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Listening for policy change: How the voices of disabled people shaped Australia's National Disability Insurance Scheme

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Voice has become an important yet ambivalent tool for the recognition of disability. The transformative potential of voice is dependent on a political commitment to listening to disabled people. To focus on listening redirects accountability for social change from disabled people to the ableist norms, institutions and practices that structure which voices can be heard in policy debates. In this paper, I use disability theory on voice and political theory on listening to examine policy documents for the National Disability Insurance Scheme in light of claims made by the disability movement. Although my study finds some evidence of openness in the policy development stage, the scheme falls short of valuing the diverse voices of disabled people as partners in shared dialogue.

Keywords: disability; voice; listening; intersectionality

Points of interest

- The principle of voice puts responsibility for policy change onto disabled people
- Examining how disabled people are heard is important in order to promote voice that matters
- The new National Disability Scheme in Australia value the voices of disabled people as active agents of policy change but does so in limited and uneven ways
- This could be improved by ensuring that disable people are central to the implementation and evaluation of the scheme, better represented on the board and engaged as partners in a dialogue about support needs
- Recognition of diversity amongst disabled people is also important for valuing voice

Introduction

Voice is optimistically embraced as a solution to democratising social policy. Empowering service users to 'have a say' in the policy process calls into question the bureaucratic post-war welfare state. At the same time, since the politics of voice emerges from the collective claims of social movements it provides an alternative to the individualistic and market-driven emphasis on 'consumer choice' associated with neo-liberal policies. If the transformative promise of voice is to be realised, however, scholarship must extend to a concern with how voice is heard and valued. The persistent agenda of empowering service users is here supplemented by a new interest in listening that challenges the way established hierarchies of attention privilege certain voices while undervaluing others. This focus on listening is significant insofar as it shifts accountability for policy change from marginalised groups to the norms, institutions and practices that structure which voices can be heard in policy-making and service delivery.

The National Disability Insurance Scheme (NDIS) is an example of the benefits and limitations of listening as a tool for policy change. It constitutes a path-breaking reform of disability support services in Australia, the significance of which is likened to the introduction of universal national healthcare (Medicare) (Manne, 2011; Steketee, 2013). The NDIS is one of the 'big ideas' taken forward from the 2020 Summit – a forum then Prime Minister Kevin Rudd convened to discuss ideas about the future of Australia (Soldatic & Pini, 2012). The government referred a national disability long-term care and support scheme to the Productivity Commission for inquiry in 2009 in response to the summit and a series of reports outlining: significant unmet need, the unsustainable current system of provision and the benefits of a NDIS (see Australian Government, 2009; Disability Investment Group, 2009a, 2009b). The Inquiry can be characterised as an act of open listening insofar as what was heard demanded significant change to the existing system of overlapping Federal and

State responsibilities for the funding and administration of specialist disability support services. In the overview of its findings, the Productivity Commission challenges the use of the term 'system' to describe current arrangements, which it criticised as *'inequitable, underfunded, fragmented, and inefficient'* (2011, p. 5). Instead, it proposed a universal national insurance scheme, in which individualised funding largely replaces block-grants to service providers.

The introduction of the NDIS is not, however, simply a top-down story of government action. It represents a significance achievement for the disability movement – mobilised around the Every Australian Counts campaign – towards greater participation and inclusion. The campaign focused on amplifying the voices of disabled people[i] and their advocates, expressing 'the difference an NDIS would make to their lives' (Steketee, 2013). Disabled people were figured, not as tragic victims, but as active campaigners for policy change. At the same time, the NDIS is also shaped by neoliberalism as a driving-force in the restructuring of disability supports. In this context, there is concern that disabled people are more likely to be offered limited opportunities for consumer choice rather than rights to participation and voice at all levels and stages of the NDIS (Leipoldt, 2011; Soldatic & Pini, 2012).

