

The Hon. Kevin Andrews MP
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Joint Standing Committee on the National Disability Insurance Scheme
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Dear Mr. Andrews

General issues around the implementation and performance of the NDIS

The first general issue around the implementation and performance of the NDIS is the often-promised freedom of choice and control, as against that the distinct lack of this in practice. As a New South Wales resident, I had absolutely no choice about whether to enter the NDIS. This was because the NSW State government decided to close the NSW Department of Ageing Disability and Homecare, transferring funds, clients and responsibility to the NDIA. I have never felt more abandoned by an elected government in my life. What hurt more was that it was my own state Liberal Party that moved with sickening haste to dispatch me off to a federal agency which was and continues to be highly dependent on the church and charitable sector for the delivery of services.

This was something I made clear in a recent NSW inquiry into the operation of the NDIS and, I stand by these two submissions.¹ It is also noteworthy that the inquiry's final report supported the establishment of a state-run service provider of last resort² – a recommendation which should be

¹ See Submission 251 at [https://www.parliament.nsw.gov.au/lcdocs/submissions/61436/0251%20Mr%20Adam%20Johnston%20\(partially%20confidential\)_Redacted.pdf](https://www.parliament.nsw.gov.au/lcdocs/submissions/61436/0251%20Mr%20Adam%20Johnston%20(partially%20confidential)_Redacted.pdf) as at 8 August 2019

See Submission 251a at <https://www.parliament.nsw.gov.au/lcdocs/submissions/61437/0251a%20Mr%20Adam%20Johnston.pdf> as at 8 August 2019

² See 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 : Final report (Ordered to be printed 6 December 2018 according to Standing Order 231) <https://www.parliament.nsw.gov.au/lcdocs/inquiries/2496/Final%20report.pdf> as at 8 August 2019. Note particularly, Recommendation 12:

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.

taken up as a matter of urgency by the State government, but which to this point has been rejected.³ It would seem to me that increasingly governments at the state and federal level want as little to do with their own citizens as possible. You are far more content to dispatch us off to the church or charitable sector and then throw taxpayer dollars at these organisations.⁴ You claim that this gives the disabled an ordinary life. I can assure you that with every year that passes under the NDIS that life becomes ever more ordinary, ever more miserable and, ever more difficult for people with disabilities and their families.

Nobody bothered to ask either me or my mother whether we wanted to leave the state-based service. Nobody bothered to ask me whether I ever really wanted an NDIS,⁵ though this gives me the opportunity to cite two submissions I gave to the Federal Parliament advocating against the establishment of an NDIS.⁶ Given what has occurred subsequently one feels now justified in saying "I told you so!" While many may have supported (and still support) the concept of an NDIS, the reality is very different. My view has always been that it is an oppressive, centralist and ultimately a fiscally unsustainable regime. I also note that it appears to have grown an unfortunate subculture of assessors, advisors and planners amongst others, who are making money out of the unfathomable fog of regulations, guidelines, specialist reports and plans which are foisted upon people like me and our families.

While one has had to deal with many such people, I find their role and the necessity for them as being one of the great failures of the NDIS – and many of them to be reprehensible. Again, there was many a politician and activist who talked about the NDIS making people's minds easier and simpler. The exact reverse has occurred. I must now deal with planners who, every 12 months will have a veto over almost every aspect of my life. If this happened to any other person or group it would potentially be regarded as a breach of privacy, a breach of human rights, an assault (if not battery) or even some weird form of voyeurism. However, as it is NDIS planning, it is all strangely lawful. Never

³ The Government response said:

NSW will also continue to actively work with the NDIA to support its work to establish its Maintaining Critical Supports capacity, and to strengthen the Participant Pathway for participants with specific needs. The Committee's recommendations that the NSW Government be established as a service provider of last resort to ensure crisis situations are appropriately managed (Recommendation 13) and reinstate its role in delivering specialist disability supports, particularly for those with complex and challenging needs (Recommendation 12), are noted. However in the context of the NDIS, the Commonwealth retains primary ongoing funding responsibility as provider of last resort and for providing a safety net for participants.

