask ‘what are your goals?’ we would inevitably draw a blank”.

Loss of support from poorly expressed claims

Under the NDIS, Chris was required to nominate the supports he needs and wants. He stated that he doesn’t need help with anything. His support providers have taken this to be the truth. Sadly, it is far from the truth. Chris has an extensive history of violent sexual abuse and neglect. He has significant ongoing issues with illicit drug abuse, suicidal ideation, self-harm and assaultive behaviours towards adults...he was receiving intensive support for these issues. after transitioning to the NDIS Chris failed to engage with [disability service provider X]. Consequently, his previously approved NDIS support package has been halved”. (Churchill et al., 2017)

Gaps filled by welfare organisations

“We have found that we have the NDIS plan, and then we have the ‘actual’ support needs and goals for the client. The goals and support needs in our client’s NDIS plans are over simplified to the extreme, leaving us to fill in the gaps, without the dollars to support the work

Resource intensive and emotionally challenging boundary disputes

[AATA 3099 \(9 August 2018\)](#) Ms Mazy was refused funding to administer regular medication for diabetes – determined to be a health related need. Overturned on appeal - her intellectual disability meant she couldn't administer this herself - she therefore needed help to do this in the community – this help meant she could participate in her chosen activities

Rigid individual funding boundaries for service obstruct holistic support

- inadequate recognition or funding of need for skilled coordination, consultation or training across different services and systems (Churchill et al., 2017; OPA, 2018)

Unrealistic requirements for contracts and signatures from people without capacity or authority to sign (OPA, 2019)

Thin service market for people with high complex support needs – provider withdrawals and scarcity results in long periods in remand (OPA 2018)

Changed funding model for participants attending day centres - less of choice and access to skilled support

...the consequence for our son is that he can no longer pursue activities he enjoys and which help manage his behaviour. The expectation is that he attends with an untrained carer and travels in a taxi. Trained and consistent staff are essential to his ability to make sense of his world. His NDIS plan does not cover him for supervision by an educator, but an untrained carer at a lower rate which does not fulfil his needs. (Age, 13 Oct, 2018)

Inequitable outcomes

Findings from large scale evaluation of pilots (Mavromaras et al 2018)

- Works best for participants and families able to strongly advocate for themselves.
- **Poorer outcomes for NDIS participants with intellectual disability**, psychosocial disability and complex needs or with older carers facing their own health issues or from CALD backgrounds.
- Struggling with complexity

Cost pressures and roll over provisions more likely to impact people with intellectual disabilities living in supported accommodation without strong advocacy support

Roll over of existing government contracts particularly re supported accommodation –represented ‘in kind’ commitments to the NDIS - participants [predominantly people with intellectual disability] were required to use these service providers (Neville et al 2019)

...lot of pressure on the NDIA to keep costs down and I think their response to that...was that they did interim plans and they did low cost interventions. (Senior public servant, Neville & Carey 2018, p. 24)

- **Inconsistency of packages for people with ostensibly similar needs**

“There is greater than expected variability in package costs for participants with similar conditions and levels of function (suggesting inconsistencies in planners’ decisions).” (Malbon et al., 2019)

Loud complaints on numerous fronts

Mirror many of the issues at high level identified in respect of people with intellectual disabilities

This system was judged “unapproachable” and “lacking in fairness and transparency” (Ombudsman 2018)

‘evidence received during ... recent public hearings seems to be indicative of a culture developing in the NDIA that is not placing the participant, and those who support them, at the centre of the Scheme’. (Joint Parliamentary Standing Committee on NDIS, 2017)

‘...failing to live up to promise of individualized resource packages tailored to the needs of each participant- instead applying bureaucratic, standardized administrative logics’ (Carney et al., in press p 1)

‘...prices are incentivizing cost-cutting and creating imperatives for low quality provision...[because] pricing is predicated on under-classification of workers and insufficient time for workers and supervisors to do their jobs well’. (Cortis et al. 2017)

