Dear Commissioners,

Introduction

As a participant in the Natonal Disability Insurance Scheme (NDIS) continual references to a care economy frighten me. Whether it is in the disability sector, the aged care sector or the childcare sector, it seems that all human life and activity have been reduced to a financial transaction in the economy. One feels less like a citizen experiencing quiet enjoyment of their life and, more like a product be bought and sold on the open market. I do wonder at what point this economic framework may breach anti-slavery laws and, whether anyone has given any due consideration to such a possibility.[1]

Certainly, I have thought through, and cannot resolve the incongruity, between finding the live trade in sheep and cattle inhumane, while characterising the NDIS and My Aged Care as social reforms. Certainly, my experience has been one of being tossed between care providers and what the NDIS Agency will or will not approve. Further, despite being surrounded by paid case managers and plan managers, my mother and I spent many days emailing and, on the phone, reminding providers of services missed, or chasing applications made for equipment.[2] In the end, key choices and decisions are not mine as a participant. The key transactions, financial and otherwise, remain those approved by Agency and provider. Whether I am in receipt of products or whether I am the product, often feels like an open question.

Is this care?

This NDIS is not an easy or welcome process, even if I am disabled and dependent upon it. The (very poor) implementation of the NDIS has been an almost daily problem for me, now 52, wheelchair bound with cerebral palsy. It is equally a problem for my mother who, as she puts it, 'stopped having birthdays' a long time ago but is still my principal carer. Yes, paid workers come from NDIS providers,[3] but my mother Sally is indispensable, not only because of who she is, but

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[1] See the discussion in my submission: ACCC Digital Monitoring Inquiry, Adam Johnston submission (27 July 2021).pdf as at 13/9/2025, where I argue in part:

> With the National Disability Insurance Scheme, you have no choice but to engage with their "marketplace" much of which is now mediated online through portals, emails, and webpages, as is much of government more generally. If you also have a certain level of incapacity, you have no choice but to deal with the NDIS because it is a nationally legislated monopoly. Yet it provides no services and outsources service delivery and its disabled participants to charity. The modern charity is very much about the financial return or profit on activity, while the NDIS itself has a financial substantiality requirement in its legislation. If this is now the regime people with disability are going to be required to 'live' under, it should be subject to ACCC and State Fair Tradi ng jurisdictions. Indeed, I have had cause to wonder whether under the NDIS/charity cartel, I am the customer or the product? Either way, one potentially dubious charitable provider is much the same as the next to me, while my disabled existence generates their (untaxed and arguably immoral) profits.

[2] My commentary on the care economy will be principally NDIS-related but one only must have a cursory read of the media (print, broadcast and social) to know that all aspects of the so-called care economy are riddled with staffing and training problems, as well as allegations of abuse and neglect. Why would anyone want to be subject to that?

[3] Note that the word 'worker' rather than 'carer'. Section 5(1) of the *NSW Carers (Recognition) Act 2010 No 20* [https://legislation.nsw.gov.au/view/whole/html/inforce/current/act-2010-020 as at 26/12/2024] means my mother is a carer but that no-one else who deals with me is entitled to that description. This has never stopped organisations and individuals using derivatives like 'care worker' or 'paid carer'. Unless

because of all the gaps she fills doing all the things that are not on any paid worker's work instructions.[4] This can even involve cleaning up after themselves for some so-called workers. You get to the point where you are beyond complaining to the National Disability Insurance Agency (NDIA), non-government organisations (NGOs), the Minister (who just refers it to the NDIA anyway), the NDIS Commission or the Ombudsman. All bodies find a way to pass the complaint parcel to someone else. In the end, a complaint body will determine something 'resolved,' 'outside jurisdiction,' 'vacated through passage of time' or some other form of words to close a matter.

A complainant's views might be considered, if you had a response to a complaint, which while normal, could not be guaranteed. It was also often so delayed, that you had forgotten about a complaint (or the facts had changed so much, the complaint was irrelevant – perhaps this was the point?

The fact that the NDIS Quality and Safeguards Commission ('the Commission') had to be brought in as an amendment (more like an afterthought) to the NDIS Act is demonstrative of the

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you knew about the Act would you know the difference or appreciate the misrepresentation? (More information on *NSW Carers (Recognition) Act 2010* go to https://dcj.nsw.gov.au/community-inclusion/carers/nsw-carers-recognition-act.html as at 26/12/2024)

My reason for raising the NSW Carers (Recognition) Act 2010 is the NDIS legislation's lazy assumption of and reliance on 'informal care'. Former NSW Labor MP and Disability Services Minister John Della Bosca argued that one of his reasons for involvement in the 'Every Australian Matters' campaign' was because of the number of elderly parents who approached him to ask, 'What will happen to my disabled child when I die?' Della Bosca may have thought the NDIS provided an answer. For many of us though, the Scheme is an administrative Frankenstein-like behemoth and the stuff of many nightmares in the here and now. John Della Bosca has changed nothing and neither has his Scheme.

And before you think I'm overstating it, see: https://www.google.com/search?q=why+i+hate+the+ndis&rlz=1C1CHWL_en&oq=why+i+hate+the+ndis&gs_lcrp=EgZjaHJvbWUyBggAEEUYOTIHCAEQIRiPAjIHCAIQIRiPAjIHCAMQIRiPAtIBCjQzNzIyajBqMTWoAgiwAgE&sourceid=chrome&ie=UTF-8 as at 26/12/2024. Would it really be that easy to find people saying publicly that they hate the NDIS if it was working well?

For academic confirmation of serious flaws in the NDIS, including a lack of trust between all parties, see for example, David, C., Johnson, B. & Ramcharan, P. (2024) NDIS partnership working? Paradoxes, contested spaces and aspirations of disability leaders, family carers and disability services. *Australian Journal of Social Issues*, 59, 227–243. Available from: https://doi.org/10.1002/ajs4.280 as at 26/12/2024.

