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Journal of Intellectual & Developmental Disability

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/cjid20

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To cite this article: Christine Bigby (2020): Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together, Journal of Intellectual & Developmental Disability, DOI: 10.3109/13668250.2020.1776852

To link to this article: https://doi.org/10.3109/13668250.2020.1776852

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Published online: 24 Jun 2020.

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JOURNAL OF INTELLECTUAL & DEVELOPMENTAL DISABILITY
https://doi.org/10.3109/13668250.2020.1776852

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ORIGINAL ARTICLE

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Dedifferentiation and people with intellectual disabilities in the Australian National Disability Insurance Scheme: Bringing research, politics and policy together

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ABSTRACT

Background: Dedifferentiated policy treats adults with intellectual disabilities as part of the larger group of people with disabilities. The implications of the dedifferentiated National Disability Insurance Scheme (NDIS) for adults with intellectual disabilities are explored.

Methods: Analysis of peer reviewed and grey literature between 2014 and 2020 about design of the NDIS and outcomes.

Results: Many participants experienced problems with NDIS implementation. Outcomes for adults with intellectual disabilities compared poorly to other groups. They were disadvantaged by standardised planning processes relying on self-expressed needs and omission of supported decision making. As the NDIS matures, it is becoming more differentiated but issues relevant to adults with intellectual disability remain largely invisible.

Conclusions: Further shifts towards standardised planning and functional assessment may be disadvantageous for adults with intellectual disabilities for whom support needs are dependent on social and contextual factors, and exercise of choice on support for decision making.

KEYWORDS

Dedifferentiation; NDIS; adults with intellectual disabilities; disability policy; individualised funding

Dedifferentiated policies are characterised by the "dismantling of special arrangements for vulnerable groups, dissolution of categories and growing individualism" (Sandvin & Soder, 1996, p. 117). Reflecting some features of neo-liberalism, this type of policy shifts the focus from collective responsibility and group solidarity to the individualism and the choice associated with decentralisation and the marketisation of services (Tossebro et al., 2012). For people with intellectual disabilities, dedifferentiation emphasises each individual's needs and functional abilities and their membership of the generic group "people with disabilities," rather than the impairement-specific group "people with intellectual disabilities."

For almost three decades, dedifferentiation has characterised some welfare policies in the United Kingdom (UK), Scandinavia and Australia (Bigby & Ozanne, 2001). For example, in Victoria, Australia, the 1986 Intellectually Disabled Person's Services Act was replaced in 2006 with the generic Disability Services Act. Similarly, State Disability Plans replaced plans such as the 1988 Ten Year Plan for the Redevelopment of Intellectual Disability Services. Internationally, the extent to which policies affecting people with intellectual disabilities are dedifferentiated has been variable. For example, English community care legislation that does not differentiate people with intellectual disabilities has long co-existed with more differentiated policies such as Valuing People (Department of Health, 2001).

The drawbacks and benefits of dedifferentiated policy for people with intellectual disabilities, and the resultant trend away from specialist provisions have been explored conceptually and empirically (Bigby & Ozanne, 2001; Clegg & Bigby, 2017; Felce, 1998). Dedifferentiation has been perceived as reflecting the preferences of people with mild intellectual disabilities because it avoids drawing attention to differences that are often devalued, or to the stigmatising label of intellectual disability. It is also seen as beneficial to promoting inclusion in mainstream, rather than specialist or segregated, services. Furthermore, it has been suggested that a dedifferentiated approach strengthens collective advocacy and increases the possibility of bringing about rights-based and structural changes to society (Clegg & Bigby, 2017). On the other hand, some drawbacks of dedifferentiation are suggested as a tendency to cultivate a lack of accountability, where neither mainstream nor disability services take into account the unique issues shared by people with

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intellectual disabilities, or sub-groups of this population, and thus fail to deliver the skilled support required to enable a good life. For example, Felce (1998) suggested that as people with intellectual disabilities become one of the many groups for whom managerial staff are responsible, recognition of the unique challenges associated with supporting people with intellectual disabilities may be lost. As a result, issues around communication and decision making, or being engaged in meaningful activities and social relationships, or continuing development of skills, will be poorly understood by staff who have no direct expertise in, or knowledge of, the relevant issues. Other drawbacks of dedifferentiation can be found in its tendency to obscure the diversity of people with intellectual disabilities, or downplay the impact of intellectual impairment on individual functioning or barriers to inclusion, which are critical in making accommodations and providing quality support (Clegg & Bigby, 2017).

