Supplementary
Submission
No 251a

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

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LEGISLATIVE COUNCIL

PORTFOLIO COMMITTEE NO. 2 – HEALTH AND COMMUNITY SERVICES

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

Supplementary Submission

Dear Mr Donnelly,

(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales

I wrote to you previously in a submission dated 21 July 2018.

Since then, I've been confronted with even more even more evidence of the NSW State Government's departure from direct disability service delivery and oversight. This came when I complained to the State and Commonwealth Ombudsman's offices about a provider charging me for a service which I did not receive. As the instance of charging occurred in December last year, I discovered this in an account received by mail February this year, whereupon I raised it with both my plan manager and the service provider.

As July was closing and neither agency has been able to provide a straight answer as to whether the charge will ever be repaid, I sent the question off to both Ombudsman offices; the State Ombudsman given that the provider used to be the Department of Ageing, Disability and Homecare (ADHC – now Australian Unity) and the Commonwealth Ombudsman because plan management is now part of the ballooning 'third sector' bureaucracy created by the *National Disability Insurance Act 2013 (Cth),* all of which continues to be uncritically subsidized by State and Commonwealth alike.

Both Ombudsman offices referred me off to the newly established NDIS Safety and Quality Commission.[1] While agreeing to the referral, I described the change as 'regrettable'; both because yet another Commonwealth bureaucracy is created, while resolution of complaints and problems with NDIS providers is that much further away from end users (participants) as a result.

Advantages of State-based management

There were always good reasons at on policy, practical and pragmatic grounds to keep service delivery functions at a State or local level. Under ADHC I knew who was responsible in my locality for service delivery. It was also relatively easy to escalate matters. Some years ago, when my wheelchair broke in pieces (due to age), we moved quickly to replace it that weekend, knowing I would be bedridden otherwise.

When the then NSW Attendant Care Scheme declined our equipment funding request based on a lack of prior approval for a relatively simple shop floor manual wheelchair, a quick Ministerial email had the Attendant Care office rethinking its guidelines. My local Homecare manager was then asked to submit an approval form. This was all sorted out in a week or two; a timeline unimaginable at the National Disability Insurance Agency (NDIA). The earlier cited example of a charge levied for services not delivered in December last year still standing unresolved today optimizes the delay and dysfunction of the NDIS as a Scheme and the NDIA as an entity. You will note that in complaint emails to both Ombudsman offices I say:

> *As an NDIS participant, I am sick and tired of chasing providers to simply have them do their job. Things worked much better under the old system, when budgets were a matter for the Department of Ageing and Homecare*.[2]

I meant these remarks when I wrote them, I mean them now and, I mean the Committee to see them clearly. And they do not relate to one incident; rather there have been a series of stuff-ups, bungles, and delays happening regularly, ever since I entered the NDIS. Quite seriously, if the NSW Government offered to put ADAC back together tomorrow, I would happily transfer.

Great expectations not realized

Defenders of the NDIS would say that it is a new expanded system which gives 'choice and control'. My prior submission addressed the fiction of choice and control; therefore, the only real question to ask is how many 'second chances' should I give an overwhelmed and overstretched 'new system'? The NDIS has tested my patience and endurance, as well as that of my family, particularly my mother. She remains my principal carer into her 70s and, we see no sign of this ever changing.

For a system that made promises akin to a new era of 'milk and honey' the NDIS has in truth been a savage dash to grimly hold on to what you had with ADHC, hoping that a half-witted planner with a social work degree and a grade point average just above absolute zero, does not delete critical supports from your planning document. By writing many letters to MPs, Ombudsman offices and the NDIA itself, I have pretty much managed to hold onto my ADHC-style services.

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[1] See Appendix 1.1 and Appendix 1.2

[2] Ibid

These personal care supports are vital for me and Mum to continue to be able to live together in the family home. But why should it involve so much of what can only be described as “administrative trench warfare?” I have been a Homecare client since 1987, yet with the NDIS everything had to reassessed and, with that, there was the worry of losing resources and ADHC staff (State employees) which both I and my mother relied upon. We also felt more willing to trust them, as they had been background-checked by the State and came with the State’s imprimatur. While no system is perfect, no provider in the NDIA can claim the position of ADHC; even though most ADHC care staff transferred to Australian Unity (the company that took over ADHC).

The Commission

Now we have an NDIS Safety and Quality Commission. But has no-one in the State or Federal Parliaments or bureaucracy seen what this has done? As someone with a disability, a large part of my life and access to goods and services has now been partitioned off to the church and charitable sector, while oversight of same has been equally partitioned off to an NDIS specialist quangos, like the Commission. What an incestuous little club that will likely turn into; to the advantage of everyone except the participants at the end of the line, one suspects!

For a Scheme that claimed it wanted to integrate people with disability into the community, I’ve never felt more disturbed and uncertain in my life, nor worried so much about the future for me and my mother. I’ve also never been further away from services which are truly publicly run (and publicly accountable) with the option to make a complaint to a public Department or Ombudsman that any other NSW resident can access on similar terms. The NSW Government must bear a measure of responsibility for this; you ripped ADHC out from under me and many others. This came after a formal meeting with and plea to then NSW Disabilities Minister the Hon. Andrew Constance MP, not to proceed with the NDIS.[3] However, even in 2011, the NDIS ass (you could hardly call it a horse) appeared to ‘have bolted’. It is disturbing and depressing how most of my predictions about the NDIS have come to fruition.

