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Does the Australian National Disability Insurance Scheme enhance personal quality of life?¹

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ABSTRACT

The Australian National Disability Insurance Scheme's (NDIS) marketbased paradigm, which prioritises "person-centred planning" and "self directed care", supports independence and the social and economic participation of participants. This article examines the NDIS's philosophical congruence and whether it affirms the dignity of people with an intellectual disability and enhances their quality of life. A philosophical methodological approach considers the NDIS paradigm from John Macmurray's personalism, which posits persons as people who act and are individual, interactive, interdependent, relational, social beings, who respond to their lived experiences. To indicate the relevance of Macmurray's personalism, this article examines data on the practice of disability services to suggest another side to the paradigm that underscores the NDIS. The focus of the NDIS on "markets" and "business" could tear a seam in a paradigm designed for people to realise their personal nature, interdependency, and affirm their personal dignity. A Macmurrian human nature is richer than person-centred planning, since this analysis reinforces the importance of personal relationships in people's lives to the application of the NDIS. A failure to give priority to this dimension may invalidate personal flourishing, friendships, living a meaningful life, and having a valued role in society.

KEYWORDS: John Macmurray; metaethics; NDIS; personalism; quality of life and support plans

Introduction

The aim of the National Disability Insurance Scheme (NDIS) is to ameliorate the inequitable access that people with disabilities and their families experienced in accessing funding and service delivery. The Productivity Commission noted that prior to the NDIS the disability services system was "underfunded, unfair, fragmented and inefficient" (2011, p. 2). The National Disability Insurance Act (2013) established the NDIS as the method of providing support to Australians living with a disability, their families, and their carers. The Act also established the National Disability Insurance Agency (NDIA), as the independent statutory authority, to implement the NDIS. Bigby (2014) raised some insightful questions concerning the NDIS, which included:

- How can the National Disability Insurance Agency (NDIA) ensure that more money

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- in the system changes the quality of services and improves service user outcomes?
- What steps are necessary to ensure that the market will provide what people need or want? And
- How can the NDIA ensure that everyone benefits equally from the scheme, regardless of the amount of social capital they have? (p. 96)

Henman and Foster (2015) noted that no one model of governance is ever complete, although models of disability support governance are useful as tools for analysis and reform. The authors concluded that of the four models they assessed, “no one model is universally applicable to people” (p. 233), nor have they considered “the nature of the organisation or person providing care” and that “[t]he quality of these services providers and the relationship with the service user is of critical importance in the quality of the provision and governance of disability services” (p. 248). There is a risk to any disability model of governance that relationships and quality will command less attention, albeit “the balance between the different mechanism” (p. 248) is critical if the NDIS is to meet its intentions (People with Disability Australia, 2015).

This article argues that quality and relationships are dictated by the ethics, either explicitly or implicitly, in governance models. That is, ethics matters in governance models: Clegg (2000) suggested that while prioritizing “ethical provision” as a deliberate import is “risky”, it establishes a dedication to “becoming an ethical practitioner” (p. 9) since it could contribute to robust and mature emotional interactions with colleagues. Further, Reinders (2002) argued that people with intellectual disabilities need friends and building meaningful and varied social networks is “to build a moral culture in which [people with intellectual disabilities] can flourish” (p. 4). Bigby’s questions are pertinent and follow from her research (see Bigby, 2008, 2010, 2013; Bigby & Wiesel, 2011; Clement & Bigby, 2010) and the lived experiences gleaned from the SHUT OUT report (Attorney-General, 2009). The opening quotation from the SHUT OUT report from a person with a disability is indicative of the need for any disability services system committed to excellence to enact ethical practices that respect people and their human needs. The report opens with these words:

Until the concept of disability disappears and is replaced by a society that is structured to support everyone’s life relatedness and contribution – until that day my life and opportunities and the lives of every other person who carries the label “disabled” depends upon the goodwill of people in the human service system. Goodwill is no substitute for freedom. (p.1)

An analysis of submissions from people with disabilities, their families, friends, and carers (56% of submissions) indicates that their greatest barriers were exclusion and negative social attitudes with people being at best treated differently and at worst being excluded and abused (p. 3). The report critically highlighted the lived experiences and the prominence of anguish, relational paucity, and social isolation in the lives of people living with a disability. The Disability Care and Support Report (Productivity Commission, 2011), which followed directly from the SHUTOUT report, and the Every Australian Counts campaign articulated systemic issues and proposed solutions for a new national disability strategy.