‘In general, participants and families are overwhelmed, confused and anxious about the market and how to engage with the NDIS, let alone navigating to a new service provider’. (Joint Parliamentary Standing Committee 2018, p 25)

‘Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government. ...[p]articipants, their families, carers, and service providers expressed dissatisfaction with plans being developed over the phone; the skills and competence of planners; inconsistency of planning decisions; delays to plans and plan reviews; and the Agency’s lack of transparency. (PC 2017 p 26)

Some louder than others - unbalanced media and advocacy

- Only one advocacy organisation consistently raising issues specific to people with intellectual disabilities (see NSW CID 2014, 2017, 2018) - while also running a campaign to retain state funding
- 394 media stories less than 6% mentioned people with intellectual disability

Thank you for the heartwarming story about a young woman whose life has been enhanced by the National Disability Insurance Scheme. It is well known that the NDIS works best for people who can self-advocate or have family or friends to advocate for them. You will not hear such glowing stories about the thousands of people with a disability who are living in disability accommodation, who are unable to self-advocate and do not have family support. The NDIS has a fundamental weakness, in that it does not fund independent advocacy for people who need it. Without advocacy, our most vulnerable Australians are unlikely to be any better off under the NDIS. (Age 25 Nov 2018 Phil Lipshut, president, Supportive Families and Friends Association Eastern Metropolitan Region Inc.)

...some of those physical disability groups, they can ramp up hundreds and hundreds of members who are all quite capable of ringing their local MP and writing a letter, and that's not the group of people with an intellectual disability. And often their families are fatigued, they're fatigued through a life of caring, and you know, they're just not going to be able to do that lobbying in the same way. (senior b'crt 2)

Continuous rebalancing – and differentiation

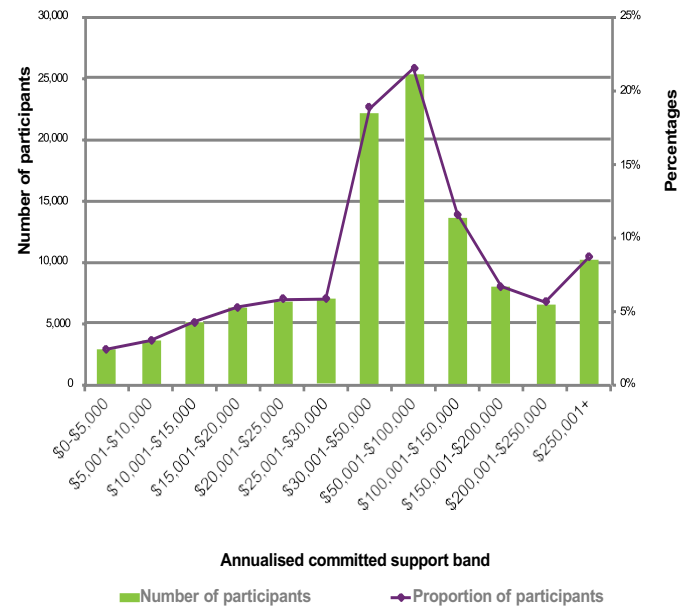
- **Recognition of need for consultation with people with intellectual disabilities**
 - ‘we want to hear from you guys’ (Walsh, 2014 cited in Bigby, 2015)
 - Intellectual Disability Reference Group to Independent Advisory Council
- **Recognition of specialist knowledges needed for many groups**
- Autism Advisory group, NDIS Mental Health Sector Reference group, Industry Reference group
- And specialist advisors - autism, psycho social disability but not intellectual disability
- **Less transactional processes** – ‘new pathway - face to face planning – single point of contact –better trained planners, more transparency in plans and funding decisions (NDIS 2018)
- Specialist pathway streams 4 groups utilising disability specific expertise - **complex support needs – psycho-social disability- hearing – early childhood early intervention**
- Better connections to mainstream - skilled contact person to assist (NDIS 2018)
- More strategic, differentiated and longer term mainstream and community capacity strategy – (ILC strategy, 2019)
- Trail of functional assessment – achieve greater equity
- Attention to interface with health (COAG 2019).
- Trail of support for decision making programs. (DSS, 2018)

