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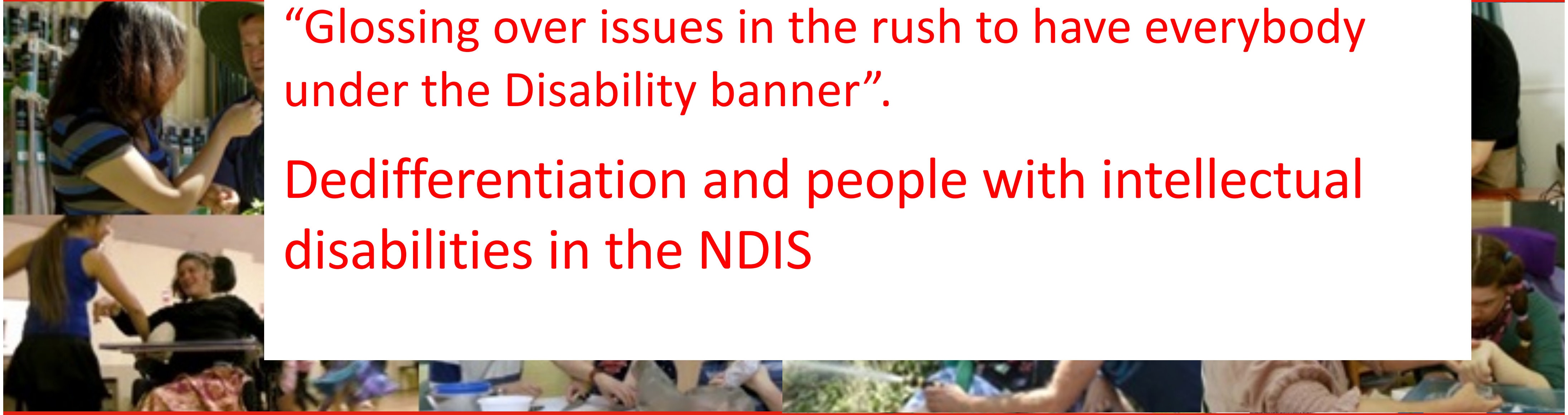

“Glossing over issues in the rush to have everybody under the Disability banner”.

Dedifferentiation and people with intellectual disabilities in the NDIS

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Dedifferentiation – What does it mean?

> "…dismantling of special arrangements for vulnerable groups, dissolution of categories and growing individualism" (Sandvin & Soder, 1996, p117)

- Emphasises each individual's needs and functional abilities – their individuality and choice
- Reflects neo-liberal changes to welfare states – individualism, choice and reliance on markets
- For people with intellectual disabilities - regarded as members of the generic group 'people with disabilities' rather than the impairment specific group *people with intellectual disabilities*.
- Dedifferentiation has been apparent in Australian disability policy since late 1990s (Bigby, 1999)
- For example, replacement in Victoria of the Intellectually Disabled Persons' Services Act 1986 with Disability Services Act 2006
- Debates about benefits and risks – in principle and empirical evidence (Bigby & Ozanne 2001; Clegg & Bigby, 2018)

Potential benefits and risks of dedifferentiation

- Reflects the preference of people with mild intellectual disabilities
- Avoids attention to devalued differences or stigmatising labels
- Promotes inclusion in mainstream rather than specialist services (that in the past have often been segregated and poor quality)
- Strengthens collective advocacy by people with disabilities

But

- Neither mainstream or disability services take account of the unique issues shared by people with intellectual disabilities or sub-groups of this population
- Obscures the diversity of people with intellectual disabilities – particularly people with severe and profound intellectual disability
- Underestimates the impact of intellectual impairment on individual functioning or barriers to inclusion confronted

Dedifferentiation revolves around recognition and response to difference

- How to support dignity, competence, and citizenship of people with intellectual disabilities and self-advocates and others who don’t want to be tarred with a 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.
- Australasian Society for Intellectual Disability position statement concludes (2017)

“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”

Leaves open the question of when differentiation necessary

The NDIS an exemplary dedifferentiated disability policy

"…built on a universal assessment framework: people with a disability, no matter the specific diagnosis or how the disability was acquired, will be assessed according to their capacity to function. It is a significant shift from past practice, in which most disability support was funded for specific diagnoses or on the basis of how impairments were acquired. (Gibbs, 2013, p. 39)

Key objectives of the Scheme are to:

- "support the independence and social and economic participation of people with disability"
- enable them "to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports" (NDIS, 2013, section 3, (1) (c, e)).
- as an insurance scheme to have regard to financial sustainability (NDIS, 2013, section 3, (b))

Adults with intellectual disabilities are the largest single group of adult participants, an estimated minimum of 29.53% (NDIS, 2019).

Aims and method

- Explore the nature of dedifferentiated approach of the NDIS policy and its implications for people with intellectual disabilities – and ask should it be more differentiated
- Focus on design and implementation around planning and decision making, and evidence about outcomes for this group.