The aim of this article is to stimulate a conversation on how we can influence the NDIS to address this essential business and how we can indelibly mark a disability services system with integrity in order to positively answer Bigby’s (2014) questions and meet the challenges detailed in the SHUT OUT report (Attorney-General, 2009).

Emerging Pitfalls for the NDIS

As a discipline that emphasises critical thinking, philosophy can explore questions that yield a shrewd analysis of this inquiry. Specifically, the focus of ethics includes:

- How do we interact with each other?
- How should we live?
- What is Good? Right? Justice?
- What are rights and responsibilities? And
- How do we understand what the moral principles that affect decision-making are?

There are three reasons why these questions are germane to people with intellectual disabilities and the NDIS. First, living with an intellectual disability is individualised; the implications differ for each person. Specifically, it affects his or her thinking and planning, concentration, everyday living interactions, dialogue, interpersonal communication, memory, and so forth. Gilmore and Cluskelly (2015) found that up to 50% of people with intellectual disability are “chronically lonely” (p. 194), which compares with around 15– 30% of people in the general population. They noted that the problems that people experience through loneliness, such as physical and mental health problems, are most likely compounded for people with intellectual disabilities, (2014, p. 196). Second, the NDIS is a market-based service system, which, as has been argued, is “a system of choice” that will meet its social objectives without an equivalent resource input into health, housing, and education (Stephens, Cullen, & Massey, 2014, p. 263). Further, O’Connor (2014) argued that the NDIA “seems to assume an orderly world” (p. 22), which is atypical of any marketplace. These observations and the ethical questions outlined above impact upon the supply-side axis of any market-based service; that is, without additional resources to health, housing, and education, the demand created in the market may lead to the needs of people being unmet or services only being available in the for profit sector of the market. Nonetheless, services such as these could be perceived as integral to the essential business of the NDIS in contributing to personal flourishing and living a meaningful life. Third, the statement by the first CEO (chief executive officer) of the NDIS, that “the biggest [financial] cost in the [NDIS] scheme is personal care” is another good reminder of needing to prioritise the human and social dimension of the marketplace (Bowen, 2016). Several components can be identified as critical elements as to how personal care is offered. These include:

- How workers interact with the people they serve (or work with);
- How people work with each other;
- How workers engage with their line management;
- How workers understand their employer; and
- How relationships are formed between government and people living with an intellectual disability.

These components positively or adversely influence how both individual and systemic relational spheres are structured. This assumes that individuals and organisations aim to offer a high-quality service and be responsive (i.e., a desire to be effective), be accessible to all people who need them (i.e., equitable), and to maximise the use of resources available (i.e., efficient). The NDIS’s vision of “optimising social and economic independence and full participation for people with disability” (NDIA, 2013, p. 4) is a noble aspiration, which it may struggle to realise unless greater attention is focused on ethics and ethical practices. What follows from these potential pitfalls is a failure to give importance to the nature of interpersonal interactions between people and the impact of institutions and service

systems on personal lives. This article considers one ethical dimension, to illustrate important gaps that could adversely impact on the provision of personal services to people with an intellectual disability. There are other dimensions and many more questions, such as

- What does it mean to live a flourishing life?
- What, if any, role could a code of ethics play in service provision?
- To whom should these codes be addressed?

The notions of “good”, “justice”, and so forth are also highly relevant. However, the issue discussed in this article is our human nature: what commonality do we share as human beings?

Human nature and personal planning

The rationale for human nature is based on the belief that the most common desires we have as humans, notwithstanding meeting our physical needs, are the everyday experiences of mutually valued friendships, of being in love or knowing we are loved; and being part of our local community is also important. Judging a person to be a person with the same needs as yourself or indeed a friend changes our perception of their lived experiences and possibility challenges us to think about and interact with people in different ways. Philosopher John Macmurray, whose corpus extends from the 1920s through the 1960s, presented insights on human nature which suggest that personal flourishing, friendships, and having a valued role are integral to our nature as people. The wisdom of utilising Macmurray’s (1936, 1963) concept of personalism lies in his understanding of the nature of persons as relational beings. His typology transcends needs as an hierarchical and contestable system to posit people as more than mere animals, whose goodness is derived from our human nature; who, as people, are ends in ourselves; who excel in friendships with other people; and who achieve self-realisation through being “ourselves” – “expressing our own reality in word and action” (Macmurray, 1936, p. 219). Macmurray’s methodology on human nature reveals limitations in how the new market-based system is interfacing with personal lives.

