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Dear Mr. Andrews

General issues around the implementation and performance of the NDIS

I write again, noting the front-page headline of the *Daily Telegraph* on August 31st, 2019, attached to this submission.¹ The committee should consider this article when reflecting on the operation of the National Disability Insurance Scheme. It is to be wondered why, in the face of evidence such as this, any government could see it as reasonable or proper to put the care of many thousands of people with disability across Australia in the care of the charitable sector.

This newspaper headline, along with many others should demonstrate to the committee that the NDIS is not an affirmation or fulfilment of the rights of individuals with disability. Rather, it leaves us vulnerable to more abuse, neglect and fraud. As the old saying goes – the more things change, the more they stay the same.²

While the NDIS Agency will probably go to some great lengths to prove otherwise, the newspaper article just confirms my day to day experience of how little things have changed – and certainly not for the better. Indeed, while it is the story of a regularly admitted and readmitted hospital patient presented in an essay by the Hastings Centre comes from a clinical perspective, its real goal is to tell

¹ I also note articles on-line like *NDIS: Ex-boss Chris Tanti shocked by costly dinners, hotels* (31 Aug. 2019) <https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=2ahUKEwiGyovK38zkAhWDbisKHQBZAXAQFjAAegQIBRAB&url=https%3A%2F%2Fwww.dailytelegraph.com.au%2Fnews%2Fnsfw%2Fexboss-shocked-by-ndis-cash-spent-on-five-star-hotels-dinners-and-limos%2Fnews-story%2F9567ccf2ce6e62e721ac071053fc8b3c&usq=AOvVaw0wu6nFbTuaSfUIG2caPmi9> and *NDIS: Less a scheme than a scam* | *Daily Telegraph*, (30 Aug. 2019) <https://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&cad=rja&uact=8&ved=2ahUKEwiGyovK38zkAhWDbisKHQBZAXAQFjABegQIAxAB&url=https%3A%2F%2Fwww.dailytelegraph.com.au%2Fnews%2Fopinion%2Feditorial-gladys-berejiklian-makes-passable-imitation-of-michael-daley-from-election-debate%2Fnews-story%2F82e13f26db1ab61592172df9ce9b1b7f&usq=AOvVaw0bja5C1vn8P37fsadcoWNT> as at September 13, 2019.

² The quote is: The more things change, the more they are the same. [Alphonse Karr](https://www.brainyquote.com/quotes/alphonse_karr_125474) https://www.brainyquote.com/quotes/alphonse_karr_125474

Jean-Baptiste Alphonse Karr was a French critic, journalist and novelist https://en.wikipedia.org/wiki/Jean-Baptiste_Alphonse_Karr as at 12 September 2019

the human story of frustration at the hands of chronic illness, repeated hospitalisation and effective institutionalisation.³

While the NDIS would assert that it does not institutionalise anybody, the existence of your disability is not something you as an individual have a choice in.⁴ As I have said to this committee before, the choice not to enter the NDIS was never a viable one for me because of the extent and nature of my disability. For the Agency to claim it does not or has not institutionalised me (or many others) is laughable. It has.

You do not need physical walls or doors to hold someone with a disability in your custody. You simply need to establish an administrative framework upon which a client group will be made dependent. Both providers and participants in the NDIS are reliant on the Agency, while for better or worse (much worse in my view) participants will be dependent on NGOs.

And if National Disability Services (NDS) represents the best of disability advocacy bodies, then it is hard to see why I or any other person with disability should accept any claim that these advocacy bodies represent us, or that we should have to be dependent on them or their banker the National Disability Insurance Agency. Based on media reports cited NDS should not be recognized in any representative capacity. They should have all NDIS funding withdrawn. And just as Patient R questioned the control of every aspect of what passed for his 'life' in the hospital, the same could be asked of the control the NDIS has over the 'lives' of scheme participants and their families, through the mandatory NDIS Participant Plans.