Debates about dedifferentiated policies revolve around recognition and response to difference. Such debates are essentially concerned with how best to support the dignity, competence, and citizenship of people with intellectual disabilities, while drawing attention to their needs for support and safeguarding that stem from the core features of intellectual impairment, which are the very reasons for their historic exclusion from citizenship in the first place. The position statement on dedifferentiation of the Australasian Society for Intellectual Disability (ASID) leaves open the circumstances in which more differentiated policies might be beneficial to people with intellectual disabilities, concluding that we should:

> 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. (ASID, 2017)

The Australian National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a major social reform which, when fully implemented, will double government funding for disability services in Australia, remove block funding, and create a market for disability services. It is an exemplary dedifferentiated disability policy that as Gibbs puts it was built on a universal assessment framework, which meant:

> 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)

Put very simply, the NDIS provides individualised funding for "reasonable and necessary" disability supports (NDIS, 2013, section, 34) for an estimated 460,000 participants with permanent and significant impairments to enable the purchase of services. Key objectives of the Scheme are to "support the independence and social and economic participation of people with disability" and 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)). The requirement to have regard to financial sustainability (NDIS, 2013, Section 3, (b)) distinguishes the NDIS, as an insurance scheme, from previous disability related "welfare" provisions.

The dedifferentiated *Every Australian Counts* campaign helped to garner political and public support for the NDIS. The campaign successfully bridged competing interests of different impairment groups, their families, and service providers. Indeed, the idea of the "NDIS captured the imagination of every stakeholder in the disability sector" as "everyone was united in campaigning for Every Australian to Count" (Galbally, 2016, p. 11). It was also claimed that the campaign demonstrated the lived experience of disability as a "form of expertise that could contribute to momentous and pervasive policy change" (Thill, 2015, p. 21). Certainly, co-production and attention to the lived experiences of people with disabilities featured strongly in the Scheme's implementation (Joint Standing Committee on the NDIS, 2019; Mellifont & Smith Merry, 2016; NDIS, 2019).

This study explored the dedifferentiated approach of the NDIS and its implications for adults with intellectual disabilities. Adults whose primary disability was recorded as intellectual disability make up the largest single group of adult participants in the NDIS, an estimated 29.53% (NDIS, 2019). If those with autism and intellectual disability recorded as a secondary disability are included, the proportion is even higher. The main focus of this study was on the Scheme's design, particularly planning and decision-making provisions, and evidence about experiences and outcomes for people with intellectual disabilities.

Approach

The body of peer reviewed literature concerned with the experiences or outcomes for adults with intellectual disabilities in the Scheme is small, with only 10 empirical papers, and 19 commentaries published between 2014 and February 2020. The Scheme's implementation was

hurried and likened to "building a plane whilst flying it" (Whalan, Acton, & Harmer, 2014, p. 7). This has meant that the Scheme's operating systems, policies and procedures were, and remain, in a constant state of flux. The fast rate of change contrasts sharply with the slower pace of academic research and peer reviewed publication and means that policy or operational shifts often precede research findings. However, the rigorous reporting requirements imposed on the NDIS, combined with an exceptionally high degree of public interest and scrutiny, has resulted in a large body of grey literature about the Scheme. This comprises commissioned research reports, commentary from advocacy bodies, policy documents and reports of parliamentary inquiries and other public bodies. For example, the National Disability Insurance Agency (NDIA), responsible for administering the Scheme, reports quarterly to the Disability Reform Council (DRC). This council oversees the implementation of the NDIS as part of the Council of Australian Governments, the peak intergovernmental forum. As of May 2020, there were 26 such reports to the DRC and 19 communiques from the DRC about the NDIS. A Joint Parliamentary Standing Committee of both houses of the federal parliament was established in 2014. The Standing Committee has already conducted 15 inquiries into various aspects of the Scheme and published 12 final reports and one interim report. Many of these inquiries have involved public submissions and hearings. A further report on NDIS Costs was commissioned by the Productivity Commission – designer of the Scheme's original blueprint – in 2011 (2011, 2017).