<https://www.parliament.nsw.gov.au/lcdocs/inquiries/2496/NDIS%20-%20Government%20Response.pdf> as at 18 August 2019

⁴ As a result, I ask whether I and indeed all people with disability are still citizens of Australia? It seems we have been reduced to some lesser status – See Adam Johnston, The NDIS: The Mark of Pre-War or Post-War Public Policy Making?, NewMac Postgrad Journal

<https://novaajs.newcastle.edu.au/hass/index.php/humanity/article/view/63> as at 18 August 2019

⁵ I had prepared the attached ministerial memo for a meeting with then NSW Minister for Disability Services Andrew Constance, as a preliminary document to a meeting where I unsuccessfully attempted to persuade him not to proceed with the NDIS in NSW.

⁶ See Senate inquiry National Disability Insurance Scheme Bill 2012 – Submission 440

<http://www.aph.gov.au/DocumentStore.ashx?id=dc64c892-b41d-48b5-9916-7f4b90e71ee3> (Principal submission) <http://www.aph.gov.au/DocumentStore.ashx?id=c59725d8-263e-48d8-8fb4-60303c4280a8> (supplementary)

mind the old saying that life is what happens to you while you're making other plans, you must make a plan that satisfies the NDIS. Who is exercising choice and who is in control here?

I certainly knew it was not me. My very first planning meeting with Uniting (the local area coordinator) was memorable for one thing. It opened with me conducting a 10-minute argument with two staff from Uniting as to whether my mother should be allowed to enter our own living room where the planning meeting was going to be conducted. It was only when I insisted that firstly everything that affects me affects her (as she was and is to this day my principal carer) and that I would not proceed without her, that this matter was resolved. It is highlighted to underline to the committee that while on the one hand the NDIS and its charitable partners will include informal carers as part of their assessment of disabled persons need the support, they are fundamentally anti-the Australian nuclear family. Loved ones are expected to be silent partners; used and abused by the NDIA for its purposes but never heard from.

The only reason why I believe this conflict has not occurred again in my case was that somebody must have taken note that this was not an argument worth having with me. However, the NDIS should be held to account for its hypocrisy in how it deals with families and carers. It will lecture us ad nauseam about what it thinks we need, and how it would expect our families to continue to support us (people with disabilities), even as both parties age and accumulate the chronic conditions that tend to come with growing older. Just how cruel the agency can be was brought home to me in a two year find with the NDIS that was on the verge of going to the Administrative Appeals Tribunal.

From our very first plan my mother and I made clear that we wanted an adapted motor vehicle so that Mum did not have to lift me into our current station wagon. This was agreed initially with Uniting and listed as a goal. After the plan was submitted several months went by. As nobody contacted us, Mum and I started looking for vehicles. We found one and contacted the NDIA. This was where the problems began. First of all, they said the vehicle was not included in the plan; subsequently they claimed that vehicle modifications were included in the plan. The next argument was that I needed an occupational therapist's report to justify that vehicle modification were reasonable and necessary. Several months later a staffer of the NDIA rang me complaining that the OT's report was inadequate and that I would need to source another one. At this time, I had initiated several complaints and at least one FOI to establish where my application was up to. My mother had also taken a nasty fall, resulting in a broken elbow and had just arrived home to recuperate.

Interestingly, it was my mother's broken elbow that breathed new life into the car modification application. It was explained to me that this represented a change in circumstances. While welcome in some respects, it left a bitter taste in my mouth that the NDIA took some level of administrative comfort in my mother's pain and distress. If anything, I thought it distinctly inhumane and an example of elder abuse by the NDIS.⁷ Why did my mother have to be injured before the NDIA would

⁷ I fully expect to be abused, neglected and defrauded by the NDIA and its charitable partners myself. This was something I made clear to the McClelland Royal Commission into Systemic Child Abuse and Neglect. There is no reason to believe that the combination of vulnerable people reliant on church and charitable organisations (many of which were found wanting by Justice McClelland) will happen again in the NDIS. We will have

take seriously our claims for vehicle modification? This had been a two-year battle, during which we had lost the opportunity to purchase two potentially appropriate vehicles. And, through all of this it had been the responsibility of my mother and I to source all the professionals and ensure all the reports were provided to the NDIA. This involved uncounted hours of work, numerous phone calls and hundreds of e-mails.