The aim of this paper is not to reiterate the pervasiveness neoliberalism but, rather, to examine how the claims of the disability movement are heard in the face of such dominant discourses. In exploring how listening matters in the development of the NDIS, I begin with an overview of disability theory on voice. I then consider how theories of political listening, understood as an open and democratic practice, address some of the limitations of voice as a political strategy. The final section demonstrates the possibilities and limits of political listening in an analysis of policy documents for the NDIS. I argue that despite open listening in policy development, the NDIS offers limited opportunities for people with disabilities to continue to be engaged as partners in shared dialogue. I conclude by offering

recommendations for further valuing the voices of disabled people at all stages in the policy process.

Disability and voice

Over the past several decades, the disability movement and critical disability studies have challenged the dehumanisation of disabled people as objects of intervention. The dominant, individual model represents disability as a personal tragedy requiring cure or care by the medical and allied professions (Oliver, 1996). Within the context of these relationships, the expert voices of professionals are privileged at the expense of the devalued experiential knowledge and voices of disabled people. This enables professionals to exercise paternalistic power in making decisions about fundamental elements of disabled people's lives such as where and how they should live, whether or not they should work, the type of school they should attend, the type of support they need and whether or not they should become parents. More broadly, in public debates, disabled people are routinely 'spoken *about*, rather than listened *to* as experts' (Newell, 2006, p. 280). This means that disabled people are both subject to stereotyping and, at the same time, systematically marginalised from debates about policy direction across a wide range of areas relevant to disabled people's lives; from disability-related benefit reform in the UK to stem cell research in Australia (Briant, Watson, & Philo, 2013; Goggin & Newell, 2004).

In challenging professional dominance, voice has become an important yet ambivalent principle for the recognition of disability. Helen Meekosha (2001, p. 240) draws attention to its significance in her argument that:

> Attempts by disabled people to speak for themselves mark a crucial shift in the
> nature of the political relations of disability to a stage in which they no longer
> accept Others as effective speakers on their behalf … disabled people contest the

world views of those who in the past had represented their interests, and had thereby assumed, from their silence, their incapacity.

At the same time, however, the principle of voice is ambivalent since there is no guarantee that disabled people will be heard or heard on their own terms. With the shift to a neoliberal rationality increasingly underpinning the provision of disability services, there is concern that disabled people are more likely to be offered limited opportunities for consumer choice rather than rights to recognition, presence, participation and voice in the public sphere (see Meekosha, 2001; Yeatman, 2000).

Gerard Goggin and Christopher Newell (2005) argue that the terms of public debate about disability are delineated in such a way that the biomedical standpoint is taken for granted whereas the everyday knowledge of disabled people is either rejected or reduced to the individualised demands of interest group politics. More insidiously, perhaps, Newell (2006) points out the biomedical perspective also selectively mobilises the voices of disabled people, in ways that function to reinforce its dominance. Here the story of the 'tragically disabled' individual is appropriated in order to elicit public support for some form of medical-technical intervention that will make 'the problem' go away (Newell, 2006, p. 279) . In this salvation narrative, the biomedical profession are constructed as caring experts while people with disabilities are represented as lives not worth living without medical-technical intervention.

This practice of appropriating voice for disabling ends is not limited to the biomedical profession. In the field of research, qualitative approaches seek to move away from the tendency to treat disability as an object of study and instead offer disabled people the opportunity to speak for themselves. These approaches do not necessarily entail listening to disabled people on their own terms, however, because their voices remain subject to interpretation by researchers (Ashby, 2011). David A. Gerber (1990) powerfully illustrates

the limitations of the interpretive paradigm in his re-evaluation of Robert B. Edgerton's study *The Cloak of Competence: Stigma in the Lives of the Mentally Retarded* (1967, sic). Gerber found that participants in Edgerton's study challenged the label applied to them and analysed their problems as stemming from oppressive social practices rather than their presumed impairments. Instead of listening to these critiques, however, Edgerton interprets them as evidence that participants are in denial about their condition. Gerber argues that this rejects the authority of participants' voices and their right to be heard since what they have to say is reduced to a manifestation of their supposed impairment rather than taken seriously as a significant critique of disabling social processes. This practice of appropriating the lived experience of disabled people is deeply problematic insofar as it benefits the careers of researchers while the social circumstances of disabled subjects remain unchanged (Ashby, 2011; Oliver, 1992).