While there are often concerns about the quality of research based on grey literature, it can be a valuable source of timely knowledge that offers a broader picture on similar topics explored in academic journals (Lawrence, Thomas, Houghton, & Weldon, 2015). Accordingly, this study drew on grey and peer reviewed literature about the experiences of people with intellectual disabilities, their families and allies within the Scheme. It explored literature published between 2014 and 2020 that focused specifically on adults with intellectual disabilities and the NDIS, or on NDIS policy that was generally relevant to adults with intellectual disabilities. A web-based search using Google Scholar identified 62 such items. This figure excludes reports of government inquires and communiques noted above as well as the quarterly reports of the NDIA. Google Scholar goes beyond original published research and tends to be more inclusive and outperform both Web of Science and Scopus in terms of its coverage of the literature (Tilbury, Bigby, & Hughes, 2020). Also included was a 12-month period of mainstream Australian print news media. A search of this media, using Factiva, was undertaken for the 12 months from July 2018. This search identified 304 articles about the NDIS, of which 24 had a specific focus on adults with intellectual disability.

Many of the grey literature reports were lengthy. The author read the executive summaries of the grey literature items and retrieved, and read, sections in the main body of reports that were relevant to the experiences of adults with intellectual disability. All peer reviewed items were read and, together with the grey literature, analysed using as a framework the following questions in respect to adults with intellectual disabilities. Did the design of the NDIS take into account the impact of intellectual impairment on individual functioning or reflect existing knowledge about decision making and planning with this group? What were the experiences of adults with intellectual disabilities with the NDIS and their outcomes, particularly in respect to planning, and exercising choice and control? And how did these compare to other groups of NDIS participants?

Findings and discussion

Heavily critiqued NDIS implementation

The implementation of the NDIS has been relentlessly scrutinised by the press, advocacy groups, parliamentary enquiries, and other public bodies (Joint Standing Committee on the NDIS, 2017, 2018, 2019; Office of the Public Advocate, 2018). Ultimately, almost every aspect of NDIS implementation has been critiqued. Individual experiences of inordinate delays, unjust decisions, market failure, and unskilled staff have been amplified in the media and government. Other reports have collected and synthesised such experiences through research and public submissions to draw out the systemic issues undermining the implementation of the Scheme. For example, a 2019 Federal Government report that reviewed the NDIS legislation acknowledged "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). Earlier reports were even more forthright. The Joint Standing Committee on the NDIS noted in 2017 that "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" (p. 71). And the following year, the same committee found that "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 Standing Committee on the NDIS, 2018, p. 11). The problems identified in such reports appear to have been experienced across many different disability groups. In spite of such concerns about implementation, support for the underlying intent of the Scheme remained strong (NSW Council for Intellectual Disability (CID), 2014, 2019).

Design problems specific to people with intellectual disabilities

An overarching issue in the design of the NDIS was the poor fit between people with intellectual disabilities and individualised funding schemes. For example, in one study, an academic expressed the view that the NDIS had been "designed with a very different idea of who a disabled person is in mind [from that of a person with intellectual disability]" (Bigby & Henderson, 2018, p. 15). Reflecting neo-liberal origins, individual funding schemes transform people with disabilities from clients into consumers, privileging individual choice and self-defined needs. The underlying assumptions are that participants in such schemes have the capabilities to be good consumers; to lodge claims, articulate needs, make decisions, identify and exercise control over service delivery, and, if necessary can access social capital for support. Dowse (2009) highlighted the mismatch between such expectations and characteristics of people with intellectual disabilities well before the roll out of the NDIS when she argued that moves to privatise and marketise choice, a characteristic of individual funding schemes, worked best for "particular kinds of consumers in a contemporary landscape which privileges competence, capacity and individual independence" (p. 573).