While we are doing that, probity and competence questions should be asked of all NGOs and their staff. Given ongoing revelations about Bupa Aged Care⁵ no-one should think that NDIS providers are

³ See Hastings Center email <https://mailchi.mp/thehastingscenter/hastings-partners-on-unprecedented-genetics-resource-hub?e=1a166b26fc> as at 12 September 2019

New in *Hastings Center Report*: Patient as Gift

"I had cared for him many times in the past," writes a physician about an extremely difficult patient. "He had been sick for nearly three decades and was a constant presence in the hospital. Among house staff, he was notorious. During sign-out, the residents would eye the list of patients, spot Mr. R's name, and sigh. Sometimes they'd groan. If they verbalized anything, it was usually to the effect of, 'Oh, I took care of him before. He's tough.'" But once the physician listened to him tell his life story – starting with his devastating diagnosis at age 40 and what it meant for him to lose nearly everything to illness – her view of him changed, and so did he. [Read the essay for free.](#)

The Patient as Gift: <https://onlinelibrary.wiley.com/doi/10.1002/hast.1027> as at 12 September 2019

⁴ If Australia spent more on research, many could realistically hope to live without impairment. Refer to Appendix 1, which accompanied my prior submission. There are also clear alternatives emerging to the hiring of human carers – see *Robots Could Be Key To Managing Australia's Ageing Population*, <https://10daily.com.au/news/tech/a180521pcg/robots-could-be-key-to-managing-australias-ageing-population-20180523> and *EXCLUSIVE: The Leading Tech That's Bringing Companion Robots To Life*, <https://10daily.com.au/shows/10-news-first/queensland/v190830slecn/exclusive-the-leading-tech-thats-bringing-companion-robots-to-life-20190830> as at 13 September 2019.

This is important because as my mother and I age, we will become increasingly frail, vulnerable and available to those with dark intentions inhabiting the NGO sector.

⁵ See e.g.: *Bupa Aged Care faces ACCC action over alleged false claims at aged care centres*, By business reporter [Stephen Letts](#) Updated 16 Apr 2019, 2:49pm <https://www.abc.net.au/news/2019-04-16/accc-takes-action-against-bupa-aged-care/11018960>; *Bupa makes formal apology for aged care failures*, By Nick Grimm on AM, <https://www.abc.net.au/radio/programs/am/bupa-makes-formal-apology-for-aged-care-failures/11508586> as at 13 September 2019

any different; the *Daily Telegraph* front page article which prompted this submission adds weight to my belief that the disability sector is as 'broken' as the aged care sector. Yet all governments continue to fund appalling service with obscenely large amounts of taxpayers' money. This should stop right now and, a complete audit conducted of all NGOs receiving public funds, regardless of whether this funding is direct or via a tax expenditure. We then need to work out whether the NGO has a representative client base that still wants it to exist.

Note however, it should be service users, clients, families and carers who determine an organisation's future, not the gaggle of self-interested, high maintenance 'do-gooders' who can too often constitute the Board or Executive Committee. On this basis, I would be happy to see NDS, as well as many other advocacy and charity groups pass into history. After all, many of the same people advocated for the NDIS. While paying with their jobs and careers in the NGO sector hardly seems to be enough, it is a start.

Every Australian deserves better than what is on offer from the NDIS. This is regardless of whether you are elderly, disabled, chronically ill, caring for someone in any of these situations, or a taxpayer having a hole burnt in your pocket. Yet, our governments continue to prop up 'the same old (charitable) suspects'. Why? It certainly can't be justified as effective or humane public policy. Furthermore, it is the bureaucracy of the charity sector that is benefiting from this administrative shemozzle not people with disabilities or our families. And what can we expect the future to hold? Cartoonist David Pope put it aptly in 2017 with this:

[But THIS time, it'll work...](#)

Posted on [May 3, 2017](#) by [David](#)

[*Rorts and blowouts: the folly of public subsidies to private providers of "human services"*](#)



(Public Sector Informant, May 2017 | [Gallery of most recent cartoons](#))⁶

⁶ Taken from *David Pope cartoons* <https://www.scratch.com.au/tag/ndis/> as at 13 September 2019

My only comment on the cartoon is that there is little reason to see not-for-profits as any better. They can lose and misappropriate funds (as well as commit all other forms of abuse⁷) just as readily as anyone else, while benefiting from tax exemptions at the same time.

