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REPORT



Dedifferentiation and difference: People with profound intellectual and multiple disabilities and the National Disability Insurance Scheme (NDIS)

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ABSTRACT

Dedifferentiation represents the merging of the wider “intellectual disability” category with the broader one of “disability” generally; a product of the ascendance of the social model of disability. The recent re-emergence of the significance of impairment and embodiment in disability theory re-establishes the importance of situated experience and reinserts realities of difference in the dedifferentiation/difference debate. This paper highlights these issues by exploring the experiences of people with Profound Intellectual and Multiple Disabilities (PIMD) and their decision-making supporters in the context of the National Disability Insurance Scheme (NDIS) in Australia. Lived experiences accessing, planning for, and implementing NDIS supports illustrate some limitations of dedifferentiation in social services, highlighting the need for recognition of realities of embodied difference for people with PIMD. Here, our systems and theories are most uncomfortable, our ideals of inclusion are most challenged in practice, and some balance between realities of difference and ideals of dedifferentiation is most needed.

KEYWORDS

Dedifferentiation; NDIS; profound intellectual and multiple disabilities; PIMD; lived experience; intellectual disabilities

Dedifferentiation and difference

Dedifferentiation, in advocacy, social research, public policy and social services, includes people with intellectual disabilities within the wider “disability” group. Sandvin and Soder (1996) introduced the term “dedifferentiation,” a concept taken from biology that describes how specialised, differentiated cells revert to a simpler, more general form of cell (such as a stem cell), thus losing their complexity of function (Cai, Xiaobing, & Sheng, 2007, p. 656). In the disability field, dedifferentiation describes the merging of “intellectual disability,” and other disability “types,” into the broader “disability” group; losing the “specialisation” of particular impairments or challenges. The difficulties of living with intellectual disabilities are seen as a product of systems of social oppression and discrimination; as social constructs, removed from the realities of bodies and minds (Oliver, 2013).

For many in the international disability rights movement, impairments are not the problem: society is the problem. ... [I]f social and environmental barriers are removed, impairment is no longer a disadvantage. It becomes a neutral characteristic (Shakespeare, 2013, p. 93).

Thus, dedifferentiation addresses socially oppressive barriers to inclusive and equal treatment within our social systems using theory, policy and services that avoid specialisation.

Dedifferentiated policy and social service provision usually involves an emphasis on *ability* rather than disability (Goodley, Lawthom, & Runswick Cole, 2014), and are aimed at achieving neo-liberal goals of independence, autonomy, and self-determination (Tabatabai, 2020). Dedifferentiation seeks to deconstruct and overcome barriers in society that make inclusion difficult *within* mainstream services; such as in education (Rogers, 2013); health care (Office of the Public Advocate Queensland, 2016); or employment (Lantz & Marston, 2012). This shift includes steps away from specialised services for people with intellectual disabilities (Clegg & Bigby, 2017), which are seen as segregated and exclusionary, harking back to the days of institutionalisation. Dedifferentiation assumes that all people can participate in social, community and civic life if appropriate accommodations, technology, therapeutic approach, and shifts in wider social attitudes are made, and specific *impairments* are thereby neutralised and “overcome.” It could be said that a commitment to dedifferentiation underpins the Australian National Disability Insurance Scheme (NDIS).

The NDIS as a dedifferentiated reform

The NDIS is a significant reform of the Australian disability services sector founded on a human rights

model. The NDIS provides an entitlement to people with disabilities to access an individualised funding package in order to enable them to pursue their goals, live independently, access the community, and generally exercise their human rights within society.¹ The scheme is now in operation Australia-wide, with over 350,000 participants as at the start of 2020 (National Disability Insurance Agency, 2020).

The NDIS is underpinned by ideals of self-determination (Bigby, 2014); uses individualised planning and funding (Curryer, Stancliffe, & Dew, 2015); and makes assumptions at every stage about the capacities and capabilities of those who interact with it (Cukalevski, 2019). It is founded on dedifferentiation; all disabilities should be treated similarly, barriers to inclusion can be removed by funding, supports and assistive technology, and all participants are able to participate fully in its implementation and practical operational requirements in their quest to lead “independent” lives.

This article uses practical problems with the NDIS to critique dedifferentiation in practice for people with a particular “type” of disability; those with profound intellectual and multiple disabilities (PIMD). People with profound intellectual and multiple disabilities lie perhaps the furthest away from our shared constructions about inclusion and autonomy (Vehmas, 2010), such as being able to comprehend verbal language and complex ideas (Vehmas & Makela, 2008), being able to deal with complex social systems, and attaining goals of independence and self-determination (Goodley, Lawthom, Liddiard, & Runswick-Cole, 2019; Simpican, 2019). The experiences of people with PIMD and their supporters illustrate the flaws in assumptions made by the social model of disability and its dedifferentiated systems, and demonstrate the value of reconceptualising embodied difference and lived experience of impairment into both activism and social services.

