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To: Commonwealth Department of Social Services
From: Adam Johnston, Proprietor, ADJ Consultancy Services
Date: 17 June 2016
Re: National Disability Insurance Scheme
(NDIS) - Code of Conduct
Discussion Paper

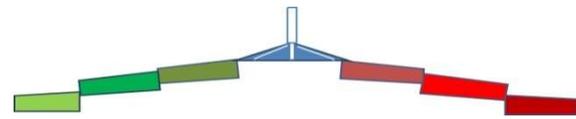
Dear Sir

As a current, though very dissatisfied participant in the NDIS, I do not see how establishing yet another bureaucratic body will improve the safety or quality of a fundamentally flawed organisation in the National Disability Insurance Agency (NDIA). As I have said in prior consultation regarding the proposed Quality and Safety Framework,¹ I do not think many people will complain. This is because people with disabilities are highly dependent on service providers; even where malfeasance has occurred, it is still doubtful that there would be many complaints due to that dependency.

Equally, while it is always appropriate for service providers to keep adequate and complete records, as well as to have an appropriately trained staff, who apply equally scrupulous standards of conduct, it is an unrealistic expectation that this will always happen. Therefore, jurisdictions like New South Wales should never have been allowed to divest themselves of all responsibility for direct service delivery. As a former client of the former Department of Ageing Disability and Home Care, one felt entirely abandoned by my state government.

If the Commonwealth had declined to enter an intergovernmental agreement with the New South Wales that permitted the State government to close the State disability and home care service, we would now not need to be dealing

¹ See generally <https://engage.dss.gov.au/wp-content/uploads/2015/05/Submission1.docx> as at 16 June 2017



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through another process about a *Code of Conduct*. The *Code* should in no way excuse the Commonwealth for its complicity in the closure of the NSW Disability and Homecare Department. Should policy makers insist on NGO involvement, the State Auditor should regularly and publicly audit their books.² I would also call for regular public examinations of all service providers, as if they were public agencies undergoing a Budget Estimates-style process, recommended in my submission to the NSW Government's inquiry into Recall Elections.³

Furthermore, the proposed commission is not necessary if we consider the fact that the New South Wales Ombudsman incorporates the former Community Services Commission. These bodies could have their powers enhanced, so that they not only covered complaints about service providers but could check (and potentially enforce) the service standards of providers. Some industry ombudsmen have power to make binding rulings⁴ and the NSW Ombudsman (and like bodies in other States and Territories) should be given a similar power. I have always believed that administrative and oversight functions should be held at the State level; this is the level of government closest to people.

Further, the NDIA should be devolved back into reconstituted State-level agencies like the NSW Department of Ageing, Disability, and Homecare, with an overarching Commonwealth Act, guaranteeing service reciprocity across State borders.⁵ Sadly, this is not the direction of policy, though a reconsideration of the NDIA and its enabling legislation would be appropriate.

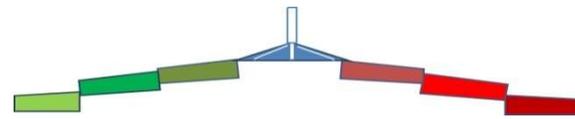
² This does not happen in NSW, despite a long standing recommendation of the NSW Parliament's Public Accounts Committee as a result of a review of the Audit Office; see

<https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/5507/Efficiency%20and%20effectiveness%20of%20the%20Audit%20Office%20o.pdf> (Recommendation 5) and my submission at <https://www.parliament.nsw.gov.au/committees/DBAssets/InquirySubmission/Summary/48395/Submission%20No%207.pdf> as at 16 June 2017

³ See my submission at http://www.dpc.nsw.gov.au/_data/assets/pdf_file/0008/131120/06_Johnston.pdf as at 16 June 2017. My proposal applied Recall Petitions to not only politicians, but bureaucrats, judges and indeed anyone who has stewardship of public money. This puts NGOs under scrutiny as well.