The design of the NDIS failed to take account of overseas evidence that individualised funding schemes were relatively disadvantageous for people with intellectual disabilities compared to other groups of people with disabilities (Carey, Malbon, Olney, & Reeders, 2018; Lord & Hutchinson, 2003; Needham, 2013; Williams & Dickinson, 2016). It was noted for example that:

> … individuals with physical disabilities are able to take better advantage of these opportunities [from individualised funding] than those with intellectual impairments. In the latter, good outcomes appear to depend upon strong advocacy or brokerage support. (Carey et al., 2018, p. 26)

In the earliest stages of the roll out of NDIS, commentators, academics and advocates drew attention to these issues (Bigby, 2014; CID, 2012; Clift, 2014; O'Connor, 2014). For example, CID, the largest state based disabled persons organisation of people with intellectual disabilities, foreshadowed the need for strong support mechanisms. As consumers, CID argued, people with intellectual disabilities would need "access to very considerable support and skills training" to make choice and control real (2015, p. 12).

The NDIS legislation expected that participants would direct their own plans, manage funding, determine their needs and make decisions (NDIS, 2013, s.31, s.17A(1)). Their need for support in interacting with the Scheme, and the limitations some might have with self-direction and decision making were acknowledged (2013, s. 31) through qualifying statements that self-direction of plans would be "so far as reasonably practicable," and participants had capacity to make their own decisions "so far as reasonable." The NDIS legislation also acknowledged the role that families or other informal carers would play in providing support to participants. Despite this recognition, no formal scheme for supported decision making was put in place to ensure decision support was available. No safeguards against paternalism, exploitation or simply neglect by informal decision supporters were implemented. And no formal mechanisms were embedded to assist with engagement with the NDIS, or any meaningful participation in planning and the implementation of plans when self-direction was not "reasonably practicable." These omissions were inherently disadvantageous for people with intellectual disabilities, many of whom are reliant on support to participate in decision making and do not have strong reserves of social capital (Bigby, 2008).

Exclusionary planning design and processes

NDIS standardised-administrative planning processes aim to treat like cases alike and rely on the self-expression of needs by participants (or by supporters on a participant's behalf). The legislation requires that participants prepare a statement about their personal goals and circumstances. Next, the NDIA and the participant jointly prepare a statement of supports, specifying the amount of funding from the Scheme (NDIS, 2013, s.33). The process is managed by a planner or Local Area Coordinator (LAC) who is unlikely to have professional qualifications, skills or experience in working with people with disabilities (Joint Standing Committee on the NDIS, 2019). There is no statutory requirement for negotiation in the planning process, nor is there a requirement for a face-to-face meeting in order to agree on the statement of supports (Carney, Then, Bigby, Wiesel, & Douglas, 2019).

Carney et al. (2019) suggested an "ethic of justice" underpinned the planning approach of the NDIS. It was aimed at impartiality and "based on abstract principles applied consistently to all participants" (p. 783). This type of planning is fundamental to the actuarial

approach of insurance schemes and supports the calculations of typical cost profiles. Despite this imperative, it was clear there had been expectations that planning processes would be person-centred and lead to tailored individualised packages of funding (Carney et al., 2019; Collings, Dew, & Dowse, 2019; Joint Standing Committee on the NDIS, 2019; Tune, 2019).

Responding to this sentiment, the standardised approach was strongly reaffirmed in a report of the review of the NDIS, released in late 2019. Following a series of quotes from submissions that illustrated participants expected differences in NDIS funding would be linked to their goals and aspirations, the report stated:

> It is, however, important to note that a participant's goals and aspirations are not intended to have a significant bearing on the level of funding provided in their NDIS plan. Rather, 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)

The design of the planning process gave limited attention to the difficulties people with intellectual disabilities were likely to experience with the self-expression of needs or formulation of goals. As such, the process was anathema to person-centred planning (Lyle O'Brien & O'Brien, 2002), which is designed to accommodate people with intellectual disabilities through skilled facilitation of input from multiple sources to ascertain their aspirations and needs. The NDIS process did not reflect an ethics of care, that views each participant as unique, and adopts a "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). An excerpt from a report by a non-government agency adeptly captures the disadvantages of the NDIS style of planning for people with intellectual disabilities:

