Disability Care & Support

Response from Trevor Robinson

The proposed National Disability Insurance Scheme (NDIS) is flawed, as it only serves to stigmatize people with disabilities as economic burden, necessitating additional funding. What's required is critical assessment of existing management and service delivery models and a shift in the philosophical approach to care.

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Summary

Disability is a subject intensely avoided by politicians and policy makers, considered unworthy of national agenda status. So it pleasing to see elevated discussion on disability funding and service delivery.

However, the jump to discover new funding models disregards fundamental flaws in the existing system, both in methodology of funding and quality and quantity of service delivery. To fuel inefficiencies and biases with greater funding only serves to make the disability sector more dysfunctional, with unmet need still present.

Those seeking a social insurance model specifically created for people with a disability, while altruistic in nature, have ignored the wider negativities any scheme incurs. Instead of promoting inclusion of people with disabilities within Australian society, advocates for the scheme have highlighted the burden that people with disabilities have on the Australia's economy, necessitating a special fee, tax or levy to alleviate the problem. While the aged, the indigenous or the displaced (refugees) place similar burdens on the economy, why is it that the disabled are only marginalized group singled out?

Finally, the paths that lead to this review require critical review. In over twenty years of involvement in the disability arena, my family and I have never voted for a candidate to represent my family's interests specifically on disability issues, my family and I have rarely been surveyed by disability organisations or government departments to ascertain our views or concerns, and my family and I have never been given choice on what service or model we prefer to use. And I'm certain our lack of voice within the disability community is the majority experience. Those representing the disability community do so under a false, and possibly political, premise. They are the elites of a community, telling rather than asking the disability community what they need.

Introduction

Firstly, allow me to say thank you for providing me this opportunity to comment of the Disability Care and Support review by the Productivity Commission. Due to a myriad of competing tasks, I was unable to attend the various consultations the Productivity Commission had on this subject. Therefore, to be here today greatly satisfies my democratic drive.

Credentials

Before I detail the crux of my argument against an NDIS model, let me outline my credentials for providing evidence at this inquiry. Hopefully my experience and expertise qualifies my rationale of reasoning to my evidence. First and foremost, it demonstrates my family's firsthand experience of a dysfunctional disability system, and our genuine and, importantly, pragmatic desire to get things right for the betterment of people with a disability. And secondly, my evidence has a high degree of academic credibility and validity towards and from a social and disability perspective. We have no funding master to please, political agenda to push or personal aspirations to be recognised or accredited. We just seek an egalitarian Australia, where everyone is valued and no-one is singled out.

Trent, the eldest of my four sons, was born 26 years ago with a severe developmental delay, resulting in significant brain damage and epilepsy. Consequentially, Trent has a cognitive age of 3 to 5 year old, with challenging behaviour that requires 24 hour supervision and attention. Despite Trent's severe disability, we have lived and worked in many different locations; from the highlands of Papua New Guinea to the Goldfields of Western Australia. Because we're lived in various locations, we have firsthand experienced of disability service delivery in NSW, WA and the ACT. We currently live in Canberra.

Due to Trent's challenging behaviour, and recent changes in family dynamics, Trent lives in emergency supported ACT government accommodation. Trent has been in emergency accommodation for almost **seven years**. During these seven years we have heard promise after promise of permanent accommodation, with the only surety in the next glossy government report stating that everything in the disability is rosy.

As for myself, I was involved in a motor vehicle accident in 2008, which left me a T5 complete paraplegic.

Neither my wife nor I sat on our hands, waiting for someone to help us with Trent. We became extremely proactive and vigilant on disability issues. My wife or I have been heavily involved in disability issues, serving as members of various committees, groups or panels. Until February of this year I was Chair of the ACT Governments' Disability Advisory Council, a position I held for nearly three years. I was also a member of the ACT Accessible Transport Group, Taxi Review Panel, ACT Strategic Government Group and a working group reviewing the ACT Disability Services Act.

We had to be pro-active on Trent's behalf and lobby, threaten or plead. Trent would have floundered if we waited for services to come to him.

From an academic perspective, I have a Masters in Applied Anthropology and Participatory Development, a Masters in Marketing Communication and I've nearly finished a Masters in Social Research. Most of my research has concentrated on the social attitudes of people with disabilities, specifically families and folk with spinal cord injuries, as well as the attitude of others towards people with disabilities.