[4] I have had disability workers complain to me of participants who have no day-to-day written behaviour plans and/or other management plans. What am I supposed to say? The NDIS is the mess that all Governments left as they negligently threw people with disabilities and our families to laissez-faire marketers (those clothed in the alleged benevolence of churches and charity).

These providers have been singularly good at catching taxpayers' pennies, while closing their ears and averting their eyes to the pounding of participants and families, for greater, better, faster and more reliable service. This might sound like a parody from the old British TV comedy *Bread,* but the designers of the NDIS promised a needs-based, demand driven process. Instead, we are delivered into a corrupt Ponzi scheme for organised crime, where the underworld only has to be slightly more organised than the chaos which passes for both the Commonwealth Government and the NGO sector, in order to cream billions of dollars off the taxpayer. See e.g.: *Luxury cars bought as part of multi-million NDIS fraud*, police claim, Topic: Police, Wed 22 May 2019, https://www.abc.net.au/news/2019-05-22/ndis-fraud-police-charge-five-in-western-sydney/11138928 as at 27/12/2024. While this is an example of a criminal enterprise that has been stopped, how many billions have been lost and will continue to be lost?

governance vacuum at both the political and administrative levels of the NDIA and its providers. It seems to be that if everything looks all right (at least publicly), and everyone gets paid (the sole goal of many providers) the NDIS can roll on.

But it can't and it shouldn't. There have been too many deaths under the NDIS already. If we can start with Anne-Marie Smith,[5] David Harris,[6] Jeff Barker,[7] an Aboriginal woman who was lowered into bathwater that was so hot, it severely burnt 40 percent of her body[8] and Jack Bailey, a Brisbane university student, who died from a lack of supports and an active plan. This was despite Jack, his family and friends making repeated appeals to the NDIA.[9] Meanwhile, there are the litany of deaths the NDIS admits to in public reports, such as the one undertaken for the Commission, covering the years between 2013 and 2018. The Australian Institute of Health and Welfare dataset indicated that there were potentially

> '9,062 [avoidable] deaths among 526,515 people accessing disability services under the National Disability Agreement (NDA) from 2013 to 2018'. [10]

And these are just the ones we know about, and I have not yet discussed deaths highlighted by the Disability Royal Commission ('the DRC'). The Simpson and Troller submission outline oversight regimes pre and post the NDIS, [11] all of which were and continue to be inadequate in

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[5] See ABC News, Integrity Care directors ordered to stand trial over death of Adelaide woman Ann Marie Smith, by court reporter Evelyn Leckie, https://www.abc.net.au/news/2023-12-14/integrity-care-directors-to-stand-trial-ann-marie-smith-death/103230252 and more generally https://www.google.com/search?q=anne+maire+smith&rlz=1C1CHWL_en&oq=anne+maire+smith&gs_lcrp=EgZjaHJvbWUyBggAEEUYOTIJCAEQABgNGIAEMgkIAhAAGA0YgAQyCQgDEAAYDRiABDIJCAQQABgNGIAEMgkIBRAAGA0YgAQyCQgGEAAYDRiABDIJCAcQABgNGIAEMg8ICBAuGA0YrwEYxwEYgAQyDAgJEAAYDRjHAxiABNIBCjU4MjEyajBqMTWoAgiwAgHxBZhhJdvggfrI&sourceid=chrome&ie=UTF-8 as at 18/04/2025.

[6] See generally, https://www.google.com/search?q=david+harris+ndis&sca_esv=c9e5fc76374a9bb1&rlz=1C1CHWL_en&ei=FtQBaN2SCMy4seMPtJXjgAk&ved=0ahUKEwjd9bqz3uCMAxVMXGwGHbTKGJAQ4dUDCBA&uact=5&oq=david+harris+ndis&gs_lp=Egxnd3Mtd2l6LXNlcnAiEWRhdmlkIGhhcnJpcyBuZGlzMgYQABgWGB4yCBAAGKIEGIkFMgUQABjvBTIIEAAYgAQYogQyBRAAGO8FSKFVUIkTWNlEcAF4AZABAJgB7QGgAccHqgEFMC4zLjK4AQPIAQD4AQGYAgWgApYIwgILEC4YgAQYxwEYrwHCAg0QLhiABBhDGNQCGIoFwgIKEC4YgAQYQxiKBcICBRAAGIAEwgIFEC4YgATCAhoQLhiABBjHARivARiXBRjcBBjeBBjgBNgBAcICBxAAGIAEGA3CAgYQABgNGB6YAwCIBgG6BgYIARABGBSSBwUwLjMuMqAHojayBwUwLjMuMrgHlgg&sclient=gws-wiz-serp as at 18/04/2025.

[7] See Bill Shorten MP, Press Release: Another tragic death by neglect in the NDIS, 28 June 2021, https://www.billshorten.com.au/news/bill-s-media-releases/another-tragic-death-by-neglect-in-the-ndis-monday-28-june-2021/ as at 27/12/2024

[8] See Joanna Woodburn, Federal Court action against disability care provider Live Better after bathwater burns death, ABC Central West, Tue 26 Mar 2024, https://www.abc.net.au/news/2024-03-26/disability-care-provider-in-court-over-bathwater-burns-death/103630294 as at 27/12/2024.

[9] See Emily McPherson, Jack's last act was to ask about his NDIS plea. Now his family want action, 9 News, 28 Aug. 2024, https://www.9news.com.au/national/jacks-last-act-was-to-ask-about-his-ndis-plea-now-his-family-want-lessons-to-be-learned/40089ca1-983e-4bf9-97bc-e81bac22443e#:~:text=Now%20his%20family%20want%20lessons%20to%20be%20learned&text=Jack%20Bailey's%20family%20and%20supporters,he%20needed%20it%20the%20most as at 28/12/2024.

[10] NDIS Quality and Safeguards Commission ('the Commission') Potentially avoidable deaths of people with disability in Australia in 2013-2018, Last updated 18 December 2024, https://www.ndiscommission.gov.au/about-us/what-we-do/research-and-investigations/death-people-disability#:~:text=This%20report%20summarises%20the%20findings,NDA)%20from%202013%20to%202018 as at 28/12/2024.