> The 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, Sotiri, & Rowe, 2017)

A further concern about planning, particularly relevant to people with severe and profound intellectual disabilities and their families, can be found in the underlying assumptions about self-expression and the relevance of life goals in areas such as employment and education. Plan goals have to be written in the first person, as if they have been expressed by the participant him/herself. Unlike person-centred planning – which also uses first person language – the NDIS adopted this without any processes to justify the goals as being the person's own. Damian Palmer (2016), the father of a young woman with profound intellectual disabilities, regards this practice and the requirement to create goals for all aspects of his daughter's life as a failure by the NDIS to understand or accommodate people with profound intellectual disabilities. He wrote:

> 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". (p. 8)

Unsupported decision making

The absence of a formal scheme for supported decision-making meant participants relied on their own informal network, or on existing service providers, for assistance with decision making around planning and during the initial stages of plan implementation. The risks of adopting such an approach have been highlighted in a body of literature that points to the limited extent to which adults with intellectual disabilities participate in decisions about their own lives and the paternalistic stance some decision supporters take during the process (Antaki, Finlay, & Walton, 2009; Bigby, Whiteside, & Douglas, 2019; Dunn, Clare, & Holland, 2010). Yet there were no mitigation strategies for such risks embedded in the NDIS. As Carney et al. (2019, p. 809) noted:

> … there is 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. Informal supports, while in theory closest to the person and thus most capable of knowing or 'reading' the will and preferences of the person being supported, may be unduly protective and risk-averse, and accountability can be difficult to ensure.

There are provisions in the NDIS legislation to appoint and enable *nominees* to exercise proxy decision-making on behalf of a participant. However, the legislation lacks detail about the appointment of nominees and the specific means for monitoring the exercise of their power. To date, these provisions have been little used, and statistics of such appointments are no longer reported in the NDIA

quarterly reports. The provisions have also been criticised as a form of "guardianship light", which lack the due process or protections afforded by the appointment of an actual guardian (McCarthy, 2014).

A shift to greater differentiation

As issues with NDIS design and implementation arose, many organisations lobbied about issues specific to their mission or their constituents. The Summer Foundation, for example, led a campaign focused on moving young people with acquired disabilities out of nursing homes (https://www.summerfoundation.org.au). The Victorian Office of the Public Advocate (2018) led another concerned with people with complex support needs, and the CID (2012) led another still about access to the NDIS for people with mild intellectual disabilities living on the fringes of society. Many of the issues raised by these specific interest groups were relevant to various cross sections of NDIS participants, who also benefited from the resultant changes. For example, since 2013 changes have been made to more practical aspects of planning, such as the abandonment of phone planning. Other changes are foreshadowed, such as the commitment to better trained planners and greater transparency and consultation before the finalisation of plans (Joint Standing Committee on the NDIS, 2019). Nevertheless, the fundamental approach to planning remains unchanged.

The NDIS has adopted a more differentiated approach, albeit on an ad hoc basis, in its response to some of the issues raised by the media, advocacy organisations or during inquiries. In 2019, for instance, the Prime Minister commented that the "cookie cutter approach was not working" (Morrison, 2019), which might be interpreted as a need for more differentiation. Meanwhile, some specific differentiated initiatives have already been implemented. One prime example is the creation of separate access pathways for people with complex support needs, psycho-social disability, hearing impairment and families seeking early childhood intervention. Other important differentiated initiatives can be found in the establishment of impairment specific advisory or reference groups (Joint Standing Committee on the NDIS, 2018), and in the prioritisation of moving young people with acquired disability and complex needs out of nursing homes (Michael, 2019).

The issue of supported decision making has also found its way onto the agenda. First, a small pilot program was funded in 2015 that aimed to match volunteer supporters with people with intellectual disabilities in the Barwon launch site. Then, in 2018, a program was launched in each state to provide decision-making support for people without family or other informal supporters. Notably, the review of the legislation (Tune, 2019) recommended that supported decision making and guardianship should become priorities for the forward workplan of the Disability Reform Council.

