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Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme

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This paper questions whether Australia’s new disability support regime, the National Disability Insurance Scheme (NDIS), can meet its aims for people with disabilities who also experience complex social disadvantage, using the examples of people with intellectual disabilities from cultural and linguistically diverse backgrounds and those who cycle in and out of the criminal justice system. The paper undertakes a critical analysis of the proposed eligibility requirements under the NDIS and assesses the risks of marginalisation in the proposed approach for people with intellectual disabilities who also experience other complex individual and social disadvantage, and begins to ask, “Will the NDIS meet its aims if it does not address these complexities?” The analysis suggests that under the draft rules for eligibility the onus is on individuals to prove their eligibility for supports funded by the NDIS on a case-by-case basis and, moreover, to prove that receiving such support will reduce their future dependence on the system. This raises a number of issues for those whose experience of disability is tied to complex and intractable social disadvantage, and raises questions about the NDIS’s ability to meet its aims in relation to rights, choice, and control. The paper demonstrates the ways in which people with disabilities who are already at risk of disengagement from support systems and social exclusion risk further marginalisation in the context of an NDIS, as it currently appears to have little capacity to recognise and respond to their complex need for disability social support.

Keywords: intellectual disability; complex social disadvantage; cultural and linguistic diversity; criminal justice system; disability support; National Disability Insurance Scheme (NDIS)

The Australian disability social support system is undergoing extensive restructuring to meet the growing demand for government-funded support. From 2013, a new disability support scheme is being phased in and administered under the National Disability Insurance Scheme (NDIS). For the first time in Australia, people with disability will have a legislated entitlement to social support (NDIS, 2013). Funding for the model is premised upon an insurance-based system, where persons with disabilities are assessed first for their eligibility to access the scheme and then to ascertain the level of funded support required (NDIS, 2013). Thus, as in any insurance scheme, individuals must put forward their individual claim for disability support (Golosov & Tsyvinski, 2006). The NDIS is
Thus an administrative system to redistribute resources based upon the assessment of such claims.

The model of a disability support insurance scheme was first proposed by the Whitlam Government (1974). However, while supported by the Australian disability community, the Bill did not pass into legislation due to the broader political upheaval at the time (Steketee, 2013). Since then, new disability policy developments have largely been administered under the two-tiered system of a federated government through a range of intergovernmental agreements (Soldatic & Pini, 2012). Initial service development in many areas was in direct response to the disability communities’ advocacy on a number of matters, including the closure of state-funded institutions and informal family support (Clear, 2000). Under the various state-based service systems there was no nationally consistent delivery of services, and minimal control and benchmarking of quality at the national level (Soldatic, 2010). Finally, it was difficult for people with disabilities to move interstate as their service funding was tied to their state or territory of residence and was non-transferable (Australian Productivity Commission, 2011a). Thus, people with disabilities had little control over, and little input into, the support services they received (Soldatic & Pini, 2012).

Given this backdrop, the Australian disability community has welcomed the advance of the new national insurance scheme and the National Public Inquiry’s new policy impetus for disability support reform (Australian Productivity Commission, 2011a). This innovation in policy and service delivery attempts to address long-term inequities and unmet need in disability welfare provision, marking a turn in people with disabilities’ struggles for self-determination and other rights (Australian Productivity Commission, 2011a).

Key innovations under the scheme include: (a) universal provisioning of disability supports and funding, including adult acquired disability; (b) individualised funding packages; and (c) self-administration of disability supports and services. “The scheme is a new way of funding individualized support for people with disability that involves more choice and control and a lifetime approach to a person’s support needs” (National Disability Insurance Agency, 2013, p. 2). This idea of “need” is expressed through a tiered system of support, where Tier 1 aims to address barriers to social and economic participation (such as systems discrimination); Tier 2 focuses on information and referral (particularly targeting increased access to local level mainstream services); and Tier 3 is for people with lifelong and profound disabilities, requiring disability specific support and services (Productivity Commission, 2011, p. 6). For many people within the disability community, the NDIS system and its administrative framework suggest the establishment of new social policy understandings that are more reflective of the right to choice and control over decision-making in line with one’s interests and needs.

Under the NDIS framework, people with disabilities are active bearers of rights rather than passive recipients of welfare. This new paradigm of disability support appears to be in line with the recently enshrined United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2006), which “promote[s], protect[s] and ensure[s] the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities” (Article 1). The proposed NDIS has been applauded by much of the Australian disability community because of the promise of “reasonable and necessary supports, including early intervention”; individual “choice and control” around goals and the planning and delivery of support to reach these goals; “support [for] the independence and social and economic participation of people with disability” and giving “effect to certain obligations that Australia has as a party to the [Convention on the Rights of Persons with Disabilities]” (National Disability Insurance Scheme Act, 2013). Further, the NDIS
framework suggests that assessment is premised not upon impairment per se, but the ways in which impairment is situated in relation to environmental barriers that affect a person’s full participation (National Disability Insurance Agency, 2013).