[11] See Submission to the Disability Royal Commission from Jim Simpson [Council for Intellectual Disability] and Julian Trollor [Department of Developmental Disability Neuropsychiatry UNSW Sydney], Review of Deaths of People With Disability, 24 March 2023,

my view.[12] Also, while I have been involved in academia,[13] I do not approach this submission from an academic perspective but a personal one.

How can I not fear the correlation and apparent causation between disability comorbidity and premature death. This is particularly when Simpson and Troller observe:

> 'Of particular concern is that a high proportion of the excess mortality in these populations is potentially avoidable- for example, the overrepresentation of deaths due to injury and poisoning among the autism cohort, and the high proportion of deaths due to cardiovascular disease, infections and respiratory causes in people with intellectual disability. In [other] work published..., 38% of deaths of people with intellectual disability were found to be from potentially avoidable causes (Trollor and others 2017)– a figure more than double that of the general population. Data linkage research has similarly revealed high rates of potentially avoidable deaths among Western Australians

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https://disability.royalcommission.gov.au/system/files/2023-09/Review%20of%20deaths%20of%20people%20with%20disability.pdf as at 30/12/2024. This is taken from the webpage Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ['the DRC'], Review of deaths of people with disability, Publication date 25 September 2023, Commonwealth of Australia, https://disability.royalcommission.gov.au/publications/review-deaths-people-disability as at 30/12/2024.

[12] I acknowledge that I had a personally, very successful career of about 8 years with the NSW Ombudsman from 2004 to 2012. From law student to complaint handler to project officer and researcher, I was lucky to be surrounded by colleagues and an Ombudsman in Bruce Barbour, who were prepared to risk my employment, throw interesting, unusual projects my way, and see what I would do. The number of times they renewed my contract, often in times where the State Government was calling for efficiency dividends, was a great source of pride and confidence. I survived many of the cuts and, even when this was not the case, re-applications for positions vacant, soon had me rehired.

One opportunity came when the NSW Community Services Commission became the Community Services Division of the NSW Ombudsman. Hearing some horrendous allegations from aged parents, siblings and others about the filthy, abusive, violent and neglected condition of people living in disability group homes, I could scarcely believe what I heard or the notes I took. Regardless, these were then referred for potential investigation by the Ombudsman (meaning a delegated Investigator) or referred to an Official Community Visitor, as deemed appropriate. The system worked to a point, but it relied on peoples' ability and willingness to complain, as well as both resources to both investigate and conciliate/resolve matters. Equally, there was never enough time, money or people, so cases had to be triaged.

No doubt, the NDIS Commission does likewise today, but the DRC shone a light on the many things being missed, and the dark results for those who could not complain. In many ways, the NDIS takes the same problem, gives it to a national commission, but does nothing to change or improve the problem. In my own interactions with the NDIS Commission, you are waiting so long after making a complaint, that you've even forgotten about it, the provider/worker/other has moved on and, on these or another basis, the Commission closes the matter. So, what is the point?

[13] While my PhD studies did not end as I had hoped or planned, I am still proud of the body of scholarship I was able to produce at Macquarie University, Sydney, if not a final tome (for a variety of reasons, many of which are not important anymore). Time confirmed my fears of the NDIS as a folly of both social and economic policy. See URL: https://web.archive.org/web/20240803030352/https://researchers.mq.edu.au/en/persons/adam-johnston?utm_source=email&utm_medium=email&utm_campaign=sharelink as at 30/12/2024. While I may no longer retain a personal page (as neither a student or employee of the University) much of my work can still also be found at https://researchers.mq.edu.au/en/searchAll/index/?search=Adam+Johnston&pageSize=25&showAdvanced=false&allConcepts=true&inferConcepts=true&searchBy=PartOfNameOrTitle as at 30/12/2024

> with intellectual disability, including an overrepresentation of deaths from influenza/pneumonia, epilepsy, and cellulitis'.[14]

How can we draw but the darkest of conclusions about NGO care, when we add to the above, the story of a child supposedly in respite care being hit and killed by a train?[15] Meanwhile, other major providers like Life Without Barriers (LWB) seem only too willing to eschew responsibility for a range of basic care and management responsibilities.[16] Why should any of these widely reported incidents, give us with disability or our families any confidence about the competence of NGO staff that the Federal Government and the NDIA have chosen to rely on?

Government abandons its citizens.

This was after all Australian governments actively removed themselves from having any direct service delivery capacity of their own. This was something I[17] and others[18] have been citing as a deficiency for many years. Even a review by the NSW State Parliamentary Committee has recommended that:

> 'the NSW Government reinstate its role as a public sector safety net to capture people with disability, particularly those with complex and challenging needs [and] the NSW Government be established as a service provider of last resort to the National Disability Insurance Scheme to ensure crisis situations are managed appropriately [and] the NSW Government address service gaps by investing in services and supports for people with disability, regardless of their eligibility for the National Disability Insurance Scheme.'[19]

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[14] Jim Simpson and Jullian Troller, op. cit., p.1.

[15] See Celina Edmonds and Evan Young, Civic Disability Services chief apologises to family after 'entirely preventable' death of 11yo autistic boy, Thu 16 Feb 2023, https://www.abc.net.au/news/2023-02-16/civic-annie-doyle-apology-disability-royal-commission/101984668 as at 31/12/2024.

[16] See The DRC, Report finds service provider failed to prevent violence and abuse against residents in group homes, 28 February 2023, https://disability.royalcommission.gov.au/news-and-media/media-releases/report-finds-service-provider-failed-prevent-violence-and-abuse-against-residents-group-homes as at 31/12/2024. In particular, the DRC observed:

> The report makes 34 findings, including that the CEO of LWB, Claire Robbs, was reluctant to accept that there had been any significant deficiency in the operations or services provided by the organisation identified by the Royal Commission. An embargoed copy of the report was provided to LWB ahead of the CEO's appearance at [a] Public hearing [No.] 32 on 16 February 2023.