Although some subgroups of adults with intellectual disabilities will benefit from the shift towards greater recognition of difference among people with disabilities, people with intellectual disabilities have seldom been distinguished by the NDIS as an impairment group facing distinctive issues. There are, for example, no strategic advisers for intellectual disability. Nor is there a specific access pathway. In 2019, there remained a sense among many observers of an "inadequate focus on people with intellectual disability in the design" of the Scheme (CID, 2019).

One of the few acknowledgements of this group's issues was the establishment in 2014 of an Intellectual Disability Reference Group following significant advocacy by CID (2014). This reference group advises the Independent Advisory Council, which advises the Board of the NDIA. Though symbolically important, it has not met regularly and it has made slow progress in the absence of strong parallel advocacy about the issues raised.

There are significant obstacles to advocacy about the unique issues for adults with intellectual disabilities. Some of these are embedded in the very characteristics that differentiate this group of adults from other impairment groups, which include their difficulties with self-advocacy and heavy reliance on skilled support to identify or articulate issues of concern. This point was poignantly made by a family member and a senior bureaucrat who said:

> … 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. (Lipshut, 2018)

> … 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. (Bigby, forthcoming)

Such problems are compounded by the absence of a national organisation resourced to represent issues for people with intellectual disabilities. The small state bodies that make up *Inclusion Australia*, the "national

voice for Australians with intellectual disability," are poorly funded and there is no dominant profession that leads dissemination of knowledge concerning practice or research about adults with intellectual disabilities.

Relatively poorer outcomes for people with intellectual disabilities

Since the first launch sites, and despite the heavy critique in the media and elsewhere, participant self-reported satisfaction with the NDIS has been high and outcomes positive (NDIS, 2015, 2019). However, despite standardised planning aimed at producing equitable funding allocations, the data point to inequities between people with similar support needs as well as differences in outcomes between different impairment groups. For example, analysis by Malbon, Carey, and Meltzer (2019, p. 6) found there had been "greater than expected variability in package costs for participants with similar conditions and levels of function." Meanwhile, the largest university-led study to date found that people with intellectual disabilities had benefitted less than other disability groups and were at risk of inadequate levels of support (Mavromaras et al., 2018). Compared to other groups, they had higher levels of unmet demand, exercised less choice and control over supports, gained less clear benefits around social participation, had poorer average levels of wellbeing, were least satisfied with NDIS processes, and were more likely to be unable to navigate the NDIA website and obtain information about services (Mavromaras et al., 2018). While the study found groups, such as people with psycho-social disability or rural dwellers, were also relatively disadvantaged on some of these indicators, those with intellectual disabilities consistently fared the worse.

Cutting the data in another way, Mavromaras et al. (2018, p. xv) found those unable to advocate for themselves or who struggled to "navigate NDIS processes are at risk of receiving lower levels of service than previously." Given the other finding of this study and existing knowledge about the difficulties many experience with self-advocacy, the majority of participants in this group are likely to be adults with intellectual disabilities. Indeed, media case studies and reports by non-government services and advocacy bodies have captured instances of people with intellectual disabilities receiving inadequate funding from the NDIS due to the reliance on self-expression of needs during the planning process (Office of the Public Advocate, 2018). One study documented the loss of intensive assistance from block-funded community justice services on the transition to the NDIS, when young men have failed to engage in the NDIS claim process or experienced reduced levels of funding stemming from difficulties nominating their own needs without access to skilled facilitation for the planning process (Churchill et al., 2017).

The only other publicly available large-scale data set is from an NDIA internal survey administered to participants and their families during initial plan development and subsequent reviews. Only selective data, up to June 2018, is reported. This makes comparison on items across groups difficult, yet these data indicate relatively poor outcomes for adults with intellectual disabilities in terms of open employment and participation in mainstream services. For example, they were less likely to be in open employment (23%) than other adult participants (43%), and more likely to be in low paid and segregated Australian Disability Enterprises, many of which are similar to sheltered workshops (74% compared to 49%). However, more adults with intellectual disabilities had a work goal in their plan (58%) than any other group (NDIS, 2018). At follow up, adults with Down Syndrome were more likely to have increased their community and social participation, but this was in disability-specific, rather than mainstream, groups.