A better way

As I’ve said previously, there must be better ways to truly improve the lives of people with disability, beyond placing them in the care of charity and, leaving them to contend with the effects of their disability for the rest of their natural lives. Indeed, the NDIS Agency itself would seem to have a limited appreciation of the value of technology for enhancing people's lives and/or technology acting to compensate individuals for the deficits caused by disability. Two examples are prominent: Victorian Legal Aid launched proceedings in the Administrative Appeals Tribunal for NDIS participant Jessica King. Agency assessors initially decided that Jessica's physiotherapy and gym membership were not reasonably necessary in the management of her cerebral palsy. However, the absence of these services exacerbated her condition, making it more painful and rendering her unable to walk, with or without crutches. The Tribunal found that these services were reasonable and necessary and should have been funded, but as Jessica's mother Gail told *The Age:*

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[3] See Briefing for Minister, 18 October 2011, attached

> This whole process has set her right back and that's what I'm angriest about..(the Agency) have robbed her of months of treatment. And we're supposed to (be) grateful for this scheme.[4]

But in an even more pointed example of the Agency's inability to understand the value of current technology, much less what might be possible in the future, there is the case of Sydney mother and former academic Kirsten Harley. With advancing motoneuron disease she applied for communication technology to address the time when her disease robbed Dr Harley of speech. The Agency rejected this application. Dr Harley told the ABC that:

> My impression of what [the NDIS assessors] was saying is that the disease is likely to progress rapidly and therefore it's not worth spending the money…The whole point of the NDIS is to promote independence and to promote a place in society for people with significant disability.[5]

In response, the Agency cited its high case load, of 100,000 participants last year, claiming many of these people had no support previously.[6] This demonstrates the real power of NDIA planners over participants and families, even in the allegedly new model of disability service and support system which claims to be centred on participant need and aimed at improving their participation in the community.

Quite clearly, communication technology was essential to Dr Harley. While unaware of the ultimate outcome in the case, an argument could be mounted on the grounds of early intervention. Early intervention is usually considered aggressive treatment of a disability for a young child, to improve their ultimate life outcomes.[7] While Section 25 of the NDIS Act does mention young children with developmental delay as one of the groups meeting the criteria, this is not the only criteria and nor is it written as a pre-determined to early intervention supports. Indeed, this section gives the Agency CEO (or delegate) a wide discretion aimed at alleviating and mitigating disability, as well as aiming to maintain current abilities.[8] A Note under the section also gives guidance that people with degenerative conditions may qualify for the NDIS based on early intervention considerations.

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[4] Miki Perkins, Woman with disabilities scores landmark win over NDIS, June 18 2017, The Age, Victoria, http://www.theage.com.au/victoria/woman-with-disabilities-scores-landmark-win-over-ndis-20170615-gwrz7c as at 22 June 2017

[5] Dan Conifer, "Terminally ill mother fears NDIS 'writing off' people with neurological conditions," Updated 15 Apr 2017, 3:11pm, Sat 15 April 2017, 3:11pm, http://www.abc.net.au/news/2017-04-15/terminally-ill-mother-fears-ndis-writes-off-people/8445228 as at 22 April 2017

[6] Ibid

[7] See e.g.: "Support for your child: What is the Early Childhood Early Intervention (ECEI) approach?", https://www.ndis.gov.au/ecei as at 6 June 2018

[8] See NDIS Act, above n 2, s.25(1)(c)(i) with states that a person will meet the early intervention requirements if:

> the CEO is satisfied that provision of early intervention supports for the person is likely to benefit the person by:
> (i) mitigating or alleviating the impact of the person's impairment upon the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management; or
> (ii) preventing the deterioration of such functional capacity;

There has been some criticism that after the 2017 budget, the Agency began using annual support reviews to significantly cut back services to various NDIS participants. In particular, *The Australian* newspaper reported that:

> The early years of the $22 billion program's rollout saw wild variability in the value and type of support being granted to participants, forcing (Agency) executives to come up with a way to claw back funding that has "an impact on sustainability". In the process, people with disabilities and their families have been shocked by sudden reversals of fortune.[9]

A lack of ambition

Despite the vagaries of government policy and especially consistency in funding, there is arguably a blind spot in many advocates' view of disability. In my opinion, this has a detrimental effect on the application of technology and the potential for so called "blue sky thinking" about technological applications in the future. This blind spot affects advocates and academics in the disability sector in numerous ways. Firstly, many derive their identity and some their income from the belief that people with disabilities should be included in wider society as they are. To invoke the words of the Disability Discrimination Act, wider society is called upon to make "reasonable adjustments"[10] to facilitate this inclusion. While this position is consistent with many contemporary ideas about disability, it leaves completely unconsidered the possibility of changing an individual's experience through the application of technology to that individual's impairments.

There are plenty of examples where such interventions, while currently at the cutting edge of science. With the correct policy settings and fiscal incentives, these could and should become commonplace. Considering the development of medical technology like stem cells,[11] exoskeletons[12] and brain implants,[13] and the opening of centres for genetics and cellular technology,[14] the public expectation of what amounts to reasonably adjustments and thus what is necessary for economic or

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[9] Rick Morton, "Families' NDIS support slashed in crackdown" The Australian, 12:00AM May 16, 2017, https://www.theaustralian.com.au/national-affairs/health/families-ndis-support-slashed-in-crackdown/news-story/67342b4a10cd2c325d2c1a01f0911288 as at 6 June 2018

[10] Disability Discrimination Act 1992 (Cth), No. 135, 1992, s.5-6; s.30-31, https://www.legislation.gov.au/Details/C2016C00934 as at 4 June 2018

[11] See e.g. New Scientist, "The potential to live indefinitely and cure disease could lie with the placenta," Stem Cell Medicine 29 May 2018, http://view.e.newscientist.com/?qs=e746b9940ff39c130ae617dcfc6e8157d8f9a7f1a5457687eb1f263bcdcedccff844c3e409e294529dfcf62b0751ab0b2eea560efe07170ac67fdd7f8355c19684d65df31ec8db03fbbb5750816b330a33baed14619fde79 as at 4 June 2018

[12] See e.g.: Eamonn Tiernan, "ReWalk exoskeleton allows paraplegic Paul Jenkins to walk again," Sydney Morning Herald, February 13 2017 http://www.smh.com.au/technology/sci-tech/rewalk-exoskeleton-allows-paraplegic-paul-jenkins-to-walk-again-20170117-gtt5ar.html as at 4 June 2018

[13] See e.g. Bridie: Smith, "Human trials for Australian-made bionic spine to start next year," Sydney Morning Herald, February 9, 2016, http://www.smh.com.au/technology/sci-tech/human-trials-for-australianmade-bionic-spine-to-start-next-year-20160202-gmjqdj#ixzz3zik2ip00 as at 4 June 2018

[14] See e.g.: Marcus Strom, "Hope for the paralysed: UTS to establish Centre for Neuroscience and Regenerative Medicine," Sydney Morning Herald, September 16 2016, http://www.smh.com.au/technology/sci-tech/hope-for-the-paralysed-uts-to-establish-centre-for-neuroscience-and-regenerative-medicine-20160915-grgudc.html as at 4 June 2018

social participation in the community, under section 24 of the NDIS Act,[15] will change. However, as currently understood, the NDIS assumes disability and then assesses the need for equipment and support services based on reasonable necessity. However, it also makes clear under subsection 24(1)(e) that eligibility requires that the disability be presumed to be permanent. And as both Ms. King's and Dr. Harley's suggest, the Agency seems to have a limited view of the innovation and technology which would reduce and, in some cases potentially eliminate, the negative consequences of disability.