[17] See e.g.: Adam Johnston, The NDIS: The Mark of Pre-War or Post-War Public Policy Making?, NewMac Conference Proceedings 2018 and Journal of Higher Degree Research Students of Macquarie University and Newcastle University 2018, https://www.bing.com/search?q=ndis+adam+johnston+newcastle+seminar&qs=n&form=QBRE&sp=-1&ghc=1&lq=0&pq=ndis+adam+johnston+newcastle+seminar&sc=8-36&sk=&cvid=559A771430984F07B4C7C0ACA3BAA69F&ghsh=0&ghacc=0&ghpl= as at 31/12/2024. Find it also at: https://novaojs.newcastle.edu.au/hass/index.php/humanity/article/view/63 as at 3/1/2025

[18] See e.g.: Heike Fabig, NDIS: rights-based paradigm shift or same old charity?, Ramp Up 11 Apr 2013, https://www.abc.net.au/rampup/articles/2013/04/11/3734962.htm as at 31/12/2024

[19] New South Wales. Parliament. Legislative Council. Portfolio Committee No. 2 – Health and Community Services. Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales / Portfolio Committee No. 2 – Health and Community Services [Sydney, N.S.W.]: the Committee, 2018. [x, 250] pages ; 30 cm. (Report no. 51 / Portfolio Committee No. 2

Such ideas have been consistently rejected by State and Federal Governments, as children, the aged and the disabled are shuffled off to the church and charitable sectors. Yet, this has rarely ended well, if we take any notice of the McClelland Royal Commission into Institutional Responses to Child Abuse and Neglect, the Aged Care Royal Commission and the Disability Royal Commission. A few years before all of these and some in NSW will recall the Wood Royal Commission. Justice James Wood's inquiry was ostensibly about police corruption, but this necessarily opened questions about police interaction with other agencies and the effectiveness (or not) of procedures to protect children, as well as other vulnerable people.

Our current mainstream media is not short of exposé material concerning dodgy charities and increasingly 'for profit' private equity schemes in child, disability and aged care. Adele Furgeson's reporting on the Australian Broadcasting Corporation (ABC)[20] is just one example and, its impact is ongoing.

It is truly ironic that a 2018 report and the three recommendations above (which the State Government largely rejected) are now coming back to bight us all. Now, the Commonwealth is talking about something called 'foundational' supports which the States will have to provide. But with what money?[21] I understood that all the money split between the States and the Commonwealth for what was Health and Community Care (HACC) went to the NDIS.

This funds the NDIA (alongside a Medicare levy, which is still an anomaly if the NDIS does not cover health-related matters, while increasing the cost of a health levy), as well as the operations of NGO partner organisations. Increasingly however, NGO doesn't mean 'non-

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– Health and Community Services), p. xi-xii, https://www.parliament.nsw.gov.au/lcdocs/inquiries/2496/Final%20report.pdf as at 1/1/2025.

[20] Adele Furgeson has broadcast a range of stories on the failings of child care, the NDIS and retirement villages at https://www.abc.net.au/news/adele-ferguson/102592574. Entering the search terms "Adele Ferguson aged care neglect" into Google Search also produced plenty of results: See https://www.google.com/search?q=adele+ferguson+aged+care+neglect&sca_esv=109e11df013ff453&rlz=1C1CHWL_en&ei=QrAyaI-oPL-k2roPxpnAgQI&ved=0ahUKEwiP0aiQ972NAxU_klYBHcYMMCAQ4dUDCBA&uact=5&oq=adele+ferguson+aged+care+neglect&gs_lp=Egxnd3Mtd2l6LXNlcnAiIGFkZWxlIGZlcmd1c29uIGFnZWQgY2FyZSBuZWdsZWN0MgUQIRigAUiNdFDqHViPW3ABeACQAQCYAdkBoAG5C6oBBTAuNy4xuAEDyAEA-AEBmAIJoALxC8ICBxAAGLADGB7CAgsQABiABBiwAxiiBMICCBAAGLADGO8FwgIGEAAYFhgewgIIEAAYgAQYogTCAgUQABjvBcICBBAhGBXCAgcQIRigARgKmAMAiAYBkAYGkgcFMS42LjKgB4oZsgcFMC42LjK4B-cL&sclient=gws-wiz-serp as at 25/5/2025.

Despite all the failures, we continue to allow the church, charitable and for-profit NGO sectors to continue to 'care' for the very young, adults with disabilities and the aged. A Google search asking 'how many ndis participants have died due to neglect" the response is this.(as at 25/5/2025)

While the answer is summarized by AI and relies on some Disability Royal Commission data dating from 2020, I have no real reason to doubt the 432 total. Again, if this had been the crash of two 747 airliners it would have made the international news for days and been the subject of multiple public inquiries and reviews. As the numbers represent the death of those with disability, many will barely rate a public mention. Is it any wonder that I question my safety and wellbeing under the NDIS, as well as that of many others

[21] As yet, it is not even clear that anyone knows what these are: see Foundational Supports, Department of Social Services, https://www.dss.gov.au/foundational-supports#:~:text=Foundational%20Supports%20are%20specific%20supports,5.5%20million%20people%20with%20disability as at 3/1/2025.

government organisation' to me but rather 'no goddam organisation' or, when it comes to a worrying number of staff 'no good otherwise they'd have real jobs.'

Meanwhile, governments allow bodies like LWB to continue providing care services. Why?[22] I fear that it is a variant of the 'too big to fail' argument of the Global Financial Crisis.[23] Governments throwing both taxpayer and borrowed funds at poorly managed large corporates may have cushioned the blow of the GFC for some workers but many still got hurt (read: retrenched) along the way. Now, tax-exempt corporate entities, receiving large donations and ever larger public grants are providing marginal services to some of the nation's most vulnerable people. is not an attractive look – but this is what we call governance in the NDIS. Again, I (and others like Heike Faibig, cited earlier) have repeatedly warned against the NDIS's over-reliance on charity, to little effect.[24] But governments across the nation and of all political hues, have progressively hollowed out their own agencies and infrastructure during my life.