Similarly, welfare reforms targeting disabled people appropriate the social model language of 'participation' and 'inclusion' (Galvin, 2004). Nonetheless, the needs and barriers of disabled people receiving income support continue to be defined in individualised terms. It is assumed recipients either do not want to work or lack skills. This misrecognises the experience of many disabled people who, if not already engaged in part-time work, face substantive barriers such as employer discrimination and the lack of meaningful education, training or retraining opportunities (Humpage, 2007; Soldatic & Chapman, 2010). These structural barriers remain unaddressed because policy is designed around assumed needs while service users' own definition of their needs is ignored.

How, then, is it possible to distinguish between practices of voice that contribute to transformative change and those which reinforce disabling hierarchies of attention? Nick Couldry (2010) usefully differentiates between voice as process and voice as value. While voice as process is the socially grounded, embodied 'act of giving an account of oneself'

(Couldry, 2010, p. 3), voice as value is where the process of voice *matters*. For example, the biomedical perspective cannot be said to value voice *as such* since it renders possible only limited modes of giving an account of oneself – the 'tragically disabled' – and rejects others. The emancipatory paradigm of research developed within disability studies, by contrast, values the contribution that voice as process makes to transforming 'the social relations of research production' (Oliver, 1992, p. 102).

Couldry's (2010) definition is particularly useful for disability studies insofar as it privileges the practice rather than the means of voice. This capacity and principle of citizenship is routinely contravened for disabled people, particularly those with sever communication impairments (Meekosha, 2001). Appreciation of the ways in which both voice and listening are mediated (O'Donnell, Lloyd, & Dreher, 2009) offers a starting point to challenge this violation. For example, voice within the public sphere is habitually mediated by audio-visual technologies, non-verbal communication, translated into text and so forth. Approaching voice from the perspective of disability challenges the marginalisation of disabled people who use assistive technologies or non-spoken language when the use of similar technologies by others is normalised (see L. J. Davis, 2002, for a similar argument about the body). Voice, from this perspective, is not a tool to enforce the normalcy of particular communication means – such as hearing or spoken language. On the contrary, it can encourage listening to those who communicate in different ways such as Deaf people or people with severe communication impairments (Ashby, 2011; L. J. Davis, 1995; Goggin, 2009).

It is also important that voice is not conceptualised in a homogenising way.[ii] Since the 1990s, division have emerged within the Australian disability movement. This includes segmentation along impairment lines which, when combined with significant cuts to advocacy services under the socially conservative Liberal-National Coalition government

(1996–2007), arguably undermined the movement's capacity to mobilise collectively for social change (Soldatic & Chapman, 2010). At the same time, new networks and peak organisations such as Women with Disabilities Australia (WWDA) (Meekosha, 2001), the Aboriginal Disability Network NSW, the First Peoples Disability Network Australia (FPDN) (Hollinsworth, 2013; Soldatic & Chapman, 2010) and the National Ethnic Disability Alliance (NEDA) emerged. These organisations recognise diversity within the disability movement and the intersection of disability with other forms of oppression. Notwithstanding renewed opportunities for collective mobilisation made possible with the more affirmative approach to disability advocacy under the Rudd-Gillard Labor Government (2007–2013) (Soldatic & Chapman, 2010) the movement remains a diverse network. In this context, attention to voice and listening requires recognition of differences *within* the disability movement.

Listening

Given that voice has become an important tool in struggles for recognition of disability then it is vital to understand the conditions of possibility for voice that matters. The politics of voice is a powerful yet one-sided analytic tool. It has enabled disabled people to 'speak back' to dominant representations of disability as an individual, medicalised problem. Since disability is a *relationship* of power and privilege, however, then the onus of responsibility is not just on disabled people to speak otherwise about disability. Attention to listening (as the 'other side' of voice) redirects accountability for social change by calling into question ableist practices of misrecognition and appropriation, which systematically marginalise the voices of disabled people. In this way, listening not only functions as a precondition for voice but also enhances what it is possible to hear in situations of difference and inequality (Dreher, 2009; Thill, 2009).