Furthermore, as reports continue to emerge about shortfalls in care staff needed to make NDIS supports a reality,[16] the issue of labour force constraints in this area are widely recognised.[17] While the NDIA devotes part of its Annual Report to 'assistive technology'[18] this mainly seems to concern bedroom and bathroom mechanical aides, along with smart phone applications.

While these might be useful and potentially necessary, we are missing a real opportunity to use mechanisation and robotics in care.[19] Such technological investment could relieve many of the heaviest and most complex aspects of care, while giving assurance to carers (those whose role Ms Young earlier downplayed) that the ones they love would be less likely to be abused, neglected, or defrauded. Mechanisation could also free some of us who are heavily dependent on our carers from a degree of our dependency; but I note that those who have obtained exoskeletons and similar technologies have had to base themselves overseas to do it.[20] Ultimately, from the point of view of

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[15] See National Disability Insurance Scheme Act 2013, No. 20, 2013, s.24(d) https://www.legislation.gov.au/Details/C2016C00934 as at 3 June 3, 2018

[16] See e.g.: Dan Conifer, "NDIS: Report warns workforce understaffed in major cities, raises concerns over readiness," 25 February 2017, 6:57am, http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276> as ay 26 October 2017.

[17] See e.g.: Marilyn Harrington and Dr Rhonda Jolly, "*The crisis in the caring workforce,"* Briefing Book, Commonwealth Parliamentary Library, https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/BriefingBook44p/CaringWorkforce as at 26 October 2017

[18] See See National Disability Insurance Agency, Towards an ordinary life: NDIS Annual Report 2015-16, Commonwealth of Australia 7., 34-35

[19] See e.g.: Robert Sparrow and Linda Sparrow, "In the hands of machines? The future of aged care." Minds and Machines 16: 141-161, May 2006, http://profiles.arts.monash.edu.au/rob-sparrow/download/InTheHandsOfMachines_ForWeb.pdf; see also, Heather Kelly, "Robots: The future of elder care?" CNN, July 19th, 2013, 03:42 PM ET, http://whatsnext.blogs.cnn.com/2013/07/19/robots-the-future-of-elder-care/; Maureen Dowd, "Silicon Valley Sharknado," The Opinion Pages | Op-Ed Columnist, New York Times, July 8, 2014, http://www.nytimes.com/2014/07/09/opinion/maureen-dowd-silicon-valley-sharknado.html?_r=0 as at 19 July 2014. From Ms Dowd's article I note, in particular:

> Vinod Khosla, the Sun Microsystems co-founder, has predicted that algorithms and machines will replace 80 percent of doctors in years to come, making medicine more data driven and less like "witchcraft."

[20] See for example, the webpage of Australian paraplegic speaker and campaigner Amanda Boxtel, now based in the US and Canada, with her walking machine: http://www.amandaboxtel.com/index.html as at 20 July 2014; also see e.g.: ScienceAlert Staff, News – "This exoskeleton has been approved for personal use," Tuesday, 01 July 2014, http://www.sciencealert.com.au/news/20140107-25786.html?utm_source=feedburner&utm_medium=email&utm_campaign=Feed%3A+sciencealert-latestn as at 20 July 2014.

government it is the cost-savings that could result from investment in technology that needs to be considered.

Clinging to disability

Until recently, I was not aware of "ableism" as a serious academic and social concept, despite having spent all my life living with cerebral palsy, as well is having spent the greater part of my adult life in some form of tertiary study. However, it clearly does exist and, when people who I would understand as lacking the benefits of hearing campaign actively against the rollout of Cochlear implants,[21] it does cause one to pause and reflect on the neurology, psychology, and ideology of those who would prefer to be disabled.

Sparrow explains that some people who were deaf saw Cochlear as "the desire of a majority (hearing) culture to impose its language and values on the Deaf."[22] This kind of argument shows the contest between the social concept of disability and the medical construction of disability. The latter view looks at an individual's clinical condition and change it, while the former is internationally accepted and seeks to "accommodate people living with impairment (in the community)".[23] While this might be the internationally accepted standard, some advocates arguably take it further.

The ways in which people with disabilities have been shut out physically, structurally, socially, and economically from many aspects of the Australian community has been well-documented in the commentary; thought the article by Paul Ramcharan is revealing in its title that people with disabilities have apparently moved from the classification of ' deserving poor to customer'.[24] This author will return to the question of why *citizen* was not used in place of *customer?*

It is also noteworthy that some commentators argue that the social exclusion of people with disabilities can be seen in how they are "shut out" of popular culture, using what are arguably commercial and neoliberal examples. Helen Meekosha cited the 2006 *'Where the Bloody Hell Are You?'* Australian tourism campaign. This she said did what many campaigns before had done, in that:

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[21] See generally, Robert Sparrow, "Defending Deaf Culture: The Case of Cochlear Implants," The Journal of Political Philosophy: Volume 13, Number 2, 2005, pp. 135–152, http://profiles.arts.monash.edu.au/wp-content/arts-files/robert-sparrow/Deaf-Culture.pdf as at 6 June 2018

[22] Ibid, 135-6.