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[22] I ask this as a service recipient, whose reassurance is that the LWB worker I deal with worked for the NSW Department of Ageing, Disability and Home Care. Therefore, I know he is trained, competent, experienced and had his background checked. It is not possible for me to feel nearly as confident about NDIS systems. Too much of that relies on individuals and families, as well as NGOs being honest with them. The DRC's comments about LWB show it is not a trustworthy or honest organization and, it is difficult to see how mandating worker or NGO registration will improve things. Again, as one has observed previously, my dealing with the NDIS Commission can be most generously described as slow, late, disinterested and encounters which left me decidedly underwhelmed.

[23] See Mark A. Calabria, Too Big to Fail, Morning Consult, July 2, 2015, Cato Institute, July 2, 2015, Commentary,

[24] See e.g.: Adam Johnston, Current Scheme Implementation and Forecasting for the NDIS Submission 91, https://www.aph.gov.au/DocumentStore.ashx?id=e7e5b939-3a5b-4b3d-8a1c-c4cd4c43fd45&subId=720681 as at 3/1/2025. Also note, Adam Johnston, Submission to Retail digital marketplace inquiry, 27 July 2021, https://www.accc.gov.au/system/files/Adam%20Johnston%20submission%20%2827%20July%202021%29.pdf?ref=0&download=y as at 3/1/2025. I wrote this arguing that there was really far more to fear from the NDIA and its providers than Amazon. In particular, at page 1 I wrote in part:

> I would argue that government itself (State, Federal and local) has morphed into a large online retailer. Citizens have become customers and public agencies as much as private business are called upon to provide a 'return' to investors, be they shareholder Ministers or private companies. Where it is an ASX company, SME or micro-small business trying to turn a profit, I have no objection. Where governments try to make profits, or they engage third parties (like charities) and then let them make largely untaxed profits, this is where I complain. These profits are generally made off the back of the neediest and most vulnerable in our society, often financed by government subsidies. As a disabled man I find this especially reprehensible and far more objectionable than anything Amazon may have done. At least with Amazon, it is my choice whether to buy a book on-line.
>
> {As highlighted earlier] With the National Disability Insurance Scheme, you have no choice but to engage with their "market-place" much of which is now mediated on-line through portals, emails, and webpages, as is much of government more generally. If you also have a certain level of incapacity, you have no choice but to deal with the NDIS because it is a nationally legislated monopoly. Yet it provides no services and outsources service delivery and its disabled participants to charity. The modern charity is very much about the financial return or profit on activity, while the NDIS itself has a financial substantiality requirement in its legislation. If this is now the regime people with disability are going to be required to 'live' under, it should be subject to ACCC and State Fair Trading jurisdictions. Indeed, I have had cause to wonder whether under the NDIS/charity cartel, I am the customer or the product? Either way, one potentially dubious charitable provider is much the same as the next to me, while my disabled existence generates

One had initially thought this would produce more tailored, targeted and efficient services, energetically wanting my custom. However, when you outsource public functions to lazy, inept third rate, third sector rent-seekers, don't expect much beyond nothing from billions of taxpayer dollars. My views changed markedly, as I experienced NGO employment services,[25] exacerbated when one of them referred me to a decidedly dodgy Registered Training Organisation (RTO) offering *allegedly* nationally accredited qualifications).[26] Therefore, one asks again how anyone in good faith could conclude that charitable dependence and provision is sufficient to make a safe and worthwhile life. I aim to show that no such conclusion is truly possible.

My views moved even further after my own experience on a major charitable board. Refer to Appendix 1. While it is purely my impressions and reflections from that time, I do not resile from any of it, even today. The needy, vulnerable, disabled, elderly and anyone else should not ever be cast off to charity.

The more things (don't) change.

Looking back through history, which one had the privilege of undertaking research in the Mitchell Reading Room in the State Library of NSW,[27] while there were points of promising scientific study and advancement sitting alongside letters, government reports and press clippings. These raised questions of abuse, neglect and fraud, sometimes alleged at a whisper, sometimes going through the courts and then every nuance and degree in-between. Looking at Appendix 2, even in a contemporary light, little has changed. Charities still provide services to the needy today, while periodic questions persist over the conduct and probity of their management and staff.

The conclusion I draw from all of this is that it doesn't seem to matter how much you tinker with regulations, standards, or training, you still end up with the same sector. Whether you call it the care sector or the care economy, it doesn't matter and does not change much. What one knows for certain is that after 10 years of the NDIS is that the care economy is where I will need to spend the rest of my days (by virtue of disability) but it won't be through choice.

Why? If past conduct is the best predictor of future conduct, then why wouldn't I have every reason to fear many NDIS providers. However, there is no viable alternative for me, my family or many other people. States have declined to re-enter direct disability service and support provision, while the *NDIA Rules* specifically prohibit anything being funded that may restore functionality and health to participants; particularly if it is experimental.[28] This means no policy-

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> their (untaxed and arguably immoral) profits. The…documents [appended to the ACCC submission] show my doubts over the NDIS, whether it has any real idea where the money goes, or whether much can be said for the probity of its charitable service providers.

[25] See Adam Johnston, Submission – Disability Employment Services Reform, DSS Engage, 2016, https://engage.dss.gov.au/des_reform_nov16-submissions/1481501406/ as at 11/1/25.

[26] See Adam Johnston, Submission PFR356 – Human Services: Identifying Areas for Reform, Productivity Commission, https://www.pc.gov.au/__data/assets/pdf_file/0005/209750/subpfr356-human-services-identifying-reform-attachment2.pdf as at 11/1/2025.