Method

This article presents data generated from a larger project about the legal and administrative transition to adulthood of people with PIMD living in Queensland.² Defining PIMD is difficult and often contested (Nakken & Vlaskamp, 2007). The self-selection criteria of PIMD used to recruit participants focussed the project on young people at the profound end of intellectual impairment,³ who would require a substituted decision-maker if the necessity arose under the current Queensland guardianship legislation. The research used constructivist grounded theory (Charmaz, 2014) to scaffold the approach, assumptions, method and analysis.

The author conducted in-depth interviews with 18 supporters of young adults with PIMD aged between 17 and 30, living in Queensland, recruited using purposive snowball sampling. All 18 supporters interviewed were a parent of a young person with PIMD, 17 mothers and one father. Thirteen interviews were done in a “dyad,” the young person with PIMD was present. In 5 cases the young person was not able to attend due to issues reported by their supporters. Interviews were in-depth, reflexive, and narrative in style using a list of topic areas as a guide. Theoretical saturation (Bryant & Charmaz, 2007, p. 214) was achieved with 18 interviews.

This is an “insider” research project; I have a 21 year old daughter with PIMD.⁴ Insider/ in-group membership is not a disadvantage if appropriate reflexive practice is undertaken (Enosh & Ben-Ari, 2016). Acknowledged grounding within a research environment at all stages strengthens the development of understanding and theory within the relational spaces of research (Mruck & Mey, 2007). My own situated experience within the group I am studying, with careful reflexive practice, allows a form of “auto-ethnographic” knowledge to contribute more nuanced and authentic understanding, and assumptions to be explored and tested against data (Coles, 2015, p. 136).

This article presents themes that emerged from reflexive thematic analysis informed by existing theoretical ideas about dedifferentiation, with each participant’s discussion of the NDIS analysed thematically: an abductive approach consistent with constructivist grounded theory (Charmaz, 2014).

Realities of PIMD in a dedifferentiated system

The NDIS is an individualised funding model, implemented through “plans” that are set up and reviewed by planners employed by the National Disability Insurance Agency (NDIA, 2019), or outsourced to “Local Area Coordinators” (LAC’s). Plans last for one year, though subsequent plans may last for up to three years. Most plan meetings are face-to-face, and the planner will fill out a complex online form during this meeting. Participants can provide documents, reports, and other material to support their needs. Plans are, in principle, driven by the “goals” of the individual participant, but in reality are constrained by the requirements of the algorithms underlying the scheme (Carney, Then, Wiesel, & Douglas, 2019).

Successfully navigating this process is difficult for many people, especially for those with intellectual disabilities. For people who are profoundly intellectually disabled, who lack functional communication, and may have behavioural or other complex needs that mean

they cannot participate in a meeting in a strange environment with an unknown person. There are obvious problems with this assumption of administrative and financial “self-determination.” While the NDIA Act and Rules allow for “nominees” to be appointed for a participant,⁵ this does not change the assumptions of the system; that a person will be able to advocate for themselves, that their needs can be clearly articulated in terms of existing algorithms, that the profound nature of a person’s impairment is adequately recognised, managed, and supported. Within this dedifferentiated landscape, the realities of profound difference are not well supported.

All participants in this research praised the NDIS as a significant and important step forward in disability services provision and funding. All young people in the project were receiving more funding under the Scheme than previously, and supporters spoke of NDIS plans as providing four, five, or even ten times more funding than they had received before the NDIS. The NDIS brought great positive change to the lives of the young people with PIMD and their supporters, and this was acknowledged by all 18 participants. However, conversation about the NDIS always began with, “the NDIS is great, *but ...*” It is in the qualifier that insight into problems with the scheme, and with dedifferentiation more broadly, emerge. All 18 participants also discussed problems they experienced with the NDIS, and examples of difficulties fitting into the NDIS with PIMD.

PIMD is deeply embodied. One critique of dedifferentiation is that it does not allow the recognition and representation of those with more extreme differences. In the case of people with intellectual disabilities, people with milder impairments are used as “the proxies for all people” (Bigby & Clegg, 2017, p. 4), and those with more severe and profound impairments are not represented, understood, or accommodated. In this research, many supporters said that the NDIS was not able to deal with the severity of the young person’s intellectual disability. Very real impairments were challenged, downplayed, or simply ignored by the administrative and algorithmic demands of the NDIS planning system. Supporters spoke of having to argue with planners about what the participant was actually able to do, or about not being fully understood when they described the severity of the impairments of the young person they support.