[23] People with Disability Australia, "The Social Model of Disability," http://pwd.org.au/student-section/the-social-model-of-disability.html as at 6 June 2018

[24] See generally, Paul Ramcharan,, "Understanding the NDIS: a history of disability welfare from 'deserving poor' to consumers in control," The Conversation, July 6, 2016 6.07am AEST, citing National People with Disabilities and Carer Council," SHUT OUT: The Experience of People with Disabilities and their Families in Australia: National Disability Strategy Consultation Report," © Commonwealth of Australia [2009], <https://www.dss.gov.au/sites/default/files/documents/05_2012/nds_report.pdf>; <https://theconversation.com/understanding-the-ndis-a-history-of-disability-welfare-from-deserving-poor-to-consumers-in-control-58069> as 21 January 2017. Specifically, Ramcharan states:

> Resettlement back into the community started around the 1970s in Australia. Community care policies aimed to provide support, education, employment, housing and inclusion services.
> Forty years after community care started, people with disabilities are living longer. Yet in 2009, a report based on consultation with people with disabilities found there was still little social inclusion, poor quality disability services and high unemployment.

> (In) the images of everyday Australia, the Outback, the beaches, the vineyards and the restaurants, among the dozens of people represented, there is no-one with an identifiable disability. What we do see are images of vital, healthy, ''ablebodied'' European-descent Australians, with an occasional Aboriginal person as an attraction for the visitors. We see then a nation's marketing representation of how it believes itself to be; its history, geography, social reality and contemporary divisions are nowhere to be seen.[25]

But addressing the issue of exclusion goes deeper than making people with disability visible to the broader population. The more crucial questions relate to who constructs the problems facing people with disability, what is their rationale and, do those with disabilities perceive the issues the same way? In relation to the NDIS, Cate Thill argues that not only has the professional and medical establishment overwhelmed people with disabilities, but researchers have not always aided understanding by the hypotheses they have constructed. She cites a re-analysis of a 1967 study of intellectually disabled people which found:

> (Participants) in (the original) 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, (the researcher) interprets them as evidence that participants are in denial about their condition. (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.[26]

Thill makes a convincing argument that many people with disabilities, their families, carers and advocates were heavily involved with campaigning for an NDIS. The most obvious example of this was the public 'Every Australian Counts' campaign. [27] However, highlighting the NDIS assessment process, Thill points out that while the participant prepares a statement of goals and aspirations, these are then subjected to medical and economic tests, which she sees as illegitimate.[28]

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[25] Helen Meekosha, "*What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic*," Scandinavian Journal of Disability Research, Vol. 8, No. 2-3, 2006, 161, <http://s3.amazonaws.com/academia.edu.documents/7383443/Meekosha%202006.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489440202&Signature=eE%2FE3Un1tZPaA%2FkNVlwi98VA2wA%3D&response-content-disposition=inline%3B%20filename%3DWhat_the_hell_are_you_An_intercategorica.pdf> as at 14 March 2017

[26] Cate Thill, "*Listening for policy change: How the voices of disabled people shaped Australia's National Disability Insurance Scheme,"* Disability and Society on 17 Dec 2014, University of Notre Dame Australia, ResearchOnline@ND, Arts Papers and Journal Articles School of Arts 2014, citing Ashby, C. (2011). Whose "voice" is it anyway?: Giving voice and qualitative research involving individuals that type to communicate. *Disability Studies Quarterly, 31*(4) and Oliver, M. (1992). Changing the Social Relations of Research Production? *Disability, Handicap & Society, 7*(2), 101-114. doi: 10.1080/02674649266780141 <http://researchonline.nd.edu.au/cgi/viewcontent.cgi?article=1111&context=arts_article> accessed 6 November 2016.

[27] See ibid, 3.

[28] See ibid., 12-13.

The real conundrum

it is fair to say that I am yet to be convinced by the concept of disabling social processes (even as someone with a lifelong physical disability) and, while I welcome modifications to infrastructure that facilitate my inclusion in various activities, the notion that my condition is not a significant medical issue is something I find laughable. While some of the disability advocates, supporters, carers and others have been prosecuting these arguments however, the potential of people with disabilities to use technology to aggressively intervene in their impairments has been diminished.

This is partly because, as the neoliberal approach to public policy has spread from pure economics and fiscal policy, to all areas of service delivery, there has been a fundamental change in how the government views the people and the Australian people view their various governments. Now, market forces, competition and choice theory readily dominate how policy is made.

Going to the market

In the realm of social services generally and disability services specifically, this can be most clearly seen in the policy shift in NSW. This occurred in consort with the introduction of the NDIS. Prior to the NDIS, the State and Territory governments had primary responsibility for the delivery of disability services. This was usually achieved through a Department of State. In the case of NSW, it was through the Department of Ageing, Disability and Homecare (ADHC). ADHC had been in existence in NSW, in a public form, since 1943.[29] However, in 2015, the NSW Government announced that it was transferring the disability support components of ADHC to the company, Australia Unity. The $100 million received in the transaction, the Government announced in a press release, would be "reinvested into the disability sector to help with transition to the NDIS".[30]

This press release is important for several reasons. Firstly, it acknowledged that ADHC provided for 70% of disability and aged care support in NSW.[31] Secondly, it confirmed that the outsourcing of human services was being followed in other jurisdictions.[32]

Thirdly, the State government argued the outsourcing service delivery to the charitable, mutual, or private sectors would give ADHC clients and their families more 'choice and control.' Just exactly what is this 'choice and control' particularly when considered alongside the standards set in the UN *Convention* and notions of the 'reasonably necessary' in the context of Australia? Mr. Wallace's analysis suggests it might not mean that much when, as of 2013:

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[29] See Department of Family and Community Services, "Ageing, *Disability and Home Care, Home Care Service client handbook*," Department of Family and Community Services March 2014, 4 https://www.adhc.nsw.gov.au/__data/assets/file/0010/257590/3075_ADHC_HC_clientHandbook_May2014.pdf as at 21 October 2017

[30] Ibid., "Media Release Archive, *$100m to be reinvested in Disability Services after NDIS milestone"*, 28 Aug 2015, https://www.facs.nsw.gov.au/about_us/media_releases/media_release_archive/$100m-to-be-reinvested-in-disability-services-after-ndis-milestone as at 21 October 2015