[27] I thank many staff for their generous assistance, not only in retrieving records but helping me to properly handle, sort, and copy many records over several weeks. I thank them for their patience, persistence and encouragement to the man in the wheelchair (me) with one working hand, who took hours of their time

[28] See Adam Johnston, What would Grandma Say?, On-line opinion, posted Friday 15 May 2020, https://www.onlineopinion.com.au/view.asp?article=20903 as at 29/06/2025. Also note: Megan English, Adam Johnston dreaming big, Alumni Focus, December 7, 2020,

maker seems to have thought it a noble or even worthwhile idea to free us (or by extension, our families) from the experience of life with disability.

When does life without disability become the norm for all of us? If not now, when will this happen? Furthermore, why not set this as an aim for the foreseeable future? We set national and international targets for carbon emissions, vaccination rates and declare other things to be national emergencies, and every other media story breathlessly reports a crisis. While there are notable individuals, charities or movements to prevent, cure and support those with various chronic disabilities, extended, lifelong or life shortening illnesses, there is no over-arching commitment to cure and prevent all forms of disability. Nor is such action seemingly considered urgent, much less an emergency.

Why is disability simply accepted and perpetuated? Even when we have a Disability Royal Commission, my impression was of a Final Report where Commissioners were divided on many issues. Ultimately, many questions concerning the NDIS were passed to (yet another) *NDIS Review*, while Commissioners contented themselves by calling for a more inclusive society. Isn't that what we have been doing (with varying degrees of success) for the past 30 or 40 years? What a waste of time, money and effort, if that all that is produced by years of hearings, research and submissions is a final Royal Commission document of politically correct posturing and soothing wordsmithing. One tends to think of the creation of the concept of a 'care economy' as something similar; an offering that nominally normalises and justifies chronic illness and continued disability.

My good fortune

Additionally, while I can say I have had a very fortunate life, this has been due to the advocacy of both my parents, the work of several teachers (and teachers' aides) all of whom went well beyond requirements and work hours, alongside many other enthusiastic supporters. Most came from public Schools for Specific Purposes (SSPs) and while numerous people today will decry that system as institutionalised, at its best, medical need meet scholastic support. Now, I have multiple professional qualifications and paid work. My success comes from those who loved me, provided true public service as public servants and, if charity was involved (as it sometimes was), the people concerned were benevolent in nature. Support, counsel and friendship were offered with no thought of recompense. Most of these people would not even allow me to buy them a cup of tea or coffee.

And let's underline the point. The education which set me up for life was a publicly run and funded school. Manly Warringah School (sadly closed now) had funded physiotherapy, occupational therapy and nursing, which could care for all students' complex conditions. And in an arrangement with the Correspondence School, Sydney, provided a full secondary education, even if student numbers were insufficient to provide staff for every year. The point is that the State-run care and education system worked well for my, and other children's benefit. We didn't have to check individual funding packages or seek nearly as many reports. People who provided services did things that were useful and were far less likely to leave a problem in a child/family/client's lap to sort out. These were days of public service, when Australia was described as a 'mixed market' economy and no-one had coined the phrase 'care economy'. Perhaps it would have been better if they had never done so.

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https://www.mq.edu.au/macquariematters/adam-johnston-leaving-a-legacy-for-medical-intervention/ as at 29/06/2025.

Today the NDIA is the ultimate arbiter of the monetary cost of disability but knows the value of none of it, to co-opt an old phrase. Nor does its staff (or agents) seem to care much for the ongoing costs to ageing parents (physical, financial, social and psychological), not to mention ageing siblings. Many siblings are probably fearful of entering *In-loco-parentis* situations, where the care of disabled loved ones is suddenly their responsibility. Siblings will likely have their own families, jobs, medical issues and other things with which to contend. There seems little discussion of any of this, as the NDIS leans heavily, discourteously and presumptively on 'informal carers' of all ages. Meanwhile, many NGOs in the child, disability and aged care sectors have become for-profit conglomerates, accumulating many millions in public subsidies and tax expenditures. All along, people have died waiting for services, as politicians make an ever-growing list of announcements and promises.[29] Meanwhile, for every initiative launched, another closes.[30] To those who claim that bloc funding was unreliable and subject to administrative fiat, I ask: has anything changed?

Why cure and prevention matter

Until someone in governments at State and Federal levels are prepared to say they have a commitment to cure and are prepared to fund clinical research to achieve it, why would anybody believe the hackneyed phrase of 'generational change'. We made that change when it came to things like AIDS, breast cancer and Covid-19. Too many people were dying, or at risk of dying, so movements rose up, urgent action was taken by governments and people in general. We now have effective treatments.

Why can't we find the same clarity of purpose with all forms of disability? Who said that 'living with it' could ever or should ever be good enough, for individuals or our families? Rule 7.5 of the NDIS Participant Supports makes clear that policy makers will not move beyond lifelong disability. No-one asked me or my family whether we wanted this. Nothing about disability for the sufferer or their family gets easier with age.[31] And note I use the word and concept of 'suffering'; not inclusion, not diversity nor any of other glib phraseology of contemporary parlance.

These concepts and phrases are just that – talking points. We live in the real world, not a conceptual abstraction. Perhaps this marked my departure from academic thought. You could funnel the NDIS through any number of critical theories from race theory to feminism to disability theory itself. All see the world readapted to become a place where disability is theoretically 'normal', unremarkable and presents no barriers. This is because, according to 'critical theory crew' (adding in a dash of structural oppression), barriers are 'everybody else's fault'.

This presumes, erroneously in my view, that the rest of society are somehow 'to blame' for the difficulties of disability, racism, sexism or any other perceived ill. But, if most people don't live

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[29] For example see, Elderly 'dying while waiting for home care', The Australian, https://www.theaustralian.com.au/nation/elderly-dying-while-waiting-for-home-care-labor-warned/news-story/432daf09a62517c900a105d443710e95 as at 6 July 2025; and see Manni Truu, Australians with three months left to live set to receive $25k payment to help them die at home, ABC News, Sunday 15th September 2024, https://www.abc.net.au/news/2024-09-15/new-payment-aims-to-make-it-easier-for-people-to-die-at-home/104347984 as at 6th July 2025

[30] See e.g. Mary Ward, What happens when governments can't agree on NDIS funding? They cut services, April 23, 2023**,** Sydney Morning Herald, Assistive Technology Australia to shut after being denied NDIS funding as at 13/9/2025.