While the NDIS has also increased and centralised the pool of available funds for social supports nationally, funds will be limited to only a select number of people (Australian Productivity Commission, 2011a). As an insurance system, the direct provision of support is not provided by government for the estimated four million Australians living with some form of disability (Australian Bureau of Statistics, 2012). Instead, entitlement to funds will be limited to “around 460,000 Australians with significant non-age related disabilities” (Fifield, 2013, p. 4). While not all Australians living with disability will or may need to access NDIS supports, the constraints mean that almost 9 out of 10 people living in Australia with a disability will not get access to the NDIS. The important question is, who will be included in the 1 in 10 who receive support and who will miss out?

This paper examines the NDIS to explore the likelihood of people with intellectual disabilities who have complex social characteristics beyond disability being included or excluded in the 1 in 10 who receive NDIS support. To do this, the paper examines the eligibility rules of the NDIS and the framework in which it is presented, and uses two groups who have historically been marginalised from disability support systems as case studies: people with intellectual disability from cultural and linguistically diverse (CALD) backgrounds; and people with disabilities in contact with the criminal justice system.

Establishing Boundaries of Disability for Exclusion or Inclusion: Who is Eligible?

Eligibility rules are a central feature of all policy systems (Lister, 2010). These rules are developed to define the boundaries of a policy regime, to identify who is included, and to administer resources in line with the characteristics of both the group and the policy (Percy-Smith, 2000). In accordance with Madanipour, Cars, and Allen (1998), rules provide the framework for differentiating and defining groups within the group, as well as individuals who fall outside the group. As such, applying rules through policy is often a process of either inclusion or exclusion. Within the administration of policy systems, rules are central to effecting administrative determinations that decide who gets resources, how much they should get, and for how long they should have access. Thus, the rules that underpin any policy system are the critical juncture for different groups within society in realising their rights, life choices, and goals (Byrne, 2005).

While it is well established within the policy literature that “rules” may be more fluid than they appear, it is also documented that those who are able to “play the rules” include those who are literate in the language and principles of the system (Byrne, 2005). Further, those able to advocate for their needs within the boundaries of the rules are likely to already occupy a position of relative advantage within the broader group, as reflected in their level of tertiary education, professional economic status, and so on (Reay, David, & Ball, 2005).

Under the state system of disability support services, legislation clearly demarcated the boundaries of disability in terms of who was and was not eligible for social support. Under this previous system, eligibility for disability services encompassed a larger group of people with disabilities; however, there was no entitlement to actually receive a service or services. This appears to be one of the key differences in the two systems. The NDIS’s eligibility criteria thus redraw these boundaries. Prospective participants must meet the criteria outlined in Rules for Becoming a Participant in order to gain entry. Under the
scheme, a person meets the disability requirements when: (a) the person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory, or physical impairments, or to one or more impairments attributable to a psychiatric condition; and (b) the person’s impairment or impairments are, or are likely to be, permanent; and (c) the impairment or impairments result in substantially reduced functional capacity to undertake, or psycho-social functioning in undertaking, one or more of the following activities: communication, social interaction, learning, mobility, self-care, self-management; and (d) the impairment or impairments affect the person’s capacity for social and economic participation; and (e) the person’s support needs in relation to his or her impairment or impairments are likely to continue for the person’s lifetime. (National Disability Insurance Agency, 2013a)

The focus of these rules suggests a strong diagnostic frame to establish the existence and degree of impairment and an evaluative impact assessment of its interactional effects on an individual’s impairment and functioning levels in his or her environment. This reading appears to be in line with the UNCRPD definition where impairment type is first identified and then assessed for its relational impact for participation and inclusion within the broader social landscape (UNCRPD, Article 1).

What Does this Mean for Marginalised Groups?

There has been a slow-growing disquiet across a range of disability groups, suggesting a level of unease with the way rights are framed within the NDIS and the implications for marginalised groups. For example, Leipoldt (2005) argued that the focus on individualisation, in line with the central values of a market model of social care, fosters individualistic competition and consumerism that are “the root causes for much of our disadvantage and exclusion” (2005, p. 29). Leipoldt’s suggestion that individualisation and competition are likely to undermine rather than uphold social rights is supported by Hallahan (2013), who has argued that “choice and control is about the restoration of citizenship within a democracy, not a consumer identity within a market. Democracy demands a collective response, not simply an individual response” (Hallahan, 2013, p. 7). Thus, Hallahan and Leipoldt have suggested that relying on the market to deliver individual choice is a problematic framing for the full realisation of disability rights. This is partly because a market-based system requires sociocultural literacy in “choice and self-interest” (Leipoldt, 2005, p. 31).