[31] See ibid

[32] See e.g.: Leah MacLennan, "*Elderly and disability care services being outsourced to SA private sector*," Wed 8 February 2017, 5:19pm, http://www.abc.net.au/news/2017-02-08/elderly-and-disability-care-services-outsourced/8252820 as at 21 October 2017

> (In Australia) 45 per cent of people with a disability live in or near poverty; more than double the OECD average of 22 per cent. We rank 21st out of 29 OECD countries in employment participation rates for those with a disability. We rank 27th out of 27 in terms of the correlation between disability and poverty.[33]

As a client of ADHC, who was generally satisfied with the government service, it was not clear to me how a shift to the NGO sector would result in miraculous improvement. However, as I acknowledged, one is living in the age of market forces, The NDIS came into force within a context of 20 years of neoliberal theory being the dominant policy framework since the Hawke/Keating government.[34] In this time, governments at State and Commonwealth level have outsourced or sold off numerous public instrumentalities (and their clientele) to the private sector or charitable institutions. The general argument in favour of this reform has been that the private or charitable sectors are more efficient than government, or more focused and aware of client needs. The retraction of the state in the delivery of services is further justified as empowering clients by allowing them to make decisions about service provision. This is seen as actively positively giving people with disabilities choices regarding the provision of services and thereby ensuring their needs are met.

However, do these theories represent what many people want? Before dismissing them altogether, Sheldon Loman and others argue the people with disabilities require support to learn how to make decisions and what consequences flow from them. While their examples concentrate on senior school students, they say:

> One instructional model for increasing student-directed learning, that has been empirically validated, is the Self-Determined Learning Model of Instruction ..The SDLMI is a three-phase model for teaching a self-regulated problem-solving process that allows students to set goals, plan a course of action, evaluate their own performance, and make adjustments to plans or goals as needed …The instructional process consists of teaching students to pose four questions during each phase of the process that require the student to (a) identify the problem, (b) identify potential solutions, (c) identify barriers to solving the problem, and (d) identify consequences of each solution
>
> The SDLMI instructional model has been shown to help secondary students with disabilities to increase appropriate behavior in classroom and jobsite settings and to achieve transition-related outcomes such as: improved job task performance, improved budgeting and

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[33] Craig Wallace, "*Disability reform in Australia unfinished business*" [online]. Precedent (Sydney, N.S.W.), No. 125, Nov/Dec 2014: 41. http://search.informit.com.au.simsrad.net.ocs.mq.edu.au/documentSummary;dn=857499153442568;res=IELAPA as at 21 October 2017

[34] See e.g. Mark Beeson, and Ann Firth. "*Neoliberalism as a political rationality: Australian public policy since the 1980s.*" [online]. Journal of Sociology, Vol. 34, No. 3, Nov 1998: 215-231. http://search.informit.com.au.simsrad.net.ocs.mq.edu.au/documentSummary;dn=200005021;res=IELAPA ISSN: 1440-7833 as at 10 December 2017.

> personal hygiene skills, and increased success in making independent transportation arrangements.[35]

This may seem to be unquestionably beneficial for the individuals concerned and the wider community. The Productivity Commission made similar observations in its NDIS Costs Report, while conceding that there was likely a greater role for support agencies, to help those with little experience of managing their own affairs, to do that.[36]

Despite arguments for self-management, the very same report acknowledged submissions saying that some participants did not want to self-manage 'because it is perceived to be too complicated and burdensome'.[37] Furthermore, the Commission had evidence that in the first year of the NDIS, that about 80 per cent of participants let the NDIS Agency or another plan management agency administer their plans.[38] This broadly corresponds with international evidence suggesting that in comparable jurisdictions, where self-management is as low as 11 percent.[39]

Where rates of self-management did rise, these participants were children, whose allocation was actually being managed by their parents. Even then, the rate rose to only to 17 percent, where "active carers…have the time and skills to manage funds for their children."[40] Otherwise, there were clear reports of a system overwhelmed and a market that was failing.[41] Despite the many formal representations to the contrary,[42] the States and the Commonwealth have held belligerently to a market forces model.[43]

Much has gone wrong with the NDIS; indeed, as a participant, one doesn't hesitate to use the word 'failure'. As the writers cited in footnote 42 variously say, great uncertainty has been created, some

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[35] Sheldon Loman et. al, "*Promoting Self-Determination: A Practice Guide,* A National Gateway to Self-Determination:" Funded by the US Department of Health and Human Services, Administration on Developmental Disabilities, June 2010, 27, http://ngsd.org/sites/default/files/promoting_self-determination_a_practice_guide.pdf as at 18 November 2017

[36] See Productivity Commission, "*National Disability Insurance Scheme (NDIS) Costs"* Productivity Commission Study Report, October 2017, 375, <http://www.pc.gov.au/inquiries/completed/ndis-costs/report/ndis-costs.pdf>

[37] Ibid., 374

[38] See ibid., 380

[39] See Luke Bo'sher, "*Self-management: is a new world of cash payments on the horizon?,"* Disability Services Consulting, February 12, 2015, <http://www.disabilityservicesconsulting.com.au/resources/self-management> as at 20 November 2017

[40] See ibid

[41] See e.g. Peter Ryan and Sabra Lane, "*Report warns NDIS rollout will be delayed and costs will rise,"* ABC "AM" broadcast http://www.abc.net.au/radio/programs/am/report-warns-ndis-rollout-will-be-delayed-and-costs-will-rise/9064750; see also Victorian Legal Aid, "*NDIS 'market failure' leading to vulnerable people being unfairly jailed*," Thursday, 9 November 2017, https://www.legalaid.vic.gov.au/about-us/news/ndis-market-failure-leading-to-vulnerable-people-being-unfairly-jailed as at 1 January 2018

[42] See e.g. Lois O'Callaghan, "*Market Failure in Rural and Remote Areas,"* Mallee Track Health & Community Service (MTHCS) http://www.pc.gov.au/__data/assets/pdf_file/0007/219067/subpp0222-ndis-costs.pdf; see also Simon Viereck, "*Submission to (NDIS) Costs Inquiry,"* Mental Health Community Coalition ACT,https://www.pc.gov.au/__data/assets/word_doc/0006/215772/sub0135-ndis-costs.docx as at 1 January 2018