These broad trends of poor experiences of choice and control, and little change in participation in mainstream community activities were reflected in three qualitative studies of planning experiences of adults with intellectual disabilities (Collings et al., 2019; Lloyd, Moni, Cuskelly, & Jobling, 2019; Perry, Waters, & Buchanan, 2019). The majority of the 38 adults in these studies – most of whom had mild or moderate intellectual disabilities – had been excluded from any meaningful engagement in planning and relied heavily on their parents to lead the process. Many had not been present at planning meetings, and some of those who were present, reported feeling confused and unsure about what to expect. Similar experiences have been reported by self-advocates in various CID reports. One participant indicated that it would make things easier "if they could explain planning to you a little bit more because I couldn't understand it and its complicated for my mum too" (CID, 2014, p. 25). Another noted of the process that there was "too much red tape, too many steps, too many papers, too many workers who don't know what they are doing" (CID, 2019, p. 1).

Lloyd et al. (2019) concluded that the adults in their study were "not a contributing member of the planning team for most of the plans developed" (p. 8). Findings by Collings et al. (2019) and Perry et al. (2019) illustrated the dangers of reliance on informal decision support identified in the literature. For example, 27 of the 28 participants with intellectual disabilities reported that a family member who supported them largely determined

what was included in their plans, and at times overrode, failed to listen to or silenced the adult's own perspective.

Both parents and the adults with intellectual disabilities who were interviewed in these three studies expressed concerns that planning processes had not been well attuned to their needs (Collings et al., 2019; Lloyd et al., 2019; Perry et al., 2019). The adults felt their longer-term aspirations or real needs had not been captured, particularly around greater independence and intimate relationships. Parents were concerned that planners had neither the skills nor the inclination to work with the adult with intellectual disability.

A similar lack of choice and control was experienced by a parent of a young women with profound intellectual disability who represented her in the planning process. He said:

> I thought we were just meeting with a local area coordinator who was going to be supporting us through the planning process. Sat down, we had this conversation, she collected this information or whatever, and next thing we had a plan. I just said, 'What's going on? This is not the way I understood this to be working? (Henderson & Bigby, forthcoming)

A further indicator of the problems the NDIS has had in enabling increased choice and control for people with intellectual disabilities – and the detrimental impact of such – has been a growth in guardianship orders imposed on people with intellectual disabilities (Office of the Public Advocate, 2019). In Victoria, for instance, there has been a reversal of the long-term decline of guardianship orders made for adults with intellectual disabilities (Fougere, 2014; Office of the Public Advocate, 2019). Since March 2020, Victorian legislation requires guardians to make decisions based on the will, preference and rights of people with disabilities, rather than best interests, but this is not the case in all Australian states. Regardless, whatever the regime, the imposition of guardianship does mean the removal of decision-making rights.

Conclusions

The NDIS is a behemoth that has changed significantly – and continues to change – in response to the rapid intake of participants, political imperatives and public critique. Relentless and rapid change makes analysis and robust conclusions about its impact on people with intellectual disabilities a difficult task. The task is also hampered by the dedifferentiated nature of much of the NDIS data, which does not consistently or adequately distinguish between impairment groups or report co-occurring conditions such as autism and intellectual disabilities. Receptiveness of the Scheme to change, does however, leave open opportunities to progressively resolve or at least mitigate design issues that disadvantage people with intellectual disabilities.

This analysis suggests the dedifferentiated design of the NDIS, and the subsequent changes, have not taken good account of issues specific to adults with intellectual disabilities. This contention is supported by a consistent trend in the small body of evidence that suggests adults with intellectual disabilities experience poorer outcomes compared to other participant groups. The analysis has highlighted a fundamental mismatch between the type of planning most suited to people with intellectual disabilities (i.e., facilitated and drawing on multiple sources of knowledge about the person, their context and needs), and the administrative-standardised approach of the NDIS.