[31] Note earlier comments concerning ageing parents and siblings.

with the experience of a detrimental issue, on what grounds will they find common cause with those who do? It is unlikely to come from shame, guilt or lecturing people into submission, and I don't want that anyway.

Some will argue that human empathy, dignity and our common humanity makes most of us aim to be as inclusive as we can. However, the agreement and common cause, in terms of disability, will likely come from other points too. Firstly, the NDIS has no end date, the tab is getting bigger and despite both things, no-one is getting better. By better, one doesn't simply mean is in receipt of services (even if this can be described as 'better' in some cases). What we should really be talking about is 'better' in terms of diseases prevented, cured and lifelong impairment avoided. These elements should have been at the heart of the NDIS from day one, but they were not and still are not.

Lifelong disability is something I have had to come to terms with. However, this is a situation that future generations, and their families, should not have to endure. After all, if the Christopher Reeve Foundation can talk of 'Today's Care, Tomorrow's Cures' I ask: where is Australia on this path and, when will tomorrow come? No individual or their family should have to endure lifelong disability.

Finally, it is clear from Appendix 3, that the NDIA is just another bureaucracy and no better (or less complex) than the ones it replaced. And it really has been nothing more than that since day one. So, let's stop giving it any dispensations as a new, special or innovative agency finding its feet. It is a very ordinary bureaucracy, relying on an especially ordinary assortment of NGOs. These specialise in (sometimes, but not always) delivering services which too readily come with a high price tag to taxpayers, as well as an annoyingly high rate of 'ordinary-ness'. Be assured, this is not a compliment, demonstrated by what is below.

Equally, it is not for want of reports that we can claim any lack of warning about NGO corruption, incompetence and abuse of both finances and needy people; indeed, it is a worldwide problem.[32] After ten years of coping with the NDIS I am tired and cranky of being the 'honey pot' of public money for charities cum businesses. They like the profits but retain their charitable status and pay no tax. It is time for this to end and calling time on charitable status has been a policy reform long overdue in my opinion. I have also felt safer in an isolation bay suffering full blown RSV, thanks to a wonderful Irish critical care nurse by the name of Neave, than I ever will in the hands of NDIS/care economy boofheads.

One said similar things at a hearing of your inquiry into the Philanthropic Sector. It goes on unabated and still enjoys tax-free status. For me, unless an organisation has 'finding a cure' to a disease or chronic condition as its principal aim, it should not receive tax expenditures or any other benefits of charitable status. Many who are now charitable corporates would find themselves paying corporate taxes – and it's about time!

Media reports generally indicate the Australia's productivity is flat or falling. Meanwhile, public spending (especially during Covid-19) and the size of the care economy is growing. Certainly, if Allan Kohler (ABC News Financial Analyst) and the Commission's own graphics on the growth of the care economy are to be believed, it is unsustainable.

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[32] See Amanda Zhang, The Erosion of Trust - How Scandals and Systemic Failures Have Transformed Public Perception of NGOs, June 2, 2025, The Erosion of Trust - How Scandals and Systemic Failures Have Transformed Public Perception of NGOs - CTOL Digital Solutions, as at 14/9/2025.

If we must have NGOs, they must have the same accountability measures applied to them as formal government departments. After all, this is where most of the money is coming from, which likely explains lagging productivity. While money is circulating, the last Australian charity to do something truly innovative was Fred Hollow's in bringing sight to the blind. The next in my mind would be the Christopher Reeve Foundation, and various international affiliates. These bodies aim to alleviate suffering and cure diseases, not merely sustain people in chronic ill-health.

Cured, healthy people will drive productivity and have happy, fulfilling lives. Yet, few want to talk about the potential for mis-investment in the care economy. When appearing before the Disability Care inquiry, I did point out that as we spoke, scientists were protesting outside NSW State Parliament about cuts to research funding. The then proposed $22 billion NDIS represented a real opportunity cost, which may be costing the protesting researchers dearly, while potentially ensuring disability was lifelong for many, including me. Commissioners were likely less than pleased with me, but it needed saying. In many ways, I want Commissioners to be just as discomforted today because again nothing has changed.

Examples over the past 10 years (as I've been an increasingly concerned and reluctant NDIS participant, when the NSW Government withdrew State-based services with sickening speed) include the fact that:

- my sister went out and purchased me a small thermometer for the bathtub one Christmas (in the form of a small green plastic frog with a red light on its back), after hearing a bloodcurdling cry from the bathroom one day, as a disability 'worker' almost put me in a scalding tub of water. It can 'almost' happen to any of us! We are truly that vulnerable all the time.

- 'Workers' who tell me that I taught them English. How did they ever get a rental lease, a driver's licence and work rights in Australia. And how were they ever allowed to work with disabled, vulnerable or elderly people, if they did have a reasonable command of English on arrival?

- An application for a new motorised wheelchair which has taken a year just to be approved and receive funding. Despite the first meeting with a stockist (who brought a display chair that was far too big), it has taken 9 months (and for reasons I can neither remember, nor decipher from the email chains), two physiotherapists and a report only finished in September 2024. The NDIA issued a new plan in December 2024, which was posted to me and arrived in the mail on 4th January 2025. It seemed only when my mother and I started writing emails to Plan Managers, Care Coordinators and the Minister, that things began to change. Ultimately, when we said that my 7-year-old chair was becoming painful to sit in (which it was) and that we were considering buying a $50,000 chair outright ourselves and billing the NDIS later, that the plan approval appeared. This appealed to the cynic in me but again demonstrated how little former Minister Shorten has been able to achieve in terms of the wedding cake premium (other than complain about it in large part[33]) The chair appeared 14

[33] See e.g.: Bill Shorten, Opinion: BILL SHORTEN: Unscrupulous NDIS providers have taken people with disability for a ride for too long, The Nightly, 16 May 2024, Updated 16 May 2024,

months on, and while an improvement, the fact that odd plastic pieces (but fortunately not operational pieces) have fallen off, is something I have had repaired by the supplier, along with other minor modifications.