[43] See e.g. Marie Sansom, "*NDIS opening up new and competitive market,"* Government News, August 12, 2014, https://www.governmentnews.com.au/2014/08/ndis-opening-new-competitive-market/ as at 1 January 2018

programs that worked well have been trashed, some people are withdrawing from services because they just can't cope with all the change and, the notion of a viable market is a nonsense in many places, particularly in rural Australia. Given that both Bo'sher and Loman's work make the point about the considerable preparation and training resources that need to be put into self-management, how much of the funds could actively be deployed to research and technological developments instead? This is particularly when, even if you can train someone to self-manage under the NDIS, there are a range of demarcation lines and restrictions over what will be funded as "disability" and what will not. As the King and Harley cases showed the demarcation is not necessarily reasonable, with an Agency not seemingly geared towards innovation and technological enhancements of people's lives. This sometimes extends to the Agency's view of standard personal care activities. In particular, Bo'sher observes:

> NDIS funds to spend on work readiness cannot be used to purchase dental work to fix gum and teeth issues even if this would be the most useful assistance to getting a job. Self-management may be intended to provide more empowerment, but it still does not allow participants full autonomy over how to most effectively and efficiently achieve their goals.[44]

Government must return

When considering disability services and the vulnerable people who access them, this author asks whether neoliberal policy theories result in satisfactory outcomes. In arguing that they are unsatisfactory, this thesis makes the case that the government has real and abiding duties that cannot and should not outsource to other parties.[45] The argument rests partly on the notion of public citizenship and public accountability for the goods and services rendered to those in our society who are most needy.[46]

it is to be recalled that Paul Ramcharan wrote an article which briefly chartered the changes for people with disabilities, from being seen as poor and deserving to an active market customer. While

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[44] Bo'sher, above n 39.

[45] For a consideration of this issue from the US perspective see generally, Paul R. Verkuil, "*Outsourcing Sovereignty: Why Privatization of Government Functions Threatens Democracy and What We Can Do about it,"* 2007, Cambridge University Press, <http://www.langtoninfo.com/web_content/9780521867047_frontmatter.pdf>; see also from an Australian perspective, Richard Mulgan, "*Transparency and the Performance of Outsourced Government Services" Occasional Paper No. 5,* This research paper was commissioned by the Queensland Office of the Information Commissioner and prepared for the Australia and New Zealand School of Government March 2015, <http://apo.org.au/system/files/53659/apo-nid53659-12231.pdf>; Contra: Dr David Kemp MP, "*Key Speech: Public Administration in the New Democratic State*," Address to the National Conference of the Institute of Public Administration Australia, Canberra, November 1997, <http://onlinelibrary.wiley.com.simsrad.net.ocs.mq.edu.au/doi/10.1111/j.1467-8500.1998.tb01378.x/epdf> as 10 December 2017

[46] See generally, Helen Dickinson, Catherine Needham and Helen Sullivan, "*Special Issue*: *Individual Funding for Disability Support: What are the Implications for Accountability?"* Australian Journal of Public Administration, vol. 73, no. 4, pp. 417–425 doi:10.1111/1467-8500.12106 <http://onlinelibrary.wiley.com.simsrad.net.ocs.mq.edu.au/doi/10.1111/1467-8500.12106/epdf>; from an American perspective compare e.g.: Kimberly N. Brown, "*Outsourcing, Data Insourcing, and the Irrelevant Constitution,*" Georgia Law Review 49, no. 3 (Spring 2015): 607-692, <http://heinonline.org.simsrad.net.ocs.mq.edu.au/HOL/Page?handle=hein.journals/geolr49&div=20&g_sent=1&casa_token=&collection=journals> as at 11 December 2017

this author disputes elements of the Ramcharan argument, his article is nonetheless useful for historical purposes. Historically, those with disabilities were cared for by their families and, their existence and impairment could be a closely guarded secret. As Western society industrialised, many families had to move to the cities for work. Disabled people could not often keep up with the demands of the new industrialised age, so they came to live in homes and institutions run by various benevolent organisations and religious orders.

The 20th century, impacted by two World Wars and The Great Depression would see greater calls on government to provide greater protection to their populations from these extremes of violence and deprivation. This is exemplified by Sir Robert Menzies, founder of the Liberal Party and Australia's longest serving Prime Minster readily articulated the state's duty to the citizen. As noted in my prior submission (but it seems worth reminding you), in his comments on *Freedom from Want,* during his *Forgotten People* broadcasts, Sir Robert said:

> *The country has great and imperative obligations to the weak, the sick, the unfortunate. It must give to them all the sustenance and support it can. We look forward to social and unemployment insurances, to improved health services, to a wiser control of our economy to avert if possible all booms and slumps which tend to convert labour into a commodity, to a better distribution of wealth, to a keener sense of social justice and social responsibility. We not only look forward to these things; we shall demand and obtain them. To every good citizen the State owes not only a chance in life but a self-respecting life.*[47]

Reflecting on Sir Robert's words is essential. They speak to a state with purpose and, definite duties to Her Majesty's subjects (citizens) which is sadly lacking today. Meanwhile, counsel against outsourcing the provision of public goods and services to charity also comes from a well-known man, but from a distinctly different political perspective. Oscar Wilde said:

> *But (charity) is not a solution: it is an aggravation of the difficulty. The proper aim is to try and reconstruct society on such a basis that poverty will be impossible. And the altruistic virtues have really prevented the carrying out of this aim. Just as the worst slave-owners were those who were kind to their slaves, and so prevented the horror of the system being (realised) by those who suffered from it, and understood by those who contemplated it…Charity degrades and (demoralises)…Charity creates a multitude of sins.*[48]

In my view, Menzies and Wilde viewed together expose a debate that modern policy makers seem incapable of conducting. It is not just a case of can charity deliver goods or services to people, nor one of simple efficacy, but *should* some public services ever leave the state sphere? Both of the men

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[47] Petro Georgiou, "Menzies, Liberalism And Social Justice," Sir Robert Menzies Lecture Trust, 1999 Lecture, 3, quoting as at 13 March 2012, quoting Robert Menzies in a 1942 radio broadcast http://www.menzieslecture.org/1999.html; the source is: Robert Menzies, The Forgotten People: Chapter 5 - Freedom from Want, 10 July 1942, The Menzies Foundation, Menzies Virtual Museum http://menziesvirtualmuseum.org.au/transcripts/the-forgotten-people/63-chapter-5-freedom-from-want) as at 7 June 2018

[48] Oscar Wilde, *"The Soul of Man Under Socialism."* (1891) http://abetterworldisprobable.wordpress.com/2012/01/01/oscar-wilde-on-theproblems-of-charity/ as at 26 December 2013

quoted above knew what poverty and armed chaos could do to society. While the philosophies differ, they both see an active role for government in providing for a population's needs.