Susan Bickford (1996) argues that assuming responsibility for listening, as a practice of democratic citizenship, can challenge established hierarchies of voice. Since oppression

works in part by silencing or marginalising the voices of particular social groups then

listening can function, conversely, to undermine such entrenched patterns of inequality and

foster a public sphere in which a multiplicity of different voices can be heard. Bickford offers

a framework for intersubjective listening as a practice of democratic citizenship. She outlines

three requirements of what she terms political listening: openness, courage and continuation.

To use a musical metaphor, openness refers to the act of relinquishing the privileged position

of lead and becoming an accompaniment for the other; thereby constructing the self as

background against which the voice of the other is foreground as melody. Openness, then,

does not consist in the negation of the self. Rather, it entails the courage to listen across

difference in the face of uncertainty – the possibility what we hear will call into question our

own perspective, persuade us, reveal dissonance or intractable conflict or demand change.

For Bickford, listener and speaker are partners in a shared creative process with a

responsibility to maintain the listening relation. This means, whether we are persuaded by

each other or disagree, the principle of continuation serves as a guide so we nonetheless

engage in such a way that the field of possibility for shared action is 'maintained or

expanded' (Bickford, 1996, p. 170).

Similarly, Krista Ratcliffe's (2005) model of rhetorical listening across difference

consists in an active practice of openness. This openness involves the desire to 'understand'

self and other, which is explained as seeking intersubjective recognition of our sameness and

difference rather than mastery over the other. Inverting the term, Ratcliffe suggests openness

is a practice of *standing under* the discourses that shape us in order to create a space from

which the unique, changeable standpoint of the other is foreground. Openness also entails

accountability for our historically privileged position within discourse. Moreover, Ratcliffe

makes clear that it is important to consider not simply the assertions made by others but also

the discourse in which those assertions operate. This enables listeners to appreciate where the

perspective of others comes from even when they may disagree with their claims and, thereby, facilitates communicative intervention across difference rather than defensive position-taking. Finally, Ratcliffe adds a cautionary note that rhetorical listening is a shared and ongoing responsibility, which may involve discomfort insofar as it challenges us to call into question our own perspective.

Like Bickford, Romand Coles (2004) formulates listening as a significant democratic practice in its own right rather than simply a correlate to voice. He argues that if social relations are weak or power structures indifferent then marginalised groups speaking up will only address part of the problem. Without confronting the failure of social actors to listen to each other then voice will continue to be devalued. Listening *well*, for Coles, entails 'a broader notion of responsiveness' (Coles, 2004, p. 684). Insofar as voice is an embodied, situated practice he argues that literal, embodied travel within the world of the other is necessary in order to expand the capacity of listeners to respond. This is because, in situations of difference and inequality, while social relations of power may be shared, there are also meaningful ways speakers and listeners do not inhabit a 'common world'. Indeed, the notion of travelling reminds us we cannot inhabit the world of the other on their terms; that, even as we use travel as a strategy for opening the possibility of shifting perspectives, listeners too are situated and have journeyed from elsewhere.

While Bickford, Ratcliffe and Coles each articulate listening as a democratic practice, it is important to acknowledge listening can both challenge and entrench power relations shaping who gets heard in public debates (Lloyd, 2009). Indeed, as demonstrated in the previous section, selective listening can problematically facilitate the appropriation of disabled people's voices for disabling ends. Thus, this paper interrogates how 'listening' both transforms and sustains established hierarchies of attention.

The NDIS

Reform to disability support in Australia is an example of the possibilities and limits of political listening. In the remainder of this paper, I apply the frameworks provided by disability theory on voice and political theory on listening to an analysis of the National Disability Insurance Scheme. There is evidence of openness to lived experience of disability as a form of expertise that can contribute to momentous and pervasive policy change. Beyond the policy development stage, however, voice is valued only in limited ways.