For example, Harriet⁶ talked about her daughter Emma’s (aged 18 years) first planning meeting with an NDIA planner (in 2019). Harriet gave an example of what she felt was the planner refusing to understand the severity of Emma’s disability. In the exchange below, I also share a similar example from my experience with NDIA planning with my daughter, Daelle (who is

21 years old). Both of the young people we support have profound intellectual disabilities caused by underlying malformation of the brain, have multiple complex health needs that are life-limiting, use wheelchairs for mobility, are not able to feed, clothe or bathe themselves, do not have functional communication, and are not able to use augmented or other symbolic forms of communication:

- | | |
|----------|--|
| Harriet | At one point, they gave Emma a pen, they said, “she can sign the application!” Emma doesn’t know what a pen is! Anyway, later she threw it and it nearly hit [the planner] in the eye. [laughs] I bet you had similar? |
| Michelle | Oh, yes, they rang to ask about Daelle’s plan once and asked me to put Daelle on the phone! [both laugh] |
| Harriet | Yes, I wish! I wish I could put her on the phone! Emma can’t hear, she can’t speak, she can’t make any decisions on behalf of herself, and she doesn’t fit into their system. |

Similarly, Heather described the constant attempts of an NDIA planner to get her son, Robert (age 23), to answer questions in a plan meeting, because the planner misunderstood Robert’s ability to verbalise “hello.”

People think ... see, Robert says “hello.” But from that, he doesn’t know what to say next, that’s as far as he gets, it’s his only word, really. We get a lot of “hello”, and that’s what we get, and that’s it. And then we don’t really know what to say after that. And so, people think he’ll answer but he can’t. At the planning meeting, it just went on and on! I said, he can’t answer you, he doesn’t understand!

These assumptions also caused problems with interacting with the NDIA. Lydia gave an example about her daughter, Emily (age 18), who does not speak or use augmented communication, and needs assistance with all her activities of daily living:

They don’t understand that her capacity isn’t going to change based on what age she is. She can’t do it now, so why can she do it next year? A planner rang and said, “Emily is 18 now, so she can come in and do her own plan reviews.” [laughs] Well, good luck with that!

To supporters, these issues represented a fundamental misunderstanding of the nature and reality of PIMD. This is not only a source of much (often avoidable) frustration and distress, but also has very real effects as a person with PIMD interacts with the NDIA systems; from planning, using the NDIA portal to access funds, and administrative reviews. Failing to recognise that impairments are embodied and very real can have far reaching consequences for these young people.

Difference requires specialised training and expertise in NDIS planning

Dedifferentiated systems devalue specialised training and expertise, and provide general services and staff training rather than case management systems or specialist units and staff. However, specialist knowledge is required to “adequately support or adapt services to a person with intellectual disability” (Bigby & Clegg, 2017, p. 3). While some improvements have been made for some with complex needs such as homelessness, being in State care, or imprisonment, specialisation specifically for people with PIMD has not been addressed so far by the NDIA. Supporters described planners as poorly trained, lacking expertise with complex and multiple disabilities.

Brian is a 19-year-old man with PIMD and when we met, demonstrated constant repetitive behaviours and verbalisations. His mother, Mary, describes how a NDIA planner dealt with him during their first plan meeting in 2018:

It was like, sometimes I was talking to a little bit of a brick wall. I don't know whether maybe the planner just wasn't experienced, but she didn't seem to be disability friendly. He was tapping on a truck, and she said she found that annoying. Um, so she didn't have to say it like that did she? The idea was you take your young person in for half an hour to the meeting to show them what they're like, you know, in a physical, practical way, that this is the reason you're asking for all that stuff. So yeah, no experience with kids like Brian, and that's what she said to us, he was annoying.

Anne describes a similar problem with John's first planning meeting. John (age 23), has PIMD, is non-verbal, and needs complex medical care:

Well, the first of our first plan meetings was an unmitigated disaster! I think she was an NDIA planner, at the time, but very inexperienced. She was someone who must have had the capabilities to do the job but didn't know anything about disability. [...] We left, and I just requested a new planner.

After the second planning meeting, the plan John was given was not adequate for his needs.

They talk “choice and control,” but they think “dollars and cents.” And if John was in a group house – “why can't he go to a group house, where there's three-to-one⁷?” Because he can't be left alone, that's why! That's not *our* choice. And because we have control. And because that's what this is all about.