Numerous disability groups have also suggested that there are a group of people at the margins who experience multiple and complex forms of disadvantage and, therefore, do not necessarily have this literacy. However, they are forced to self-advocate in a user-led, demand-driven system (National Carer and Disability Alliance, 2013; Pro Bono, 2013). For these groups, accessing the NDIS may be a major challenge. If the onus is on the individual to prove his or her eligibility on a case-by-case basis, people with disabilities with complex social needs are unlikely to have the sociocultural literacy to interpret and activate administrative rules for their own individual benefit, one of the key reasons for the ongoing perpetuation of their social disadvantage and exclusion (see Byrne, 2005, for a full discussion of this point).

The new eligibility rules may also inadvertently facilitate easy access to the NDIS for some, while hindering others to access disability services that they need (see Mental Health Council of Australia, 2013; National Ethnic Disability Alliance, 2011; New South Wales Council on Intellectual Disability, 2011). In fact, it is the new eligibility rules that
have been a core concern of some of its most vocal critics. Primarily, the concerns raised
directly relate to the use of diagnostic categories to establish eligibility for NDIS support,
and additional barriers faced by people with disabilities who also have a range of disad-
vantages such as low economic status, poor educational attainment, coming from a cultura-
ally diverse background, having contact with the justice system, at-risk lifestyles, or
mental health issues (Mental Health Council of Australia, 2013; National Ethnic Disabil-

To understand the likelihood that these fears will be realised, we explore the potential
impact of the eligibility rules on two case study groups: people with intellectual disability
from CALD backgrounds and people with intellectual disability who cycle through the
criminal justice system. While a range of groups have expressed concern over the con-
ditionality of the NDIS, these two groups have been identified as being ill-served by the
existing Australian disability service system. Both groups have much lower levels of dis-
ability service use when compared to other groups and despite some efforts by state gov-
ernments, service access and use remains low despite high levels of need. Furthermore,
examining threshold groups enables more complex understandings of core concerns and
issues in need of redress (Morgan, 2012). Although the two groups will be addressed indi-
vidually, there is significant overlap between groups, and it is important to recognise that
people with multiple, undiagnosed, and compounding disabilities often experience other
forms social and economic disadvantage that will not be captured here (see Dowse, Bal-
dry, & Snoyman, 2009).

**People with Intellectual Disabilities from CALD Communities**

It is well documented that the need for services is high among migrants with disability
from CALD backgrounds1 (Soldatic et al., in press). For example, in its 2009 report on
government services, the Productivity Commission estimated that 1 in 4 people with dis-
abilities are either first- or second-generation CALD (approximately 1 million Austral-
ians), and that people from non-English speaking backgrounds are the second largest
group of people with disabilities, after women (Steering Committee for the Review of
Government Service Provision, 2009). Further, the highest rates of adult acquired disabil-
ity are within ethnic minority and emerging immigrant communities (National Ethnic
Disability Alliance, 2010).

Despite these high rates of disability, the Australian disability service system has not
effectively served the needs of this population group (Ethnic Disability Advocacy Centre,
2011). Recent research in the area suggests that they are four times less likely to access
government-funded disability supports (Gwatirisa, 2009, p. 19). CALD disability advocates
report that socio-economic disadvantage and low English proficiency represent a
compounding set of obstacles preventing CALD communities from accessing disability
services (Ethnic Disability Advocacy Centre, 2011). The intersection of disability and
ethnicity does not create layers of disadvantage; rather, the impact is exponential and can
precipitate new barriers to resources, opportunities, and capabilities (Goggin & Newell,
2005). The interplay of ethnicity and disability can exacerbate existing forms of
entrenched disadvantage and disempowerment and is largely related to Leipoldt’s sugges-
tion that sociocultural literacy of the service system is required to effectively activate sup-
ports to achieve the required effects (see also Soldatic et al., 2012). This is particularly the
case for people with intellectual disabilities from CALD backgrounds, who face addi-
tional barriers in accessing the disability service system due to a range of cultural barriers
(Stevens, 2010).
Among a range of explanations, there are three primary reasons for this. *First*, it is well documented that many CALD families and carers do not wish to identify their children as having an intellectual disability as this may lead to cultural forms of stigmatisation within their ethnic communities, on which they heavily rely upon for other forms of support (Ward, Amas, & Lagnado, 2008, p. 15). As a result, many children with intellectual disabilities are socially isolated from their ethnic community and the wider society, leaving them with few opportunities to develop opportunities to build their social capacities with peers with and without disabilities (Gwatirisa, 2009, p. 19). *Second*, this active process of hiding intellectual disability leads to the inappropriate identification of “need”. For example, many children with intellectual disabilities receive intensive English language support rather than childhood early interventions, such as speech therapy (Refugee Council of Australia, 2011). *Third*, new migrant communities can be hesitant and distrustful about formally engaging with government administrative processes as a result of their previous complex experiences with government in their countries of origin. Hence, many prefer to remain invisible where possible.2