Approach

- Analysis of sources through the lens of adults with intellectual disabilities
- Academic literature NDIS – policy, adult participants [excluding children] from 2014
- Grey literature – government and third sector reports from 2014 & earlier reports re design
- Significant scrutiny through Disability Reform Council, inquiries and reports of other public bodies
- Mainstream media 12 months July 2018 – 2019

Many people with disabilities have had many problems with the implementation of the NDIS

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)

“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)

“the implementation of the NDIS has not been smooth and it is evident that the pressure of rolling the Scheme out across Australia has directly impacted the NDIA’s ability to provide a consistent, effective and high-quality service delivery offering” (Tune, 2019, p.7)

Dedifferentiated reporting makes identifying specifics for people with intellectual disabilities difficult

But people with intellectual disabilities have fared worse in terms of outcomes than most other groups

- More at risk of inadequate levels of support and have higher levels of unmet demand
- Exercise less choice and control over supports,
- Gained fewer clear benefits around social participation,
- Had poorer average levels of wellbeing
- Less satisfied with NDIS processes, more likely to be unable to navigate the NDIA website and obtain information about services (Mavromaras et al., 2018).
- Less likely to be in open employment (23%) than other adult participants (43%)
- More likely to have work as a plan goal (58%)
- More likely to be in low paid and segregated employment (74% v 49%).
- Adults with Down Syndrome more likely to have increased community and social participation but in disability specific rather than mainstream groups (NDIS, 2018)

Dedifferentiated design glossed over issues specific to people with intellectual disabilities

- “the scheme itself is designed with a very different idea of who a disabled person is in mind” (Bigby & Henderson, 2018)
- Literature had identified poor fit between people with intellectual disabilities and individualised funding schemes that privilege individual choice and self-defined needs (Needham, 2013; Williams & Dickinson, 2016) .

  “…individuals with physical disabilities are able to take better advantage of these opportunities than those with intellectual impairments” and for this latter group “Good outcomes appear to depend upon strong advocacy or brokerage support” (Carey et al., 2018, p. 26)
- Researchers and commentators warned that people with intellectual disabilities didn’t conform to assumptions about consumers able; to lodge claims, articulate needs, make decisions, identify and exercise control over service delivery and access social capital if necessary. (Dowse, 2009; NSW CID, 2012; Bigby, 2014; Clift, 2014; O’Connor, 2014)
- As consumers people with intellectual disabilities would need “access to very considerable support and skills training” to make choice and control real (NSW CID 2015, p. 12).

NDIS legislation acknowledged needs for support but did not put robust mechanisms in place

- Expected participants would direct their own plans, manage funding, determine their needs and make decisions (NDIS, 2013, s.31, s17A(1)).
- Acknowledged need for support interacting with the Scheme, and limitations some might have with self-direction and decision making (NDIS 2013 section 31)
  - self-direction of plans would be ‘so far as reasonably practicable’
  - participants had capacity to make their own decisions ‘so far as reasonable’.
- No formal scheme for supported decision making or other formal mechanisms to ensure support available to engage with the NDIS and participate meaningfully in planning and decision making when it wasn’t ‘reasonable’ or ‘reasonably practicable’ to do it alone.
- This was particularly disadvantageous for people with intellectual disabilities – many of whom are reliant on support to participate in decision making, do not have strong reserves of social capital. Exemplified in design, implementation and outcomes of planning

Planning design and processes

- Administrative standarised process
- Managed by planner or LAC unlikely to have professional qualifications, skills or experience in working with people with disabilities (Joint Standing Committee on the NDIS, 2019),
- Reliant on self-expression of needs
  - statement from the participant about their personal goals and circumstances
  - statement of supports jointly determined by the participant and the NDIA specifying funding and management (NDIS, 2013, section 33).
- No requirements for negotiation or a face to face meeting to agree statement of support (Carney et al., 2019).
- Based on an ethic of justice treating like cases alike (based on functional capacity) "impartial planning, based on abstract principles applied consistently to all participants" (Carney et al., 2019, p.783).
- "participants' goals and aspirations are not intended to have a significant bearing on the level of funding provided in their NDIS plan…when comparing two participants with the same or very similar, functional capacity, of the same age and living in the same region, the NDIS is not designed to provide more funding for one participant over the other on the basis that their goals and aspirations are more expensive" (Tune, 2019, p. 64)

Exclusionary for people with more severe intellectual disabilities

- Underlying normative assumptions fail to recognise people with profound intellectual disabilities for who they are.
- Compounded by use of first-person language without processes to justify this,

> “To continue to insist, as the current NDIS planning process does, that Bethany’s plan has to articulate her goals in relation to employment, education and independence, is to fail to accept her for who she is: someone who is unable to articulate such goals. If we were to accept her for who she is we would be able to say: “To belong you do not have to achieve anything other than to live among us.” (Palmer, 2016 p. 8)

NDIS planning is anathema to person centred or relational practice

- Limited attention to the difficulties likely to experience with the self-expression of needs
- Mismatch with the type of person centred planning most suited to people with intellectual disabilities that is skilfully facilitated and draws on multiple source of knowledge about the person, their context and needs – that compensates for difficulties associated with intellectual impairment (Lyle O'Brien & O'Brien, 2002)
- Fails to reflect "an ethics of care, that views each participant as unique and seeks a more relational approach to planning, that places at its centre the dialogue between the caseworker (or planner) formal and informal supporters" (Carney et al., 2019 p. 783).