In conclusion, the charitable model is broken. It should not enjoy public confidence, and nor should it enjoy continued public funding under the NDIS. The NDIS should have inserted into the legislation a clear and legally binding objective to aim to cure all forms of impairment and disability. The Parliament should set a real-time date for this action and the Agency should be forced to report annually on the implementation of technology like robotics, exoskeletons and cellular technology leading to the expansion of regenerative and preventative medicine. As I have said in a number of places, we should aim for a world where disability is an artefact of history.

The NDIS Agency should have to report against these aspirations every year to Parliament. If clear progress is not being made the executive and board members of the NDIA should be subject to punitive measures such as a Parliamentary enquiry and the cancellation of all salaries, bonuses and benefits for that year. The government should not be afraid of including in the legislation a section which allows and officer's entire year earnings to be recouped for such a performance failure. We have seen the Closing the Gap annual report show that many gaps are not being closed. Yet no punitive action for nonperformance seems to be taken against the leadership of responsible agencies. What is the point of having the report, seeing the failure and, there still being no consequences for those responsible?

I want to see the same dynamic in disability services under the NDIS. However, I also insist that any annual report to Parliament means nothing unless a failure to meet designated targets has real and lasting consequences for the officers responsible in an agency or department. Given the dependence of people with disabilities like me on the NDIS (whether we wanted to be here or not) the failure of the Agency to deliver not just on day to day things, but also on any long-term vision of improving the health and well-being of people, will only be improved when agency officers feel their failure in the hip pocket.

The same should be true when it comes to allegations of abuse and neglect against NDIS participants. The legislation should reverse the burden of proof and, again responsible officers in both the NDIS Agency and the NGO service providers should be held personally liable for any damages and legal expenses as a consequence of prosecution. This is important because the admissibility of evidence from people with disability can often be challenged and adding to this the expense, physical access and numerous other difficulties of interacting with the court system, there are no doubt many cases which should be litigated that are never brought.⁸

Making those in charge of the NDIS personally liable for these cases (and not only piercing but permanently removing the corporate veil) is the only way, in my opinion, that people with disabilities and their families can begin to feel a degree of safety under the NDIS. Adding this to the

⁷ The line-up of scandals about disability 'service' providers just goes on and on. See e.g.: *Townsville man steals \$50k from disabled patient, spends it on Xbox, flowers and alcohol*, By [Chloe Chomicki](#), Updated 7 Aug 2019, 4:30pm <https://www.abc.net.au/news/2019-08-07/carer-ndis-patient-stolen-townsville-court/11391690> and *Occupational therapist arrested over alleged sexual assault of woman with disability*, By [Laura Chung](#) September 13, 2019 — 9.46pm <https://www.smh.com.au/national/nsw/occupational-therapist-arrested-over-alleged-sexual-assault-of-woman-with-disability-20190913-p52r79.html> as at 14 September 2019

⁸ See e.g.: *The Rights of People with Disabilities: Areas of Need for Increased Protection: Chapter 5: Criminal Justice System* <https://www.humanrights.gov.au/our-work/rights-people-disabilities-areas-need-increased-protection-chapter-5-criminal-justice> as at 14 September 2019

clear objective to cure all forms of disability and impairment are the two elements which to my mind, would potentially make the NDIS experience bearable. We should remember that US President John F. Kennedy was prepared to set a definite target date for a manned Moon landing. Why should we not set a date for the cure of disability and impairment? While it will not benefit me, unfortunately, my nomination would be 2050. In 30 years then, people will not experience disability or impairment in Australia.

Yours faithfully

Adam Johnston

14 September 2019