- My first approved motorised chair (under the NDIS) was delayed by some months, discovering by accident when ringing the NDIA that there was a file note, but none of the attached reports. These had been 'lost' and I had to backtrack through my emails to find them, as by chance the then physiotherapist has seen fit to send me a copy. Had she not, the whole process would likely have had to start again. And the physiotherapist concerned had moved home to New Zealand.[34]

- An application for a manual push chair (for mobility around the family home) took so long the old chair fell apart under me (it was being held together by black electrical tape). My mother had to rush to a stockist to hire a rental chair, to prevent me potentially being bedridden for an indeterminate amount of time. We ended up purchasing the rental chair, as the chair supposedly measured for me by an allegedly 'expert' physiotherapist (two words that should not ever appear in a sentence together) did not fit under tables or through doors. This even included problems with the toilet door! I and my mother complained to the NDIA and the NSW Health Care Complaints Commission (HCCC) (about the incompetence of the fitting), particularly when the provider company for the 'fitted' chair would not initially take back their ill-fitting, useless equipment.

One could go on with more examples, but I trust the point has been made.

Conclusion.

Finally, your discussion paper mentions AI. The more the better, if it is deployed to build models that allow the prevention and cure of disease. But recent extensive media reports on the large water demands data centres have for cooling, make me wonder about AI's productive limits on one of the driest continents on Earth.[35]

Recommendation 1: It is open to the Commission to conclude that market-based theories work in the care and support sector. In my opinion they do not, and we should re-establish State-based support services. This should not only be for those in dire need of support (as recommended by the Legislative Council Committee, cited above), but for those (like me) who preferred a government-run model, where an Agency that was clearly accountable to a Minister

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https://thenightly.com.au/opinion/bill-shorten-unscrupulous-ndis-providers-have-taken-people-with-disability-for-a-ride-for-too-long-c-14691791 as at 5/1/2025.

[34] Many people working in allied health have told me over the years they are 'leaving the NDIS'. Whether for personal, professional or financial reasons, it was not the bonanza that they had hoped for. It is not necessarily any great bonanza for participants and families either, but we really don't have anywhere else to go – see e.g.: Tom Burton, 'An oasis in the desert': Why the NDIS is a mess, Financial Review, 22 April 2022, https://www.afr.com/politics/federal/an-oasis-in-the-desert-why-the-ndis-is-a-mess-20220427-p5aggq as at 9/1/2022

[35] There will likely be a natural limited to AI. This is because technology like data centres may not be an environmental positive, due to land area and water consumed. See Calls for guidelines after Greater Western Water documents reveal potential data centre water usage - ABC News and Data centres are vital for the future and AI but their environmental footprint can be a problem - ABC News as at 14/9/2025.

and Parliament retained clear responsibility for the direct (and indirect, where necessary) delivery of services.[36]

Recommendation 2: It is open to the Commission to ask whether Australia (and the Commission, in earlier reports) has forsaken the 'Cure Economy' for the care economy? Cure means science and research. And for the record, I'll take cure over inclusion any day. We prioritise cure (or remission) for AIDS, many forms of cancer and, declared COVID-19 vaccination a national and international emergency. Yet life-long disability and its physical, social, or emotional costs (public and private) do not make the grade for scientific and productive urgency. Why?

Yours truly,

[REDACTED]

Adam Johnston

14/09/2025

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[36] It should also be noted that even academic commentaries are acknowledging the burden being placed on individuals and families – see e.g.: Dickinson, H. & Yates, S. (2023) A decade on: The achievements and challenges of the National Disability Insurance Scheme's implementation. *Australian Journal of Social Issues*, 58, 460–475. Available from: https://doi.org/10.1002/ajs4.277. This text highlights the NDIS dichotomy:

> Some (people) were happy and grateful for what they had been able to receive and the outcomes for their lives and those of their families, while others reported frustration, anger, despair, disempowerment and a feeling that interacting with the NDIS constituted 'a full time job' (see e.g. Yates, Carey, et al., 2022). Importantly, some had been able to use their education or administrative skills to make the system work smoothly and flexibly for their needs (or managed to access supports who could help them do this), while others found the learning, compliance and psychological costs too high and were not able to turn the system to their advantage. And in contrast to the stated aims of those who had campaigned for the NDIS—consistency and certainty—many participants in our studies and those of other researchers (e.g. Winkler et al., 2022) lived in constant fear that their hard-won funding would be taken away from them, having experienced this themselves or observed it happening to others (see discussion of funding cuts in the previous section). Participants can appeal unfavourable decisions—we discussed rising Administrative Appeals Tribunal cases above—however this process can be expensive, adversarial and administratively burdensome (Thompson, 2022). In the context of dozens of model litigant complaints about unfair treatment, the NDIA subsequently apologised to participants whose Tribunal experiences had been 'deficient and inadequate' (Schultz, 2022). https://onlinelibrary.wiley.com/doi/full/10.1002/ajs4.277 as at 9/1/2024.

I understand the fear, loathing and full-time job aspect. Two AAT processes took the better part of two years each to roll through the AAT system. One I lost and the other I won, just before we went to full hearing. However, the win concerning vehicle modifications was based more on my mother taking a heavy fall, breaking her elbow and this being deemed 'a change of circumstances' by the NDIA. This was only after we had provided all my mother's hospital admission, discharge and surgical records, including her x-rays. This provided an insight into the caliber of people and organization I was dealing with. Much like the Three Bears and their porridge, the NDIA a level of pain, suffering and inconvenience for both me and my mother that they deemed 'just right' (or at least that's how it seemed to me).