The NDIS is congruent with Australia’s commitment to its international responsibilities under the UN Convention (United Nations, 2006) since it “professes to be in line with the social model [of disability]” (Butterss, 2012, p.105) and indeed there is supporting evidence to demonstrate this congruency. However, a philosophical analysis does reveal some limitations to the social model of disability, for instance: postmodern and feminist approaches have noted the importance of culture and cultural processes in the creation of disability and argued that these perspectives are devalued in the social model (Corker, 1999; Shakespeare, 1997; Thomas, 2002). Nevertheless, the social model paradigm does “[a]ct as a powerful and important corrective to our understanding of disability, to simplistic views on the experience of disability and, more importantly, to the oppressive nature of some social arrangements” (Terzi, 2004, p. 155–156). What might be missing from the current understanding of relationships between disability, impairment, and society is a consideration of the nature and mode of the human person *quo* human nature. *Quo* literally means “where” and is used here to emphasise: what is it that is fundamental to our existence as human beings? This question is significant, since “to appreciate disability is to embrace our humanity, in both senses of the word: our human condition, and our highest ideals of moral obligation” (Stubblefield, 2014, p. 241).

Macmurray (1936, p. 175) argued that it is possible to identify three types of nature in the

world, with nature being the capacity for a phenomenon to behave “in a way peculiar to itself” (p. 175). He proposed a trilogy of material nature, living nature, and human nature (pp. 176–184). Material nature refers to the nature of material bodies that behave mechanically – that is, through the laws of biology and nature – and thus their behavior can be predicted. Living nature, while reliant on material nature, is more complex and includes:

The idea of adaption to environment, of fitting in to one’s place in a complex organisation or community; the ideas of progress and purpose, of the end to which the whole creation moves; the idea of service of the species and its development. (p. 181).

Human nature includes living nature, and both have life cycles with human nature revealing a symbiotic interaction with other people and their environment that importantly permits them to reproduce their kind while being able to adapt to maintain their species. Human nature is also a type of nature that expresses itself most fully in being able:

To apprehend and enjoy a world that is outside of [yourself], to live in communion with a world which is independent of ourselves. We have the capacity to know other things and other people and to enjoy them. (p. 182)

Human nature is capable of knowing, enjoying, and engaging with different phenomena in a way that contributes to enhancing its lifestyle. Accordingly then, when we “think” or “feel”, what in fact we are doing is thinking or feeling about something or someone and so “our consciousness always goes beyond ourselves and grapples with what is not ourselves” (1936, p. 183). For the personalist philosopher Macmurray, the most tangible and complete expression of human nature is through friendship:

we are only persons at all through our relations with other persons. We are real only if our personal relations are real. We are free only in and through the reality of our friendships. (p. 207).

For Macmurray, human nature is characterised structurally in terms of the relations of the person both to his or her body, other people, and the surrounding environment. His wisdom is articulating the need people have for favourable conditions such as freedom, friendships, goodness, and purpose to live a good life. We might then expect the NDIS to systematically support the development of favourable conditions in the marketplace to reinforce the dignity of people with an intellectual disability and enhance quality of life opportunities.

An observer might suggest that this focus on human nature is at best contestable and in the extreme nebulous. A possible argument that might detract from this criticism is to understand the notion of “person-centred” planning acting as a practical dimension in articulating a person’s human nature. Mansell and Beade-Brown (2004) might support this view of person-centred planning as “a family of approaches and techniques” and the important distinction from other approaches through a focus on “aspirations and capacities” that attempt to connect “individual’s family and wider social network” while focusing on “achieving goals” (pp. 1–2). In the NDIS context both O’Connor (2014) and Tracy (2014) reinforced the importance of planning. O’Connor suggested that “deep listening” (2014, p. 20) is required if we are to attend to people to express their core messages. Tracy’s emphasis on “identify[ing] the foundation ‘pillars’ of [her son] Jack’s life and consider[ing] them when planning” (2014, p. 141) reinforces how flourishing lives can be led when a person’s human nature is honoured.

Person-centred planning is an appropriate strategy to focus, coordinate, and address personal educational, emotional, medical, social, and relational needs since each person is different. However, human nature will always defy classification since it is a complex

phenomenon that weaves the multiple and variable threads that are ineffaceable to our dignity, emotions, friendships, humanity, personality, and personal life. Duns Scott (Courtenay, 1987) postulated that since each person is different, each person has a haecceitas or thisness or individuating principle. What Scott was arguing is that although we, as humans, share a human nature, how we live with our human nature differs for each of us or else we would be mere replicas of each other and our relationship to our bodies, each other, and the environment would not matter.