Clarity of Sides

The introductions done, now let me state that I'm here as an individual, representing only my family interests and opinions. Furthermore, may I state categorically that should anyone that attends these hearings claiming to represent the united and informed opinions of the disability community, they are making a false and misleading statement. Opinions within the disability community that question the scant detail of the NDIS model have been either ignored, labeled as anti-disabled, anti-change or anti-progress or considered as the vocal, misinformed minority.

What confounds me is how those lobbying for the NDIS model, those influencing, advising and committing the disability community to accepting the NDIS *carte blanche*, can do so on virtually no detail and no economic or social modeling. The NDIS is not going to be the panacea to disabilities shortcomings, either now or in the future. If anything the potential of more money has the real possibility to perpetuate problems, not solve them.

Few, if any, disability organisations have informed their members of the NDIS in an unbiased, informed manner. I should know; my family is a member of numerous disability organisations. Much of the information circulated by these organisations on the NDIS is vague, idealistic and overtly positive. This accounts for nothing more than spin or PR. Exacerbating the issue is the lack of consultation with the grassroots; I.e. the people who this proposal affects. Elitism is alive and well in the disability community. Like William Easterly's paper titled *The Cartel of Good Intentions* which discusses the problems of bureaucracy in Foreign Aid and the disconnect between recipients and aid providers, the disability community shares similar traits, with many committees and policy makers disconnected from the wider disability community.

Fundamental Opposition

My fundamental opposition to any social insurance scheme specifically aimed at funding disability services for those with severe to profound disabilities is that it subtlety labels this group as a burden on Australian tax payers, necessitating the need for an additional levy, fee or premium. While I have no objection in significantly increasing welfare funding to the disability community, I do object to the fundamental need to institute an additional payment on top of existing general tax revenues. Singling out disability as a cost burden serves only to stigmatize and devalue people with a disability to the wider Australian population.

According to treasury figures, the welfare cost for the aged is more than the disability sector, yet a new tax levy is never contemplated. Again, according to Treasury figures, the welfare cost for indigenous programs is similar than the cost of disability programs, yet again, a new tax is not considered. It cost several hundred million in pensions, benefits and entitlements to what is a small number of retired politicians, yet no tax is muted. It will cost between 4 to 6 billion dollars for the National Broadband Network (what's a couple of billion between friends), but no new tax is pondered. The government spends billions to stave off the effects of the Global Financial Crisis, but not a cent is channeled towards alleviate the crisis in disability accommodation and care. The government spends billions going to war on spurious, erroneous and misleading intelligence, yet seems keen to instigate a new tax to pay for civilized care of its most vulnerable citizens. So much for the Christian adage of the meek shall inherit the earth. God, it seems, is an economist.

However, my objection to the NDIS also has a historic and legal foundation. The *Social Services Contribution Assessment Act* of 1945 placed a social insurance levy on taxpayers for elements such as social protection and care of children, the unemployed, widows, the disabled and the disadvantaged. Although this Act was appealed in 1965, the levy, not surprisingly, was not, with contributions rolled into general PAYE income tax collection. To institute the NDIS would be double-dipping by the Commonwealth government, as the Australian taxpayer already contributes to social insurance such as the NDIS, and has been since 1945. By asking for a new funding source only reveals an existing corruption of existing tax revenues.

A Broke System

Another case against the NDIS centre's on the validity and truthfulness of bureaucratic reporting. In the three Australian jurisdictions my family's experienced – WA, NSW and the ACT – I've never once seen a report that genuinely outlines the level of unmet need in accommodation, respite care, equipment or health services. Many of these reports outline the start of new services, but are generally silent on the closure of existing programs. Until a level of honesty and rigor exists in bureaucratic reporting, the level of unmet need will continue to be masked and the poor performance of programs hidden and perpetuated.

And it is not just the level of unmet need that is at critical levels; the standard or quality of service is also extremely variable. This is acutely evident in the ACT, where respite and accommodation services are audited on a shameful six year cycle. Further emphasizing how poorly considered people with disabilities are held, ACT prisons are visited regularly by the Human Rights Commissioner, yet people with disabilities are never once inspected by Human Rights or independent agencies.