"NDIS has created a discriminatory process …goals and plans are usually developed via a long process… staff developing a close working relationship... 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". (Churchill et al., 2017)

Absence of supported decision-making

Decision making embedded in planning

- Participants have to rely on their own informal network or existing service providers for assistance with decision making during planning and initial stages of plan implementation.
- No mitigation strategies for risks identified in the literature that adults with intellectual disabilities have limited participation in decisions about their own lives and supporters often have a paternalistic stance (Antaki et al., 2009; Bigby, Whiteside & Douglas, 2019; Dunn, et al., 2010).

Few safeguards to ensure rights to participate in decision making respected

> “little evidence that NDIA planners scrutinise the approach taken by supporters, much less that they have some principles to guide a judgement about whether the way they are enacting the support is in tune with the intention of rights and principles in the legislation”.

- Nominee provisions – little used – seen as ‘guardianship light’ lacking the due process or protections afforded in appointment of a guardian (McCarthy, 2014).

Implications for choice and control by people with intellectual disabilities

- **Limited exercise of choice and control in planning** - 3 qual studies 38 adults (Collings et al., 2019; Lloyd et al., 2019; Perry et al., 2019)
- Majority (most of whom had mild or moderate intellectual disabilities) excluded from any meaningful engagement in planning - relied heavily on parents to lead the process.
- Many not present at planning meetings and some who were, reported feeling confused and unsure of what to expect.
- For 27 of the 28 adults supported by family –a family member determined what was included in plan, and at times overrode, failed to listen to or silenced the adult’s own perspective
- Adults felt their longer-term aspirations had not been captured, particularly around greater independence and intimate relationships (Collings et al., 2019; Perry et al., 2019)
- **Growth of guardianship orders** imposed on people with intellectual disabilities – reversing downward trends (OPA, 2019).

Further implications

- Some evidence of loss of services for people with mild intellectual disability from poorly expressed claims or lack of support

  "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 oversimplified to the extreme, leaving us to fill in the gaps, without the dollars to support the work. (Churchill et al., 2017)

  "Molly, 17, without any support for six months didn't understand the plan or the choices. "I had no idea where to go or what to do next" (Advertiser, 26 March, 2019)

- Despite emphasis on treating like cases alike,

  "There is greater than expected variability in package costs for participants with similar conditions and levels of function." (Malbon et al., 2019)

- Strong advocacy leads to better outcomes – unlikely to be people with intellectual disabilities

  "…those unable to advocate for selves or struggle to navigate processes at risk of lower levels of service than previously and many have had lower levels" (Mavromaras et al., 2018).

Rebalancing - moving away from dedifferentiation.

- **Recognition of need for consultation with people with intellectual disabilities**
  - Intellectual Disability Reference Group to Independent Advisory Council
- **Recognition of specialist knowledges needed for some groups** 'Cookie cutter' not working' (Morrison, 2019)
  - Autism Advisory group, NDIS Mental Health Sector Reference group and so on
  - Specialist advisors - autism, psychosocial disability
  - Specialist pathways for people with - complex support needs – psycho-social disability – hearing – early childhood
- **Less transactional processes** – face to face planning – single point of contact –better trained planners, more transparent decisions (NDIS 2018)
- More strategic, differentiated and longer-term mainstream and community capacity strategy (ILC strategy, 2019)
- Trail of support for decision making programs for people without informal support (DSS, 2018m 2020)
- Recommendation that supported decision making and guardianship should be priorities for the forward workplan of the Disability Reform Council (Tune, 2019).

Are people with intellectual disabilities benefitting from this greater differentiation ? Why not ?

- Included in some newly created categories – and benefitted from some broader changes
- Ironically, they have featured less than other groups in process changes and issues more specific to them continue to be neglected.

  > “NDIS does not really understand the unique issues associated with people who have an intellectual disability…if there is not a voice to assist those people or their families to articulate what it is that they want and need…then that group is going to become a sub-group that is ignored in the new NDIS environment….(Senior B’crat in Bigby & Henderson, 2018).

- Perhaps related to strength of advocacy, self advocacy, and voice about intellectual disability specific issues

  > “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.)

Conclusions

- “Inadequate focus on people with intellectual disability in the design and initial rollout of the scheme” (NSW CID, 2019).
- Change continues - new NDIS Plan announced November 2019 and legislative review (Roberts, 2019)
- Greater emphasis on functional assessment – to achieve equity is potential disadvantageous
  - single functional assessment is unlikely to fully capture the contextual or social factors necessary to accurately determine costs of individual support needs for a person with intellectual disability
  - person centred planning and supported decision making to understand preferences and desired supports may have to occur after funding allocated - paid from allocated funds that may take little account of access to existing social capital to absorb such costs .
- The capacity of differentiated intellectual disability advocacy needs to be proactively addressed and other strategies found to champion specific issues in NDIS administration
- Otherwise people with intellectual disabilities, the largest group of adults in the Scheme risk continuing to derive least benefit from it.
- 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)

Thank You

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