The NDIS is being implemented in the wake of the consultative approach of the Rudd-Gillard government to reforming some parts of the disability support system. The Productivity Commission Inquiry, for example, listened to the voices of people with disabilities and their advocates and used their submissions and testimonies of the lived experience of disability as evidence for why change is required. Personal stories, including heart-breaking accounts from parents who have been told that the only way they will gain access to support services is by relinquishing care of their disabled children to the state, stand alongside statistical evidence of disadvantage and estimates of unmet need (Productivity Commission, 2011, p. 112). While many of the stories to some extent reinforce the 'personal tragedy theory of disability' (Oliver, 1986, p. 6) and the dominant voice of families associated with the Howard era (see Soldatic & Chapman, 2010) the Productivity Commission simultaneously *stands under* this discourse by recognising the social barriers disabled people face and the lived experience of disability as a form of expertise that can contribute to policy development. The Commission also stands under market-based models of reform to the extent that disabled people are not just given a say, as consumers, in their satisfaction – or lack thereof – with existing care and support services. Their voices also inform discussion about implementation issues, such as the financing of the NDIS (Productivity Commission, 2011, pp. 652-653, 660).

Open listening is also practiced in the way conflict is dealt with during the Inquiry process. Listening makes public that more than one point of view exists on disability support even while these different perspectives are not necessarily reconcilable. For example, some participants agreed with the terms of the Inquiry that individualised, funded support should be targeted to people with long-term, 'sever or profound' impairments while others claimed these supports would benefit and thus should be available to all people with disabilities. Various perspectives on this issue are outlined in the body of the report (Productivity Commission, 2011, p. 166). The Productivity Commission directly engages with this debate and provides a rationale for its final decision to recommend targeted individualised supports – maintaining wider eligibility criteria would divert funds from those most in need and potentially undercut both public support for and the sustainability of the proposed NDIS (2011, p. 167). Listening does not resolve this conflict but clarifies what is at stake without silencing dissenting voices. This recognition of participants as partners in shared action, with a right to be heard even in the face of disagreement, is an invitation to continue to work together across such differences.

Beyond the inquiry stage, there is continued (if limited) commitment to value the contribution that voice can make to assessment and service delivery. One of the key objects of the *National Disability Insurance Scheme Act 2013* (the Act) is to 'enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports' ("National Disability Insurance Scheme Act," 2013, p. 3). In the assessment process, this is facilitated by the development of a statement in which participants articulate their goals, aspirations and circumstances. This statement then informs a statement of supports developed 'with' participants. In this person-centred approach to assessment, the lived experience of disability is potentially recognised as a form of expertise that shapes how much or what kind of support participants are entitled to. Experience stands alongside

medical assessments of impairment and economic considerations such as whether a particular support 'represents value for money' ("National Disability Insurance Scheme (Support for Participants) Rules 2013," 2013, p. 8). This approach mediates the dominance of the medical and neoliberal models of disability without necessarily challenging their legitimacy.

Much hinges, though, on how 'with' is interpreted in practice. For example, the extent to which the circumstances of disabled people are assessed in a uniform way against standardised criteria and then translated into administrable needs ('reasonable and necessary supports'); albeit with referenced to expressed and documented goals and aspirations (see "National Disability Insurance Scheme (Support for Participants) Rules 2013," 2013). This is an improvement on the current '"lottery" of access to services' (Productivity Commission, 2011, p. 6) where there is little uniformity and a significant unmet gap between need and supports. For example, Lillian Andren's testimony of the absurdity of a system in which resource rationing means she had to experience *daily* incontinence problems before being entitled to personal support for three showers per week (Manne, 2011). Nonetheless, it falls short of engaging disabled people as active partners in a shared dialogue about what supports would best enable them to pursue their goals and aspirations; let alone claims for self-assessment advocated by Inquiry participants and disability advocacy organisations (Australian Federation of Disability Organisations, Deafness Forum, People with Disability Australia, & Women with Disabilities Australia, 2011).