I'd like to return to my previous point of reporting for a moment to succinctly demonstrate disability's downward slide in the mind of Australia governments. According the Productivity Commission's 2006 report titled *Employment of People with a Disability in the APS* states that (quote) '*… at June 2005, people with disability represented 3.8% of ongoing APS employees, down from 6.6% in 1986.*' (unquote). The report goes on to say that (quote) '*Fewer people with disability are being recruited into the APS, and existing staff with disability are leaving at a faster rate than they are being recruited.*' (unquote). While governments scratch their collective heads, postulate how extremely complex the problem is, commissioning expensive consultants, the Occam's razor principle is generally what should be applied. For those not familiar with Occam's razor, I'll provide a quick definition. Developed by William of Occam in 14th century, Occam's razor principle determines that fewest possible assumptions general explain (or in this case, solve) the most complex of problems. Employment of people with disabilities in the

Australian Public Service declined after the removal of employment quotas. Reinstitute quotas and employment will follow. Simple! Should people with disabilities be more imbued within the Australian Public Service, it would be easier for those in power to see that people with disabilities are not an economic burden but an asset, to be treasured and valued.

Need or Want

One disturbing element of a social insurance such as the NDIS model is that it builds up a level of expectation by recipients and administrators alike. Unlike the existing systems of needs analysis whereby recipients are assessed – hopefully in a negotiated manner – on their physical, social and environmental needs, social insurance models such as the NDIS are less actuarial. They are either excessively restrained by anorexic budgets, or spend in excessively due to overestimated demand and impending end-of-year accounting. And should the latter occur, what happens to the surplus? Yup. The next political promise of an upgraded highway, a new football stadium or another Oprah show occurs.

In my time as Chair of the ACT Disability Advisory Council I saw several expensive government programs that provided negligible short, medium or long term benefit to the disability community. What worries me greatly with the increased revenues the NDIS model will provides government, the amount of money wasted on ineffective and ineffectual programs and projects will only increase with scant independent oversight, review or genuine recipient feedback.

Valued or Liability

However, there is one fundamental element that is common in all the discussion about Disability Care and Support and the argument surrounding the efficacy of a proposed NDIS scheme… people with disabilities. And who are these people? They generally tend not to be scholars, or civic leaders or tycoons of the corporate world. They generally have small social networks – leading to acute social isolation – limited education, limited employment opportunities and overall poor health outcomes. It is, perhaps, because of this lowly status that a special tax must be instigated. Since children are highly valued in Australian society, the government gives new parents a financial bonus for procreating. But people with disabilities are costly, and require a special tax. Child support is so socially sensitive within the Australian society, the government created the Child Support Agency, which costs considerably more to operate than the money it distributes among divorced parents. But people with disabilities are expensive to service, and require a special tax. The environment is so important the government spends billions on insulation and other projects. But people with disabilities are allowed to be part of a future world, and require a special tax. Displaced persons from overseas are entering Australia. As long as they don't have a disability, they don't require a special tax.

The NDIS scheme can not and should not be considered in isolation to a wider social context. To do so ignores the wider public perceptions of how such a scheme would be considered. The community outcry following a muted Commonwealth disaster levy after the Queensland floods is testimony to how Australians, already one of the highest taxed in the OECD, will respond to another impost on their already stretched pay packets.

How about this idea as an alternative scheme? Retired politicians currently cost the Australian taxpayer about hundreds of millions of dollars a year in benefits, perks and 'privileges'. What say we institute a levy to pay for this impost on the Australian taxpayer? After all, it's a drain on the budget. Or are they more valued than people with a disability?

In Closing

In closing, my short and somewhat tempered response only demonstrates that enough has not been done to rectify unmet need in disability via funding from existing tax revenues. Realistically the Commonwealth government is awash will revenue. The evidence of this is everywhere. The Department of Defence recently discovered they had a spare billion or so, so to chew up this cash they bought a couple of big planes. If the Commonwealth can increase funding to private schools, build over-priced school halls, spend billions laying internet cables and go to war on a hunch, all out of existing tax revenues, then why should the most vulnerable, the most marginalized and the least able to talk for themselves, be labeled as a burden, requiring a special tax or levy. Are they not Australians, valued as equally as everyone else?

Thank you.