⁴ See the EWON site at <https://www.ewon.com.au/page/about-us> and specifically the example of a binding decision at https://www.ewon.com.au/content/Document/Determination61_MrS_May_07.pdf as at 16 June 2017

⁵ I campaigned for and ultimately had a hand in securing national reciprocity for taxi travel concessions; see http://www.aph.gov.au/parliamentary_business/committees/house_of_representatives_committees?url=fca/concard/concardindex.htm and



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In my view, the only thing that might be beneficially nationally regulated is care staff. If they were declared health care professionals for the purposes of the *Health Practitioner Regulation National Law Registration Act*,⁶ there would be a requirement for them to be registered, trained and police checked. There would also be nowhere in the country sub-standard workers could hide. The fact that writers of the *Code* were naïve enough to think that unregistered carers would ever really be bound by the document, or that you could ever clearly oblige them to anything without some form of national registration, shows a critical lapse of judgment. Then, the belief that there is a market in human services and that we the disabled could, should or even want to be active players in that (non-existent) market is equally fanciful, but governments pursued it anyway.⁷

There has been media commentary to the effect that the NDIS could become the next “pink bats” style debacle⁸ and, given my experience of the NDIS thus far, I am inclined to agree with such remarks. One appreciates that the NDIS was a political hatchet-job designed by the Gillard Government to foil then Opposition Leader Tony Abbott; they thought he would vote “no” but were out-manoeuvred when he voted “yes”. The “Tony is a heartless politician” election campaign had to be shelved by Labor.⁹ The consequences of these entirely political calculations however, are left for the Australian taxpayer and those with disabilities, along with their families to both live with and pay for. And to make matters worse, the speed of NDIS delivery, the rolling out of discussion papers and other frameworks as the Scheme operates, shows we have learned nothing from the Pink Batts Scheme. As a result, I expect to be abused, neglected, and defrauded by the NDIA and its “partner agencies.” One is already trying to chase down \$100 mysteriously missing out of my

http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=COMMITTEES;id=committees%2Fcommrep%2Frcmw970627a_rca.out%2F0012;query=id%3A%22committees%2Fcommrep%2Frcmw970627a_rca.out%2F0000%22 as at 16 June 2017

⁶ See generally <http://www.ahpra.gov.au/About-AHPRA/Who-We-Are.aspx> as at 16 June 2017. I am on the Health Practitioner Regulation Agency's list of Lay Members

⁷ My view on this is clear and I told the Productivity Commission that a market would not work and, from practical experience, does not work. See generally http://www.pc.gov.au/_data/assets/pdf_file/0003/209748/subpfr356-human-services-identifying-reform.pdf as at 16 June 2017

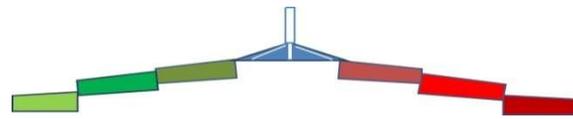
⁸ See Four lessons the NDIS must heed to avoid a 'pink batts' disaster, December 16, 2014 6.53am AEDT, <https://theconversation.com/four-lessons-the-ndis-must-heed-to-avoid-a-pink-batts-disaster-35385> as at 16 June 2017

⁹ I am a member of the NSW Division of the Liberal Party of Australia

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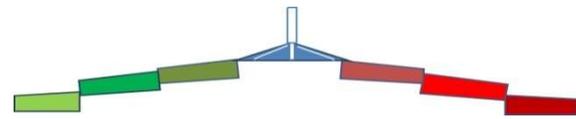
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wheelchair maintenance budget. This comes amid clear reports of an NDIS understaffed and under-resourced.¹⁰ In this environment service standards will fall and, employers will be inclined to hire whomever shows up, possibly out of sheer desperation. While acknowledging that disability services is not well paid and it hardly has a well-defined career path, there is security for all parties in disability services being both publicly run and publicly regulated.

Government policy, by contrast, is to outsource service delivery and subsidise NGOs to do this work. The complexities of this public/private hybrid model have left me drained and overwhelmed. Now I must arrange service providers, appointments, and find appropriately qualified people to conduct assessments demanded by the NDIA, as well as follow up with those who fail to deliver. In neither the Quality Framework nor the *Code* can one find any acknowledgement of the burden this places on families and NDIS participants; nor are we recompensed in any way for work that used to be done by a State agency. Ultimately, my hope is that this malicious cost and work shift comes back to bight all jurisdictions, in class actions for abandonment, anxiety, pain, and distress, as well as claims focusing on lost opportunity and economic loss. I never wanted all this work and my complaints to the NDIA, service providers, MPs and various Ombudsman offices are mounting.