Concluding thoughts - balancing competing logics

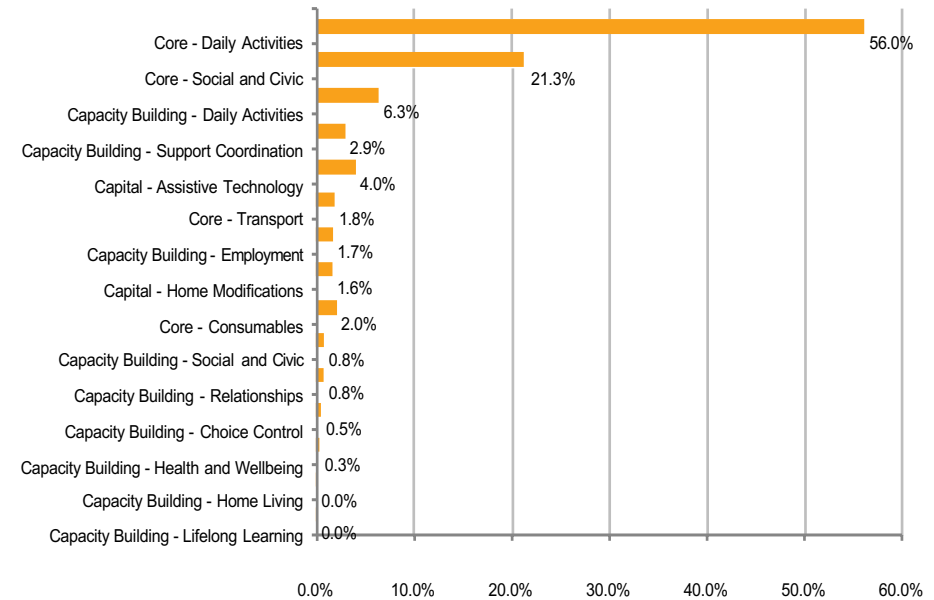
- Differentiated advocacy had strong payoffs for people with intellectual disability
- Achieved major reform to the system – many access services for the first time – hastened closure of institutions
- Common implementation issues and loud advocacy compensates for invisibility of people with intellectual disability
- Concerted drive for relational rather than transactional bureaucratic processes. ‘Cookie cutter’ not working’ (Morrison, 2019)
- People with intellectual disability benefit from rebalancing Insurance logic of equity and efficiency v logic of relational person centred planning
- Some people with intellectual disability benefit from emerging differentiation vis a vis specialist knowledge or approaches – groups who have shouted loudest or are ‘risky’ or ‘costly’
- Fundamental design issues remain largely unchallenged
- Relative silence about people with more severe and profound intellectual disability - limited progress on quality and availability of support for negotiation and decision making – or difficulties of relying on experts by experience
- Competing logics for advocates (and academics) “...we need to be able to say it's distinct but on the other hand we also need to be emphasising the commonality...” [Bigby & Henderson, 2018]
- How to support dignity, competence, citizenship of people with intellectual disabilities and self advocates who don't want to be tarred with stigmatised identity – whilst drawing attention to need for support and safeguarding that stem from core features of intellectual impairment which are the very reasons for historic exclusion from citizenship