At the time of interview, Anne and John were still waiting for administrative review of his funding for overnight accommodation at a one-on-one staff ratio rate so that John could spend up to 14 nights a year independently of his parents.

Heather was also frustrated with the NDIA planners she had met while doing Robert's plans, the assumptions made about “informal supports” (such as support provided by her as Robert's mother), and questioned how the system algorithms allocate funding in complex cases:

Yeah. It's disgusting. And it's because, see, [the NDIS] don't listen, they don't listen. They just, they hear what they want to hear is my point. Like, I tell the truth. I'm not gonna lie. I could lie to them and say I work every day and they'd give him more hours during the day. But I tell the truth and say he comes with me [to the family business], that's all they hear. Oh, he's there, we don't need to support him there, then, that's “Informal Supports.” We don't care about that; we don't need to do that. They don't care about the fact that he's 23 now. Doesn't he need some independence? [...] So, the NDIS don't hear that, and they don't want to know about that. I think it's because we don't have the right words. That is, even though we say the right information, maybe it's just not expressed in the words that they need to have on that computer.

Another key problem identified by supporters was misclassification by planners of the level of supports used to cost a plan. “High Intensity Supports” (HIS) have complex eligibility requirements and are costed at a higher hourly rate. Most of the young people in this study were eligible for HIS, often at the maximum rate. Several participants had plans incorrectly costed at a lower rate than their actual needs, or at the wrong staffing ratio. Harriet had to request a plan review (a formal administrative process) because Emma's first plan was wrongly costed at a one staff-to-two participant ratio, without HIS rates. Harriet was not sure if this was “just a mistake,” but suspected it stemmed from a serious misunderstanding of Emma's disabilities. Emma easily met the HIS criteria due to her seizures, support needs, and medical precarity. Either way, the error had caused significant problems and a lengthy administrative review:

I said, you've got to be kidding us! No way is Emma going out there without one on one! She's nonverbal, she has seizures every five minutes, she's peg-fed, she's incontinent, she can't push her own wheelchair! I mean, if she's not getting high intensity one-on-one, who is, I guess is the question?!

These examples demonstrate how specific and complex needs of people with PIMD were not well-supported by generalised NDIS staff.

Dedifferentiation and difference

Dedifferentiation, and its failure to consider the embodied realities of impairment, is in itself a form of exclusion; a redefinition that does not reflect the lived experience of all people with disabilities. There is value

in differentiation. Over-emphasis on social constructions of disability, in the absence of lived experience and realities of embodiment, leads to a kind of reductionism in the other direction; a *dis*-embodiment of impairment, a removal of the realities of an embodied person from the picture (Anastasiou & Kauffman, 2013, p. 442). The social model has made disability *only* about the social/constructed. The real differences contained in the experiences of some disabilities, in *differentiation*, should not be dismissed. This does not become a call for a return to segregation and institutionalisation, but rather an acknowledgement that inclusion needs to respect difference; that true inclusion supports realities of difference and is not simply striving to negate them altogether. There should be a way forward that allows for both approaches.

Using elements from Bigby and Clegg's critiques of dedifferentiation (Bigby & Clegg, 2017; Clegg & Bigby, 2017), this article supports two critiques of dedifferentiation in the context of the NDIS: the lived realities of PIMD are not well-represented within the Scheme; and providing appropriate support for PIMD needs specialised expertise and staff. This provides evidence for the reconceptualisation of difference in the context of intellectual disabilities, dedifferentiation, and the NDIS.

Notes

1. *National Disability Insurance Scheme Act 2013* (Cth) s 4.
2. For a PhD that is ongoing.
3. Defined as: the young person having little or no ability to use and understand verbal communication (functional communication); little or no ability to use or understand other forms of communication such as symbols or writing; little or no ability to care for themselves – requiring significant assistance or totally dependent on others for all activities of daily life such as eating, drinking, bathing, hygiene, and interacting with others and the environment; and requiring the support of a decision-maker to interact with legal and administrative systems.
4. Sherry critiques the term “insider” and provides a useful critique of the concept of distinguishing research by group/identity membership (Sherry, 2006, 99 ff.)
5. *National Disability Insurance Scheme Act 2013* (Cth) s 88 and *National Disability Insurance Scheme (Nominees) Rules 2013* (Cth) rr. 3.14, 4.6, 4.8, 4.10, and 4.12.
6. All names are pseudonyms and identifying details have been removed.
7. Three participants to one staff member.

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