People with Intellectual Disabilities in Contact with the Criminal Justice System

Understanding of the characteristics and experiences of people with intellectual disabilities who come into contact with the criminal justice system has grown significantly over the past decade. These individuals are overwhelmingly male, tend to come from deprived socio-economic backgrounds, leave school early, have unstable accommodation, and have additional issues such as with alcohol and other drugs (Green, Martin, & Simpson, 2001; Baldry, Dowse, & Clarence, 2012). Indigenous Australians are also disproportionately represented (Aboriginal and Torres Strait Islander Social Justice Commissioner, 2005). In addition, the nature of disability as experienced by this group is predominantly (but not only) related to mild to borderline intellectual disability, very often in combination with a range of mental health issues (National Mental Health Commission, 2013). Moreover, many people within this population group have a high incidence of acquired brain injury (Rushworth, 2011). The combination of these issues impacts significantly upon the person’s daily functioning and can result in compounding social disadvantage and complex service-related needs.

Service provision for this group has been the subject of growing concern in Australia for at least the past three decades. In New South Wales, *The Missing Services* report (1985) documented that people with intellectual disabilities do not get the services that they need to help keep them out of trouble with the law and this was subsequently reaffirmed in the New South Wales Law Reform Commission Report (1996), *People with an Intellectual Disability and the Criminal Justice System*. The net result of the failure to address the support needs of this group is their increasing over-representation at all levels of the criminal justice system as both victims and offenders, including in front-line policing, in the courts, and in correctional settings (Aderigbe, 1996; Hayes et al., 2007; Herrington, 2009; Holland & Persson, 2011). Moreover, the New South Wales Sentencing Council has recognised the serious consequences of imprisonment for people with intellectual disability. These consequences include entrenchment within a culture of criminality because of a desire to be accepted by peers, vulnerability to assault and mistreatment in the mainstream prison environment, and post-release readjustment problems because of impaired adaptive skills (New South Wales Sentencing Council, 2004).
The service needs of this group vary greatly, but it is recognised that there is a significant need for generic human services as well as for specialist disability services (Simpson, Martin, & Green, 2001). A further complexity arises in instances where intellectual disability is not formally diagnosed until entry into the criminal justice system. Without evidence of intellectual disability prior to the age of 18 years to inform the diagnosis, such individuals may be ineligible for specialist disability services (Snoyman, 2010). Moreover, as a result of the interaction and compounding of multiple and simultaneous disadvantage and negative events there is currently almost a complete lack of recognition of the complex needs of this group in agency responses (Baldry, Dowse, & Trollor, 2013). The net result is that people with intellectual disabilities in the criminal justice system are under-recognised, and surveillance and control agencies such as police, courts, and corrections come to dominate patterns of contact in lieu of support and care services (Baldry & Dowse, 2013).

Given their complex presentations, there is significant concern that people with intellectual disabilities who have contact with the criminal justice system will not fare well under the NDIS. Factors such as the lack of established diagnoses and the predominance of mild to borderline intellectual disability commonly co-occurring with other diagnoses, such as personality disorder and mental ill health, may mean that common or standardised eligibility assessment tools and processes will be inadequate to take account of the synergistic and multiplicative effects of these issues for the individual. Further, demarcation of mental illness, substance misuse related disorders, acquired brain injury, and intellectual disability will mean that many people will fall at the first hurdle and be excluded from eligibility because they do not fit neatly into any one diagnostic category. Thus, when coupled with poor social connectedness and the predominance of service contact with surveillance and control agencies within the criminal justice system, the likelihood of independent advocacy for the NDIS’s eligibility appears very limited.