This analysis shows too that NDIS planning processes have been neither person-centred nor have such process treated like cases alike. The 2019 legislative review signalled greater standardisation and use of functional assessment in planning to address issues of equity of funding allocations (Tune, 2019). The review also surfaced the lack of connection between individual goals and amounts of funding, which though implicit in insurance schemes, had not been well understood. Rebuttal of assumptions about the individualised and person-centred nature of NDIS planning processes does not remove the need for planning of this nature. Even if individual goals and aspirations do not inform volume of funding, they must inform decisions about expenditure, such as service type or provider, if consumers are to exercise choice and control about their lives and the support they receive. Indeed, depending on their available social capital, some adults with intellectual disabilities are likely to require ongoing support to plan and manage their services that resembles the intensity and skill associated with case management. A greater focus on functional assessment to determine funding may signal an intent that detailed person-centred planning should be done post, rather than pre allocation of funding. If this occurs, there is a danger the costs of this, as well as those of ongoing case management, would have to come from a funding allocation that has not factored them in sufficiently well, or has taken little account of the individuals' access to existing social capital to provide such resources.

A stronger emphasis on functional assessment potentially disadvantages people with intellectual disabilities, particularly those with complex support needs, in another way. A single functional assessment of an individual with intellectual disability is unlikely to fully capture the contextual or social factors that combined with

functional capacity determine support needs. Assessing support needs is the stuff of multi-disciplinary assessments combined with person centred planning processes (Bigby & Frawley, 2010).

As the analysis demonstrates, some small steps have begun to address the risks for adults with intellectual disabilities associated with the omission of supported decision making. Some form of mandated supported decision making and an explicit onus on NDIS staff to enquire into the nature of the decision support would help to set expectations about the quality of informal support, build the capacity of decision supporters for a rights-based approach, and provide criteria to assist in accountability of their practice. Such measures will be important in increasing the chances of adults with intellectual disabilities in realising the Scheme objectives of greater choice and control. However, there is still a long way to go in creating a coherent and evidence-informed scheme for supported decision making from the disparate approaches adopted by small pilot programs in each state. Notably, by funding advocacy groups to conduct these pilot programs, new questions have been raised about the distinction between advocacy and support for decision making that warrant further investigation.

Ironically, this analysis indicates that people with intellectual disabilities have benefitted less than other groups from a trend towards greater differentiation in the Scheme's operations. This suggests issues specific to people with intellectual disabilities need to be much more strongly prosecuted with the NDIA. Solutions to difficulties with self-advocacy and the relative weakness of advocacy for this group may lie with national cross disability groups having a stronger focus on issues for adults with intellectual disability, and strengthening, through core funding, the national network of intellectual disability specific advocacy. Other strategies could also be explored to champion their issues. The NDIA could, for example, adopt a more differentiated approach in respect to "expertise" and "voice." The modelling done by Every Australian Counts campaign that people with disabilities are experts on their own lives and contributors to policy has been reflected in many aspects of the NDIA's strategic and operations. However, more nuanced strategies than those that work well for people without cognitive impairments are required to "hear" from people with intellectual disabilities, particularly those with severe or profound impairment. One avenue is recognising the validity of multiple sources of expertise about this group, including family members, long-term support staff and researchers. Without a differentiated approach, the systemic issues experienced by those who have difficulties with self-expression, will remain unresolved and adults with intellectual disabilities will continue to be excluded, despite the good intentions of the NDIA in prioritising lived experience as a source of expertise.

Dedifferentiation and the NDIS reflect the characteristics of neo-liberalism in their prioritisation of individualism, choice and open markets. However, the mould required to thrive as a consumer under these conditions does not fit the characteristics of people with intellectual disabilities. To return to the ASID position statement on dedifferentiation (2017), the NDIS may be one circumstance where it is necessary to "protect and develop differentiated opportunities, services and research" for people with intellectual disabilities. The evidence reviewed in this paper suggests a more differentiated and a proactive stance by the NDIS is warranted in order to achieve outcomes for adults with intellectual disabilities comparable to other groups. Otherwise, the largest group of adult NDIS participants may continue to derive the least benefit from the Scheme.

Acknowledgements

An early version of this paper was presented at the 2019 IASSID Congress in Glasgow, Scotland in August 2019 as part of a symposium on dedifferentiation.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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