In the modern day, all people deserve public assurance that their needs will be met. Indeed, if the relevant international covenants have any meaning the State signatory must assume direct and clear responsibility. It is also important to take public notice of the facts about the behaviour of various charitable care agencies exposed by the current McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect.[49] This inquiry has provided a template showing how easily things can go wrong when churches and charities are entrusted with too much power and discretion, as well is being accorded great deference.[50]

Despite these lessons, this thesis will show that many of the same church and charitable organisations which were found wanting before the McClelland Royal Commission have been given responsibility to provide support and services under the disability insurance scheme and questions have already been raised, with Wallace remarking:

> Unless we act now, the next Royal Commission and apology will be about abuse and disability. Sadly, there are indications that what we know from the media exposés might only be the tip of a deep, ugly iceberg. We are overdue for a national inquiry into the abuse and neglect of people with disability.[51]

It is hard not to agree with Mr. Wallace on this point, particularly when reports emerged from the Royal Commission itself that demand for NDIS staff were so great, service safety and quality standards for participants risked falling.[52] Such reports, when combined with the growing efforts to have NDIS participants self-manage their care make me concerned that history is quite literally repeating itself. People with disabilities and their families are being asked to resume the burdens they carried in a bygone era, while this request is cleverly couched in the language of the market and so-called ‘freedom of choice.’ Personally, one cannot avoid feeling somewhat abandoned by my own state and federal government.

A right to try

Given my concern, technology has become a potentially viable way to argue for a substantial reform to the disability sector. This is on the basis that the NDIS is not a substantial or historic reform and, if anything, it is a disturbing retreat into history. Therefore, the disability sector must find a way to

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[49] See e.g.: Rachel Browne, 'Survivors have waited too long': 4000 institutions named in sex abuse royal commission, Sydney Morning Herald, March 27 2017 <http://www.smh.com.au/national/survivors-have-waited-too-long-4000-institutions-named-in-sex-abuse-royal-commission-20170326-gv716h.html> as at 26 June 2017

[50] There is some case law about undue influence which may be useful here, particularly where the organisation providing support and care services is a religious body; see e.g.: Pauline Ridge, "The Equitable Doctrine of Undue Influence Considered in the Context of Spiritual Influence and Religious Faith: Allcard v Skinner Revisited in Australia" [2003] UNSWLawJl 3; (2003) 26(1) University of New South Wales Law Journal 66, <http://www.austlii.edu.au/au/journals/UNSWLawJl/2003/3.html as at 26 June 2017

[51] Wallace above n 33, 44

[52] See e.g.: Samantha Donovan, “NDIS staffing demand may see drop in disability service standards Royal Commission hears,” ABC “PM” broadcast, Wednesday, July 20, 2016 18:40:00, <http://www.abc.net.au/pm/content/2016/s4504131.htm> as at 20 June 2017

overcome its attachment to "ableism”. This comes from an extreme example of identity politics, with seeks legitimacy by denying the normal, fully functional human form. Advocates and academics may applaud this, but I would suggest that it receives a far more mixed review in the wider community. All people have a desire, to some degree, to fit in to a wider community and, not merely to be included. This community by its very nature is able-bodied and, people with disabilities should be able to exercise that aspiration (should they so choose) under the early intervention provisions of the NDIS Act.

Failing the ability to intervene on the cellular and genetic level with consistency and assurance at this stage, mechanical implants and like modifications are a potential alternative. With the development of robotic hands for amputees[53] and, the increasing ability of this technology to mimic human behaviour, as well as to appear like human tissue, it is time for the NDIS to acknowledge what reasonable support should look like in the 21st century. Similarly, other people currently confined to wheelchairs may find freedom of movement in exoskeletons. These are currently widely used by industry.[54] There is currently a lack of standards surrounding the specifications of such equipment and, an international committee is currently working on the issue. This should bring benefits to people with disabilities as well as many others, with Maxwell observing:

> (The) attendee makeup of the organizational meeting for the new (international standards) committee reflected the fact that medical uses of exoskeletons represent the largest segment of this emerging industry. (More than half of attendees had a primary interest in medical applications.) Ekso Bionics is one of the more active companies in this segment. “(They) have hundreds of devices being used at customer sites, primarily in North America and Europe, on the medical side,”[55]

This is the future and, with the retreat of government from direct service delivery it is my belief that expediting such research is essential for the safety and welfare of people with disabilities. After all, why should anyone trust any of the church and charitable institutions ever again? As far as I am concerned, Archbishop Fisher's rather limp defence of the church and its finances, which appeared in the Sydney Morning Herald[56] answers nothing. No amount of good deeds can make up for what has been done, not only by the Church, but by many other allegedly benevolent bodies. I’ve been both a recipient of services and a member of a charitable board; what has sometimes passed for client service is appalling, while the approach to governance can be far less than robust. [57]

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[53] See e.g.: Outlook Web Bureau, “Italian Woman Becomes First Person to Receive Bionic Hand That Can Feel Sense Of Touch,” 4 January 2018, Last Updated at 5:00 pm, International, https://www.outlookindia.com/website/story/italian-woman-becomes-first-person-to-receive-bionic-hand-that-can-feel-sense-of/306410 as at 7 June 2018

[54] See generally, Jack Maxwell, “The promise of exoskeletons,” ASTM Standardization News, November/December 2017, 16-19, www.astm.org/sn as at 7 June 2018