As the NDIS relies heavily upon a process of self-activation for eligibility assessment, it remains unclear how many people with intellectual disability within CALD communities or those who have contact with the criminal justice system will gain access to the supports they require. This is further compounded by the assumption within the NDIS (2013) that there will be a degree of co-payment where possible. Minority ethnic parents with disabled children have lower than average incomes than the general population (Stevens, 2010, p. 12; Ward et al., 2008, p. 15). Economic stress is particularly heightened for children of refugee entrants and remains a persistent feature across generations, leaving families from CALD ethnic minority communities with few additional resources (Hugo, 2011). Similarly, people with intellectual disabilities in contact with the criminal justice system have low levels of education, are largely excluded from the labour market, and experience high levels of poverty (Dowse, Baldry, & Snoyman, 2009). The NDIS has been presented to the Australian public as the panacea to the “ills” of the existing Australian disability support system. If the NDIS is not accessible to those groups who have been traditionally ill-served by the prior system, even though they are the very groups most likely to benefit from disability supports, then there may be few “real” differences between the realities of the old and the promises of the new.

**Conclusion**

The great hope for the NDIS is that it will improve choice and control of disability supports; assist in increasing social and economic participation; and support people’s rights under the UNCRPD. While the eligibility rules broadly align with these goals, there is a
risk that the aims of the NDIS will not be realised for people with disabilities from marginalized groups. Indeed, the framing of the NDIS around an individualised market may serve to reinforce and compound existing vulnerabilities. Entitlement to the NDIS exists where needs are chronic and clearly connected to disability. For people whose disabilities are compounded by and intersected with multiple and complex forms of social and economic disadvantage, demonstrating eligibility will be an added challenge. Furthermore, having the resources, skills, language, and attitude to assert, apply for, and claim rights under the NDIS will be more difficult for groups who face other social, cultural, educational, or literacy barriers.

While the NDIS Act acknowledges the intention of the scheme to assist Australia to meet its obligations under the ratified UNCRPD, the implications for marginalised groups and the silence in the Act and policy frameworks around social categories such as class, gender, sexuality, indigeneity, criminality, culture, language, and faith, is notable and of concern. Unless the intersections of these complex factors are acknowledged and actively considered, Australia is at risk of not meeting Article 3 (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity of the UNCRPD. A long-term care and support scheme must be flexible in responding not only in terms of diversity of impairment (well acknowledged in the NDIS), but also to human social, cultural, and linguistic diversity.

Furthermore, while the NDIS and the UNCRPD align around the intention and commitment to increase individual rights, decision making, and control, this will only be realised if people from different groups have the support and capacity to advocate for, exercise, and realise these rights. Given the historic under-representation of migrants from Australia’s disability support system and the ongoing barriers many people with intellectual disabilities in contact with the criminal justice system face in accessing existing supports, marginalised groups are at risk of being beyond the boundaries of the new disability policy regime. In turn, there is a risk that they will be among the 9 in 10 who are most likely to fail to benefit from the NDIS. What will this mean for realising the goals of the NDIS and the UNCRPD around the provision of support to enable them to exercise their rights and pursue opportunities for social and economic inclusion?

Currently, the NDIS is premised on disability as a bounded uniform identity encapsulating a group of individuals with impairments of various types (e.g., physical, sensory, psycho-emotional, and intellectual). It does not conceptualise disability as one experience among a diversity of identities, and thus pays little attention to the applicability and relevance of this model to individuals with disabilities who have multiple, intersecting, and competing disabilities. Other groups, such as the two groups discussed in his paper, have been severely under-represented within the current disability welfare system. This is partly because of an historic, siloed service system. As these groups are currently absent from the proposed NDIS and its policy recommendations for national restructuring, there is a risk that the NDIS will directly or inadvertently reinforce the existing situation. Therefore, a key component of evaluating the effectiveness of the NDIS is exploring the possibilities and implications of the NDIS for groups that have historically been marginalised in the disability support system.

While the eligibility rules should facilitate access to the NDIS for people with “unambiguous”, permanent, impairments (those with high support needs), and while the most able of the disabled (those with minimal supports) will be able to access or increase their participation in the labour market, it is not currently a framework or plan for people with multiple and complex needs. Yet “people with disability and their families face many social and financial challenges and, as a group, are among the most disadvantaged
in Australia” (Australian Productivity Commission, 2011b, p. 112). What does this mean for enacting the principles and aims of the NDIS around rights, choice, control, and social and economic participation? For whom will this be the case?

Notes
1. The implications of varying migration status such as temporary protection visa holders, 457 work visas, and so forth are beyond the scope of this paper. For further information around issues surrounding disability within the Australian migration system, see Soldatic and Fiske (2009).
2. This mirrors the conditions of other national social security systems such as Medicare and the Disability Support Pension that have been researched for these communities (see Hugo, 2011).

References


National Disability Insurance Scheme Legislation Amendment Act 2013 (Cth) (Austl.).