In short “DIY (Do it yourself) care” was dumped on many of us without consultation; one never seriously anticipated the State Government ceasing to deliver services. One also never thought governments would be silly enough to trust the church and charitable sector with our care again, particularly after the revelations of the McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect. Indeed, had not Gillard’s desperation for votes met Abbott’s political rat cunning, the Productivity Commission’s *Disability Care Report* would likely be gathering dust in an archive with numerous other tomes from Australia’s most notable economic quango. And many would be so much better off if the report was indeed gathering dust.

¹⁰ See e.g.: NDIS: Report warns workforce understaffed in major cities, raises concerns over readiness AM By political reporter Dan Conifer, Posted 25 Feb 2017, 6:57am, <http://www.abc.net.au/news/2017-02-25/ndis-report-warns-major-cities-not-prepared-for-implementation/8303276> as at 16 June 2017



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My submission to the Quality Framework also called for the burden of proof to be reversed regarding any allegations against a care worker; and, for the balance of probabilities standard to be used in criminal cases, rather than beyond reasonable doubt. All allegations should be mandatorily reported to the Ombudsman and Police. Both parties should have power to initiate court actions in the name of families and NDIS participants, particularly where the latter are too afraid to act on their own.¹¹ In my view, this will be the reality in many cases and, if there was one thing that annoyed me about your *Discussion Paper* it was that all your scenarios were naïve and linear, aiming to put your Commission in the best possible light.

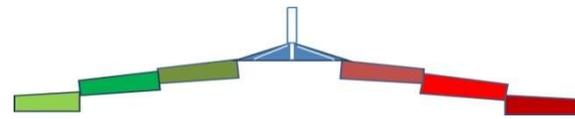
At no time did you concede there would be resistance, deception, objection, or a rejection of 'best practice;' or that the simplest response to the Commission is to become an unregistered care provider. As stated earlier, the suggestion that the Code would bind unregistered carers has the air of wishful thinking, rather than considered legal thought.

In the end, one concludes that the Government releases documents like the *Code* so they can be seen to be doing something; the *Code* itself offers little and, a generous summary of it is as something of a collection of well-meaning motherhood statements. But one does not put any more weight on it than that, nor would I rely on its contents to protect anyone from harm. And then, there are the missed opportunities. Nowhere in this *Code* is the possibility of robotic care mentioned.¹² Similarly, neither is investing in

¹¹ Refer to footnote 1, pp. 3-4.

¹² See e.g.: Sparrow, R., and Sparrow, L. 2006. *In the hands of machines? The future of aged care*. Minds and Machines 16: 141-161, May, http://profiles.arts.monash.edu.au/rob-sparrow/download/InTheHandsOfMachines_ForWeb.pdf; 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, 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."

In a rare joint interview last week with Khosla at his Silicon Valley summit, Google founders Sergey Brin and Larry Page talked about their A.I. (Artificial Intelligence) hopes. "You should presume that someday," Brin said, "we will be able to make machines that can reason, think and do things better than we can." They have always been interested in robots — they named their operating system Android — and are running "the brain project," described by Brin as "really machine-learning focused." In January, they acquired the British A.I. developer DeepMind, founded by Demis Hassabis, a game designer, neuroscientist and former child chess prodigy."



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implants to make the paralysed walk again,¹³ or the possibility of stem cell and related regenerative work that is promising much.¹⁴ I guess it comes down to where policy makers and society in general place their emphasis. If it is acceptable for chronic illness and disability to be perpetual parts of the human condition, then implementing the NDIS and propping up a bunyip aristocracy¹⁵ of churches and charities with public money to 'entertain' people with a disability until we pass into the next realm is satisfactory.