In summary, this approach to human nature has three distinctive characteristics. First, it has a positive vision of humanity. It views every person as a person of value and capable of personal growth and suggests that an explanation of our personal discomfort and anguish emanates from personal relationships. However, this experience of anguish does not have to overwhelm us. Its optimism is in suggesting we engage in outwardly focused interdependent relationships with mutual goodwill that stimulates another's personal flourishing. Second, it acknowledges that people have many different traits and relations, which are continually in a state of flux and change and respond to personal and structural dynamics. As a branch of philosophy, personalism has congruency with a disability support system since a primary and distinctive characteristic is the prominence it gives to a human person in social and political intercourse. Further, a person is subject and agent, who can act and whose personal identity is discerned and delineated through their relationships (Treanor, 2014). Finally, Macmurray's personalism is analogous to plant life: things come into being through the interaction of causes and conditions; for example, a seed sprouts into a shoot and flowers with favourable conditions of good soil, water, and weather.

Analysis of key documents

There is an increasing body of literature emerging that focuses on the NDIS. Roth (2017) presented an excellent summary of selected reports and commentary on the NDIS published by government, statutory bodies and research centres, in journal articles, the media, and non-government organisations. However, its limitations are that: (a) it is focused on New South Wales; and (b) several academic journals (e.g., RAPPID, 3(2), 2016), which critically assessed the NDIS, were excluded from the summary. This article used two data reports (Australian Department of Human Services, 2016; NDIS, 2016) from the NDIA, to assess what efforts were being made at "optimising social and economic independence and full participation for people with disability" (NDIA, 2013, p. 4). The analysis of these documents aimed to assess how the goals of the NDIS were being realised; the focus of the NDIS as a system and, from a user perspective, what contributes to personal flourishing – that is, to people living a meaningful life – and to higher levels of inclusion and belonging? The author takes seriously Goodley, Lawthorn, and Runswick Cole's (2014) argument that disability reveals to society new modalities that are "non-normative and anti-establishment ways of living life" (p. 347), which can evoke new, creative, and exciting models of living. The analysis is also informed by critical disability studies (e.g., Mladenov, 2015) and critical policy analysis (e.g., Taylor, 1997).

Data Report 1

The first data report, Market Position Statement (Australian Department of Human Services, 2016), from the NDIA focused on how disability service providers need to understand the disability market and how demand and supply variables might impact upon the market as the roll-out progresses. The state of Victoria in Australia is yet to fully transition to the NDIS and accordingly may be able to advocate for greater consideration of personal lived experiences in the supply side of the market. Similar to other reports, the Market Position

Statement gives an overview of some of the supply and demand variables relevant to the Victorian marketplace. It also considers future needs and what growth will occur following full implementation of the scheme. This is valuable data that if acted upon should realise capabilities and systems that may meet the market requirements. Indeed, the final section, “Organisational Readiness and Training Resources” (p. 51), lists two “useful resources” (p. 51) for service providers. These are: NDIS Provider Toolkit and a Costing and Pricing Learning Program. Albeit useful tools, they are somewhat myopic in illuminating certain aspects of the supply side of the market. What about the aforementioned essential business or ethical variables? What about Bigby’s (2014) questions? Or the lessons from the SHUT OUT report (Attorney-General, 2009)? What readiness and resources are being directed to these variables through this report?

Data Report 2

The NDIA has a responsibility to report to the Council of Australian Governments (COAG) on its activities. The Council is the peak intergovernmental forum in Australia that manages matters of significant interest that need to be coordinated by all Australian governments. The second report, Quarterly Report to COAG Disability Reform Council (NDIA, 2016), refers to the NDIA’s responsibility to the Council. The findings reveal there were 25,875 active and inactive participants during the 2015 reporting period (p. 21) and 1962 participants (7.6%) were surveyed to discover their level of satisfaction with the NDIA. The overall rating was +1.62 on a score extending from -2 (very poor) to +2 (very good) (2016, p. 29). This level of satisfaction should not surprise anyone, although it needs to be considered against four important characteristics:

- Funding – 82% of participants had at least one payment made against their plan
- (2016, p. 29).
- Participants are rating the NDIA as an agency.
- The report does not provide details on the nature of the questions nor the type of methodology used to collect the data.
- It is not clear from this survey how participants rate their level of satisfaction with the new service or service provider.

A further issue needs to be noted on findings from quality-of-life literature. Townsend-White, Pham, and Vassos’ (2012) comprehensive review of quality-of-life instruments “can inform governments and service providers whether services are meeting the needs of the population”; however, there is “no universal accepted ‘gold standard’ instrument” (p. 280). Rather, quality of life is but one dimension in a composite measurement system. Data such as this only further reinforces the need for research that responds to the questions that Bigby (2014) asked and particularly: “How can the NDIA ensure that more money in the system changes the quality of service and improve service user outcomes?” (p. 96).