Support packages

6.31 Distribution of active participants with an approved plan by annualised committed support band for age 25+



6.32 Total annualised committed support for active participants with an approved plan by support category for age 25+



Thank You



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References

- Bigby, C. (1999). International trends in intellectual disability policy in the late 1990s, chapter 2. In E. Ozanne., C. Bigby., S. Forbes., C. Glennen., M. Gordon., C. Fyffe. (1999). *Reframing opportunities for people with an intellectual disability*. A report funded by the Myer Foundation. Melbourne. University of Melbourne.
- Bigby, C., (2015). Is the national disability insurance scheme taking account of people with intellectual disability. (Editorial). *Research and Practice in Intellectual and Developmental Disabilities*, 1, 2, 93-97
- Clift, K. (2014). Access to the National Disability Insurance Scheme for People with Intellectual Disabilities Who are Involved in the Criminal Justice System. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 24-33. doi:10.1080/23297018.2014.910863
- Whalan, J., Acton, P., & Harmer, J. (2014). *A review of the capabilities of the National Disability Insurance Agency*
<https://www.parliament.nsw.gov.au/researchpapers/Documents/The%20National%20Disability%20Insurance%20Scheme.pdf>
- Williams, I., & Dickinson, H. (2016). Going It alone or playing to the crowd? A critique of individual budgets and the personalisation of health care in the English national health service. *Australian Journal of Public Administration*, 75(2), 149–158. doi:10.1111/1467-8500.12155
- Productivity Commission, (2017). *National Disability Insurance Scheme Costs: Productivity Commission Study Report*. Canberra: Commonwealth of Australia.
- O'Connor, M. (2014). The National Disability Insurance Scheme and People with Mild Intellectual Disability: Potential Pitfalls for Consideration. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 17-23. doi:10.1080/23297018.2014.908815
- Productivity Commission, (2017). *National Disability Insurance Scheme Costs: Productivity Commission Study Report*. Canberra: Commonwealth of Australia.

O'Connor, M. (2014). The National Disability Insurance Scheme and People with Mild Intellectual Disability: Potential Pitfalls for Consideration. *Research and Practice in Intellectual and Developmental Disabilities*, 1(1), 17-23.
doi:10.1080/23297018.2014.908815

NSW CID Position statement re NDIS quality and safeguarding April 2015.

NSW CID Conference Report Getting the best from the NDIS Making it work for people with intellectual disability August 2014

Office of the Public Advocate, (2018). *The illusion of 'Choice and Control': The difficulties for people with complex and challenging support needs to obtain adequate supports under the NDIS*. Melbourne, Vic.

Alison Churchill, Mindy Sotiri and Simone Rowe, 'Access to the NDIS for People with Cognitive Disability and Complex Needs Who Are in Contact with the Criminal Justice System: Key Challenges' (Research Paper, The Community Restorative Centre, January 2017)

Mavromaras, K., Moskos, M., Mahuteau, S., Isherwood, L., Goode, A., Walton, H., . . . Flavel, J. (2018). *Evaluation of the NDIS: Final Report*. Flinders University

Neville, Kay, Carey, (2018) Value choices in a mixed economy of care. How complex politics shapes the implementation of complex social policies *Social Policy and Administration* 1-13,

Malbon, E., Carey, G., & Meltzer, A. (2019). Personalisation schemes in social care: are they growing social and health inequalities? *BMC Public Health*, 19(1), 805. doi:10.1186/s12889-019-7168-4

Commonwealth Ombudsman(2018) http://www.ombudsman.gov.au/data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf

Neville, A., Malbon, E., Kay, A., & Carey, G. (2019). The implementation of complex social policy: Institutional layering and unintended consequences in the National Disability Insurance Scheme. *Australian Journal of Public Administration*.
doi:10.1111/1467-8500.12380

Joint Standing Committee on the National Disability Insurance Scheme, Progress Report
(7 September 2017) 46–63

Carney, T., Then, S., Bigby, C., Wiesel, I., Douglas, J. (2019) NDIS plan Decision-making: Or when Tailor-made case planning met Taylorism & the algorithms? Melbourne University Law Review.

Joint Parliamentary Standing Committee on the National Disability Insurance Scheme (2018). *Market readiness for provision of services under the NDIS*. Canberra: Commonwealth of Australia.

National Disability Insurance Scheme (2018). *Improving the NDIS and Provider Experience*.

National Disability Insurance Scheme. (2019). *COAG Disability Reform Council Quarterly Report*.

Bigby, C., & Henderson, D. (2018). Raising the voices of people with intellectual disabilities and changing systems: The contribution of NSW Council for Intellectual Disability to social change. Melbourne: Living with Disability Research Centre, La Trobe University.