WWDA and Women with Disabilities Victoria (WDV) (2011) demonstrate the significance of engaging the participation of disabled women in dialogue about the nature of supports so that they can be better adapted to their goals, aspirations and situation. In their response to the Productivity Commission's draft report, they argue that disabled people are represented only as recipients of informal support rather than recognised as both providers *and* recipients – a common circumstance of disabled women, in particular. Yet their role as

providers of informal support has implications for the type of assistance they themselves would find most appropriate. For example, disabled mothers report that their disability support does not cover enabling equipment or support for their role as mothers. The *National Disability Insurance Scheme Act 2013* (the Act) can be criticised on the same grounds. While specifically acknowledging 'the role of families, carers and other significant persons in the lives of people with disability' ("National Disability Insurance Scheme Act," 2013, p. 6) the Act fails to recognise disabled people as providers and recipients of support. This has significant negative implications for the capacity of the NDIS to listen and respond to disabled women's *intersecting* needs as disabled people *and* as women. It tacitly reproduces stereotypes of disabled women as dependent, passive and incapable. Such stereotypes can contribute to disabled women being excluded from or marginalised within decision-making processes (National Ethnic Disability Alliance, 2013).

NEDA (2013) argues that these issues are compounded for disabled women from non-English speaking backgrounds (NESB) and/or culturally and linguistically diverse (CALD) backgrounds. The adoption of NEDA's threshold recommendation that 'the cultural and linguistic circumstances, and the gender, of people with disability should be taken into account' ("National Disability Insurance Scheme Act," 2013, p. 7) indicates some sense of responsibility to listen and respond to the different concerns and circumstances of disabled people in an ongoing way. On the other hand, the rejection of NEDA's more demanding recommendation that caveats around the exercise of choice and control be removed from the Act, in favour of an emphasis on providing assistance (including independent advocacy) to support disabled people exercise these capacities, limits possibilities for more enabling listening.

The extent to which voice is valued in practice is dependent on the skills, readiness and resources of assessors and service providers to listen to disabled people in ways that

enable them to have a say. Opportunities for exercising voice and choice are limited or absent in the context of Australia's hitherto chronically underfunded and crisis-driven disability support arrangements, which further diminish expectations of support overtime and therefore peoples' capacity to articulate goals and aspirations even when arrangements improve. In the words of disability advocate Michael Bleasdale (2011, p. 3):

> People with disability and families will be expected within this new system to be quite specific about the resource demands and the outcomes they expect. After generations of being told not to expect anything, and to be grateful for what they get, significant work will have to be done, to generate the capacity within these groups to make these demands, working on their existing expertise and passions and assisting them to become fierce and effective self-advocates ... otherwise we will have a new, bigger system which is ready to respond, but which is responding to requests for more of the same

These concerns are exacerbated for groups of disabled people whose disability intersects with other forms of oppression. The situation of people with intellectual disability and children with disability requires particular attention. Because of the disabling effects of negative social attitudes about competence, cognitive or communicative impairment, age and/or lack of accessible information (see J. Davis & Watson, 2000; Dowse, 2009; Yeatman, 2000), these groups may be denied the right to be heard in the decision making process.

Likewise, FPDN argues that 'Aboriginal and Torres Strait Islander people with disabilities remain at the periphery of the disability services system' (First Peoples Disability Network Australia, 2013). This is the product of a history of profoundly disabling government programmes and services, the ongoing market and cultural failures of the system and the disinclination of Aboriginal and Torres Strait Islander people to identify as disabled people (due to different cultural meanings of impairment and disability as well as fear of compounding their experiences of discrimination) (see First Peoples Disability Network

Australia; Hollinsworth, 2013). Without culturally specific systematic and individual advocacy, capacity-building and change to the way disability services are delivered with respect to Aboriginal and Torres Strait Islander people then a self-direct approach to assessment and service delivery is likely further entrench disadvantage. In response to these issues, and the lack of any recognition of the need for specific, culturally-competent services in the Act, FPDN has developed a *Ten-point plan for the implementation of the NDIS in Aboriginal communities* (2013).