[55] Ibid, 19

[56] See Anthony Fisher, *“Where will relentless campaign leave the most needy?”* Sydney Morning Herald, February 12 2018 http://www.smh.com.au/national/where-will-relentless-campaign-leave-the-most-needy-20180212-p4z00n.html as at 20 February 2018

[57] See e.g.: Michael Evans, Patrick Begley, *EXCLUSIVE: NSW Government scraps 'follow the dollar' reform despite Sharobeem, Ella cases* Sydney Morning Herald, July 24 2017, http://www.smh.com.au/nsw/nsw-government-scraps-follow-the-dollar-reform-despite-sharobeem-ella-cases-20170723-gxgzqj.html; see also

As US President Donald Trump said in his first State of the Union Address with reference to terminally ill Americans and their access to non-approved medications:

> To speed access to breakthrough cures and affordable generic drugs, last year the FDA approved more new and generic drugs and medical devices than ever before in our history.
>
> We also believe that patients with terminal conditions should have access to experimental treatments that could potentially save their lives.
>
> People who are terminally ill should not have to go from country to country to seek a cure -- I want to give them a chance right here at home. It is time for the Congress to give these wonderful Americans the "right to try."
>
> One of my greatest priorities is to reduce the price of prescription drugs. In many other countries, these drugs cost far less than what we pay in the United States. That is why I have directed my Administration to make fixing the injustice of high drug prices one of our top priorities. Prices will come down.[58]

A right to try to would be a truly historic and revolutionary approach in Australia. It would also give people with disabilities a meaningful freedom of choice; they would have the capacity to entertain the concept of living without disability, or at least with its impact greatly mitigated. While the American example is aimed at the terminally ill, it is always possible that this will expand in future. Equally, the Australian government could use similar principles to accelerate research in a variety of fields, including medicine and technology. Over time, this would relieve individuals of impairments, negating the need to be concerned about their safety while in care.[59]

Nonetheless. there are some questions about reasonable expectations that everyone should have out of life, which people in authority are particularly reluctant to answer. While there is some provision for early intervention services for disabled children and, provision for therapy for potential improvements in some conditions, the NDIS framework does not conceive of cure or substantial improvement. These concepts may be very important to some participants in their conception of what it means to have a worthwhile ordinary life and, they may become increasingly important to a growing number of people as science and technology advances.

This is somewhat reflected in the development of the law on wrongful birth cases (at least the dissenting judgments). For example, in *Harriton v Stephens* (2006) 226 CLR 52 the High Court

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Patrick Begley, *EXCLUSIVE: Glen Ella kids' charity 'misappropriated $20 million', says NSW government*, July 22 2017, http://www.smh.com.au/nsw/glen-ella-kids-charity-misappropriated-20-million-says-nsw-government-20170721-gxfzp3.html; see also Michael Evans, Farid Farid, "*EXCLUSIVE: Revealed: Sharobeem family sent $500,000 to relative in Egypt after ICAC grilling,"* Sydney Morning Herald, July 9 2017, http://www.smh.com.au/nsw/revealed-sharobeem-family-sent-500000-to-relative-in-egypt-after-icac-grilling-20170621-gwve6n.html as at 19 February 2018

[58] Donald Trump, "State of the Union 2018: Read the full transcript," CNN Politics, Updated 0912 GMT (1712 HKT) January 31, 2018, https://edition.cnn.com/2018/01/30/politics/2018-state-of-the-union-transcript/index.html as at 7 June 2018

[59] See e.g.: Carmel Laragy, "Four Corners: can the NDIS prevent abuse of people with disability?" 4 Corners, March 29, 2017 11.13am AEDT, <https://theconversation.com/four-corners-can-the-ndis-prevent-abuse-of-people-with-disability-75286> as at 20 June 2017

decided that a child did not have a claim of negligence against their doctor, for the practitioner's failure to correctly diagnose the mother's rubella, leaving the child with significant disabilities when born. The majority refused to consider the concept of life with a disability as against nonexistence, while in a partially dissenting judgment Kirby J observed:

> (A)warding damages in a case such as this would provide the plaintiff with a degree of practical empowerment. Such damages would enable such a person to lead a more dignified existence. They would provide him or her with a better opportunity to participate in society than he or she might otherwise enjoy where the burden of care and maintenance falls on the disabled person's family, on charity or on social security.[60]

His Honour's words are notable for the use of the phrase 'a degree of practical empowerment' without clearly defining what that is. Is it an ordinary life, or anything that the justices themselves would be prepared to live out as an ordinary life, not to mention any other person? The final sentence is also revealing in its acknowledgement that care will fall on the family, charity, and the State. With the emergence of the NDIS, the third listed party funds the second, while largely expecting the first to make up the difference, as many have always done.

While this case pre-dates the NDIS, Kirby's J's comments show how little disability policy has changed, particularly as family and charity are still critical elements, even with the NDIS. It is easy to speculate that people with disabilities (and their families) may become increasingly discontent with the charitable dependence norm as they witness the advancement of science and technology. Could a reasonable expectation of an ordinary life come to have with it, as a condition precedent, the absence of permanent disability? We should at least have the right to try.

Supplementary Recommendations

1. That the Committee recommend NSW withdraw its support for the newly established NDIS Safety and Quality Commission;
2. That the Committee recognise that the Commission and other elements of the NDIS are further isolating people with disabilities from the wider community, in partitioning much of our lives off, as the specialist concern of NDIS business units;
3. That the Committee acknowledge that individualized, market-based approaches will not work for a significant number of people and, the State Government should always run some disability support and care services directly;
4. That it should not be presumed by governments (or anyone else) that the church or charitable sector is an acceptable provider of care services;
5. That, even if church, charitable or other NGOs are available and deemed acceptable, no-one should be obliged (or compelled due to the lack of an alternative) to use them.
6. That there should always be a State Government disability support and care service provider, like ADHC;
7. That should the Government not support recommendations like those above, it should grant us the disabled accelerated and enhanced access to cutting edge science and medical

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[60] *Harriton v Stephens* [2006] HCA 15 at 122 (Kirby J.).

interventions. This would give us a “right to try” and free ourselves from disability, as well as freedom from the NDIS.

Yours faithfully,

Adam Johnston