If, like me, you hold that life should and can mean so much more, then scientific research aimed at removing chronic illness and disability from the human condition becomes vitally important.¹⁶ Sadly, nothing about the NDIS or its various codes or frameworks ever seems to encompass such thinking. We are a poorer nation for it and, people will go on suffering because of this failure. Personally, one attends meetings and seminars of scientists whose work will ultimately cure me and many others.¹⁷ I don't have the funds or other capital these awe-inspiring people need and deserve to bring revolutionary, life affirming change from the lab to the patients' bedside. But governments' do, and they would have a whole lot more money if they levied taxes on churches and charities, as well as back taxes with interest.¹⁸

¹³ See e.g.: Human trials for Australian-made bionic spine to start next year - February 9, 2016, Sydney Morning Herald, <http://www.smh.com.au/technology/sci-tech/human-trials-for-australianmade-bionic-spine-to-start-next-year-20160202-gmjgdi#ixzz3zik2ip00>; also note, Japanese robot bear nurses soon to care for rapidly ageing population, Posted 24 Feb 2015, 7:00pm Tue 24 Feb 2015, 7:00pm, <http://www.abc.net.au/news/2015-02-24/japans-robot-bears-elderly-carers-of-the-future/6255734>; Paul Biegler, Elon Musk building brain-computer interface to protect against AI singularity, May 21 2017, <http://www.smh.com.au/national/elon-musk-building-braincomputer-interface-to-protect-against-ai-singularity-20170501-gvw4n1.html> as at 17 June 2017

¹⁴ See e.g.: Marcus Strom, Hope for the paralysed: UTS to establish Centre for Neuroscience and Regenerative Medicine, 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 17 June 2017

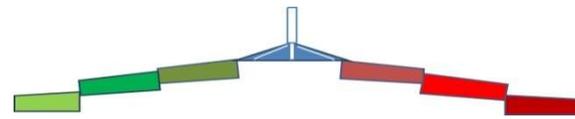
¹⁵ See https://en.wikipedia.org/wiki/Bunyip_aristocracy as at 17 June 2017

¹⁶ This has been a long-held belief of mine; see e.g. my Senate submission regarding the Review conducted by the late Justice John Lockhart at:

http://www.aph.gov.au/~media/wopapub/senate/committee/clac_ctte/completed_inquiries/2004_07/leg_response_lockhart_review/submissions/sub53_pdf.ashx as at 17 June 2017

¹⁷ See e.g. <https://www.linkedin.com/pulse/business-stem-cells-australia-daniella-goldberg> as at 17 June 2017

¹⁸ See e.g. my submission to the House Economics Committee inquiry into income tax deductibility at <http://www.aph.gov.au/DocumentStore.ashx?id=00874c93-07f4-4b37-9403-c50fef481832&subId=407687> and my submission to the Rethink Tax Review at <https://engage.dss.gov.au/wp-content/uploads/2016/06/Rethink-submission-1.pdf> and my 2015 Pre-Budget Submission at http://www.pc.gov.au/data/assets/pdf_file/0006/209751/subpfr356-human-services-identifying-reform-



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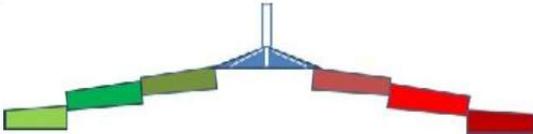
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Without action, we the disabled are left to contemplate a life trajectory of continuing chronic illness, impairment and, dependence on the charitable sector; not a particularly inviting prospect, as I have said elsewhere.¹⁹

I will support the medical scientists who offer real change and a real future, while hoping that legislators and policy makers eventually catch up.

Yours faithfully,

Adam Johnston



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[attachment3.pdf](#) as at 17 June 2017. All these documents call for major simplification of the tax laws and an end to deductions and exceptions, but unsurprisingly, no government has acted.

¹⁹ See generally, my submission to the Joint Standing Committee on Foreign Affairs, Inquiry into establishing a Modern Slavery Act in Australia at <http://www.aph.gov.au/DocumentStore.ashx?id=ff7b040b-0431-4f86-ac0d-061e6fe9fa05&subId=511149> as at 17 June 2017. I entered that inquiry because of my increasing concern (partly based on personal experience), that the sick, disabled, elderly and unemployed are being herded like cattle into relationships with NGOs by all levels of government. The exchange can contain any number of benefits for the NGO, like a government grant, positive press and, a free labour force. But, as the last point suggests, benefits for the individual can be hard to find, particularly if the participation is mandatory, but their output counts towards no financial return. Again, I remind you of my earlier comments about NDIS participants undertaking service assessment and coordinating functions; nobody seems to have seen it as important enough to ask: if we paid Departmental staff to do this under the old system, why aren't we giving commensurate support to NDIS participants and their families now?

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