A market-based model of service reform cannot satisfactorily resolve these dilemmas. By making choice and control (rather than voice and listening) the main strategies for service reform, the NDIS places the burden for systemic change onto individual disabled people. Since the capacity of many disabled people to walk away from unresponsive service delivery relationships is constrained by their dependence on the relatively ongoing provision of care and support services then this individualistic and voluntaristic strategy is unlikely, on its own, to produce meaningful change (Leipoldt, 2011; Soldatic & Pini, 2012). Yet calls from disability peak organisation and networks for the NDIS to support individual and systematic advocacy (see First Peoples Disability Network Australia; National Ethnic Disability Alliance, 2013) remain unheeded. Furthermore, an emphasis on choice is hollow in the context of 'the existing "market failure of the disability support system in Australia with respect to Aboriginal and Torres Strait Islanders with disability' (First Peoples Disability Network Australia). Similarly, in the situation of many disabled women, who routinely 'fall through the cracks' between unresponsive and inaccessible mainstream service and gender-blind disability services (Women with Disabilities Australia (WWDA) & Women with Disabilities Victoria (WDV), 2011).

The government has supplemented this market-based model with a more participatory approach to service reform. There is evidence of a concern to continue to give disabled

people, their advocates and service providers a say on issues of policy design and implementation through both the NDIS Engagement Project (a community consultation project funded by the Department of Families, Housing, Community Services and Indigenous Affairs and delivered by the National Disability and Carer Alliance) and *Your Say* (the federal government's online NDIS forum). These public forums asked questions about issues such as what qualities people value in a disability support worker or service provider and what contributes to effective planning and assessment as well as feedback on formal policy documents including the draft bill and rules. While this sort of public participation demonstrates a commitment to an ongoing process of voice, the extent to which voice is valued is nonetheless difficult to measure.

Additionally, there is (again limited) concern to continue to listen to disability service users in the governance of the NDIS. The nine member Board of the National Disability Insurance Agency (NDIA) – responsible for the administration of the NDIS – is appointed on the basis of skills, experience and knowledge of relevant fields, the first of which is: 'the provision or use of disability services' ("National Disability Insurance Scheme Act," 2013, p. 109). This, in itself, is significant recognition of service users as experts valued alongside commercial expertise in the makeup of the Board. However, the presence of service users on the Board cannot be equated with collective self-representation for people with disabilities since the criteria of experience with disability services *could* be met by the appointment of a service provider, carer or family member rather than a person with disability. The government has, nonetheless, appointed two board members with disability: advocate Rhonda Galbally and actuary John Walsh.

Rhonda Galbally has also been appointed as the Principal Member of the Independent Advisory Council. The Advisory Council was established to provide advice to the Board about how the NDIS is performing 'from the perspective of people with lived experience of

disability' (Rishworth & Macklin, 2013). Membership of the Council is made up of a majority of disabled people and intended to reflect the diversity of disability ("National Disability Insurance Scheme Act," 2013, p. 121). Galbally's dual appointment means that the Advisory Council has direct representation and a voice on the Board. Nonetheless, this arrangement falls short of demands from advocacy groups that *the Board* should consist of 'a majority of people with disabilities' (Disability Advocacy Network Australia cited in Productivity Commission, 2011, p. 427) and represent diverse disability groups (see, for example, National Ethnic Disability Alliance, 2013; Women with Disabilities Australia (WWDA) & Women with Disabilities Victoria (WDV), 2011).