Narrative

This article has argued the importance of relationships in a person’s life since, as Reinders also argued, “We need friendships if we are to flourish as human beings” (2008, p. 162). An essential constituent of friendship is goodwill and life sharing (see e.g., Aristotle, 1999), and this also applies to caring relationship. As Reinders (2000) reminded us:

Without being personally involved, very little meaning can be found [in a person’s life]. Being engaged in [the lives of people with intellectual disabilities] is where it all begins. Whatever meaning can be found will only be found in the context of that relationship. (p. 203)

The lived experience of a person with a disability offers some existing knowledge on what “works” for people who require support to deepen their personal flourishing by living a meaningful life with everyday experiences of mutually valued friendships, of loving or receiving love and knowing we are loved, since being part of our community is an important part of our lives. Ellis (2015) provided a narrative of a lady with longevity of experience in receiving personal support. She argued that “the success of my care is based on the quality of the relationships I have with my staff and the work I do to make this work for me”. This occurs since people “understand a ‘give and take’ approach, are flexible”. This has supported “a strong team culture” and she feels “very positive in my team and I know they feel positive in return”. This does not exclude occasions when she needs to “address problems with team members”. She appears to be living out her human nature, connected relationally, and, importantly, enjoying her life since, as she states,, she pays “attention to people and pay attention to the relationship”.

Areas of improvement

The deliberation from the People with Disability Citizen’s Jury (2015) revealed: “Unquestionably the NDIS is already enabling quality of life outcomes for some people that would otherwise be unattainable” (p. 15). Further, the evaluation conducted of the trial also confirmed good outcomes for some people (NDIS, 2016b). On a positive note, the findings in the Disability Care and Support Report (Productivity Commission, 2011), which in part inspired the NDIS, appear to have been effective in offering the NDIS a tonality that is congruent with contemporary service system philosophy. Nonetheless, the NDIS requires attention in at least two dimensions. First, from human nature: what does it mean for a person to develop meaningful relations and experience a quality to interpersonal interactions? And, second, what does it mean to belong, to be connected, and to be an active citizen? From the broad consensus of the wider disability community about the need for the NDIS and the bipartisan support to enact legislation, there appears to be a compelling need to focus on “better link[ing] the community and people with [intellectual] disabilities” and to support the “break down [of] stereotypes and ensure quality assurance and diffusion of best practices” (Productivity Commission, 2011, p. 2).

Everyone, I imagine, wants the NDIS to become a metonymy, an adjunct for the purpose of describing, and an enabling system that “optimize[s] social and economic independence and full participation for people with disability” (NDIA, 2013, p. 4). Indeed, many people and groups are committed to supporting the necessary building blocks to create a well functioning society in which all members can experience a good and well lived life. Nonetheless, Bleasdale (1994) offered a stark reminder to policy managers, researchers, and service personnel: “institutions do not require large buildings or bureaucracies – a management and staff who are in a position ... to organise service delivery, according to what it, the organisation, knows to be “right” will suffice” (p. 16).

Conclusion

The NDIS is congruent with Australia’s commitment to its international responsibilities and confirms the citizenship of people with an intellectual disability. Its rhetoric imagines people actively contributing to the economic and social life of Australia. The NDIS is beginning to bridge the huge gap in funding disability system that is “is underfunded, unfair, fragmented and inefficient” (Productivity Commission, 2011, p. 2). This analysis of the NDIS through the prism of Macmurray’s personalism reveals shortcoming in its ability to enhance human nature and the dignity of people with intellectual disabilities that improves people’s quality

of life. A Macmurrrian human nature is richer than person-centred planning since his analysis reinforces the importance of personal relationships in people's lives to the application of the NDIS. A failure to give priority to this dimension may validate Bigby's (2014) concerns. Her caution that increased funding may not correlate with an increase in dignity and quality of life is gaining some validity. This may be a consequence of a focus on the NDIS as a marketplace without an equivalent focus on enabling people with intellectual disabilities to lead a meaningful and personal flourishing life in a network of intimate, personal, and social friendships. The NDIS does not address our human nature. To develop fully as a person, our human nature needs to be prioritised to the personal centre of our being, since this path of self development will contribute to personal flourishing, friendships, living a meaningful life, and having a valued role, which are important dimensions in people's lives.

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