Membership of disabled people on the Board and Advisory Council of the NDIA is important in a number of respects. From a social justice perspective, it addresses claims on the part of the disability movement for disabled people to be in control and contribute to decision making at all systems levels, including governance; not just at the individual consumer level (Bleasdale, 2011; Leipoldt, 2011; Soldatic & Pini, 2012). Board members with disability also challenge normative assumptions about expertise and leadership since these attributes are usually conceived as antithetical to disability (see Kumari Campbell, 2009 for a similar argument about the disabled teaching body). Authorising other groups to speak on behalf of disabled people would have the opposite effect, reinforcing disabling cultural assumptions about incapacity. Finally, the everyday experience of disability in Australia is likened to inhabiting a 'war zone' (Meekosha cited in Soldatic & Chapman, 2010, p. 141), 'apartheid' (Goggin & Newell, 2005) or an exiled nation (Manne, 2011). Although service providers, carers and family members may travel to this zone – and are often passionate advocates of disability rights – they have journeyed from elsewhere and cannot represent the profound and systematic subjugation, inequality and exclusion faced by disabled people (Meekosha, 2001, pp. 240-242). The transformation of this experience constitutes the *raison*

d'être of the NDIS. It should not be displaced by a focus on means – resourcing service providers, carers and families; rationing resources and balancing budgets – lest it be entrenched.

Conclusion and recommendations

In conclusion, this analysis of the NDIS demonstrates the transformative role listening can play in ensuring voice matters in disability policy. Attention to listening facilitates a process of *standing under* the 'personal tragedy theory of disability' (Oliver, 1986, p. 6) by recognising the lived experience of disability as a form of expertise that can shape path-breaking reform. In order for this process to be fully realised, however, it needs to be sustained and extended. Otherwise, disabled people may be end up being marginalised within a new system that simply offers 'more of the same' rather than being genuinely included in a transformed approach to the provision of disability supports where voice is valued.

Listening can be extended, at the collective level, by ensuring that disabled people are central to all stages of the implementation and evaluation process of the scheme and by responding to claims for a greater proportion and diversity of disabled people on the board. There should be opportunities for disabled people and their advocates to continue to have a say in policy design and implementation as well as greater transparency about how their voices are being used to shape policy. Participants should not simply be surveyed, as individual consumers, about their satisfaction with the new scheme. Instead, people with disabilities must participate at the design stage in decisions about how to evaluate the NDIS so that the evidence-base for future development reflects their concerns, interests and experiences as well as those of other stakeholders such as government agencies, service providers, carers and families. Similarly, the recommendation about more disabled people being included on the board puts institutional decision-making power in the hands of disabled

people. As the appointments of Galbally and Walsh demonstrate, there are leaders within the disability community with considerable commercial expertise and governance experience.

At the individual level, listening can be enhanced with a responsive approach to assessment and service delivery. Choice in a market-based model is largely reduced to choice of provider. It thereby mediates rather than transforms established hierarchies of attention in which professional expertise dominates. Assessment remains a normalising process in which professionals largely determine the amount and type of support disabled people are entitled to. An alternative, listening model of service delivery would require assessors and service providers to stand under their historical privilege and engage disabled people in a dialogue regarding appropriate supports and how these can be adapted to best meet their needs and circumstances – with particular concern for the impact of the intersection of disability with other forms of oppression. This approach requires staff with the appropriate resources, skills (including cultural competence) and training (including assessment of gender-specific differences) to enable voice. To avoid potential 'creaming', staff also require specialised skills in interpreting 'non-conventional modes of communication' (Yeatman, 2000, p. 192) so that people with intellectual disability, communicative impairments and young children are not excluded from opportunities to develop the capacity for voice and choice. Reasonable case-loads that take into consideration the time required to build and facilitate dialogue are also crucial – particularly since disabled people continue to experience significant social exclusion and are not accustomed to being heard.

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[i] While the use of people-first language is the norm in Australia, in this paper I use 'disabled people'
to refer to people with impairments who are systematically disabled by social and cultural
processes. This is because, if disability is the product of social and cultural processes, then it
doesn't make sense to talk about disability as something someone has. It makes more sense to talk
about people who *live* with disability but for reasons of space I use disabled people. I also seek to
address the danger of reducing people to any one aspect of their experience or identity by
discussing intersectionality.

[ii] Thanks to one of the journal's anonymous reviewers for this point.