When it came to a third vehicle Mum and I were not prepared to lose it. We purchased it in the full knowledge that the NDIA had not yet fully approved our proposal. The agency then criticised me for doing this and then claimed I had provided insufficient evidence of my mother's injury. When you get to the point of scanning x-rays of a broken elbow to send it to a tribunal, a point of absurdity has been reached – something a few people in the NDIA must have realised when their complaints and resolutions team rang me to settle the case and pay for the modifications. This was gratefully accepted.

However, I tell this story because it is a small example of everything that is wrong with the NDIS. Too many of its staff seem to relish the suffering of others, to the point at which I would say many of the staff and those employed by charitable partners should not be in the disability sector. One does not deal with them happily or voluntarily, merely out of reluctant necessity. I would be happy to see many individuals and organisations on a blacklist, just to be assured that one never had to deal with them again, nor would anybody else have to suffer like me.

One of the real problems with the NDIS is its structural independence from political authority. If you consult the NDIS Act, you will find that the Ministerial Council can seek advice and give direction on general policy, but it cannot intervene in individual matters. To me this is offensive; people with disabilities deserve the same (or as close as we can make it) access to political representation that everybody else takes too readily for granted. Under the old state-based system, if something really went wrong and the service was not delivered, I could make a Ministerial representation and directions could be given for whatever the problem was to be addressed. Now, to appeal the NDIA's decisions, I must go through a convoluted process of internal appeals and external appeals to the AAT and ultimately the Federal Court.

This appears cruel. While a lawyer like me can handle these demands, many people with disabilities will not have the capacity to put up a fight that I and my mother has had to ever since the NDIS darkened our front door. I would suspect that this explains the underspend of the NDIS budget – too many people are giving up too quickly because it is all just too hard. This is no criticism of them as I fully understand their thinking. It is rather a statement on how cruel and officious our government has become that some of the most vulnerable in our society are wrapped up in evermore complex red tape and unintelligible procedures to the point where they say "bugger this I won't proceed with this claim." This is the ordinary life that the NDIS is giving us and it is far from something to be celebrated. The committee should seriously consider recommending that the states and territories take back their responsibility for disability services and start treating people with disabilities like

another Royal Commission in say 30 years at which we will ask the same question: how could anybody let this happen? See Royal Commission bundle, attached

citizens and human beings. I am sick of being palmed off to the charitable sector and that being considered satisfactory.

I am also sick of being the unpaid administrator despite having a plan manager, support coordinator, service providers and an NDIS agency full of paid staff. Yet it is me (or my mother) who scans receipts into a computer to send them to a plan manager. It is me (or my mother) who has to find various professionals to write various reports as demanded by the NDIA and it is me (or my mother) who has to backtrack when one of these agencies complain that they haven't received some essential document that they need. At least under the state-based system there was a public Department of State that did most of this paperwork. Yet, under this new system the euphemism of choice and control puts all the paperwork as well as all the strain on me and my mother. This is hardly generating feelings of positive autonomy. With every passing day I feel we are being exploited more and more by State and Federal governments who want to do "reform" on the cheap, by having the end users do all the paperwork for nothing.

Over the past several years this has involved a lot of additional and unwelcome stress and strain on both myself and my mother. We are not enjoying a quiet, easy life or even a better life. We are persisting, more out of a dogged determination to prove the NDIA and its incompetent, frustrating and unbelievably tardy staff wrong. To underline the point, a current problem I am having relates to an application for a new motorised wheelchair. The current one I have dates to 2011 and is showing its age. A service provider helped me to organise an occupational therapist to provide a report to the NDIA on the necessity for a replacement.

This report was provided to the NDIA in March; when the current chair broke down in June, I rang the NDIA to have them fund some repairs. At the same time, I enquired about the status of the application for a new chair. While a file note could be found, there were no documents attached to it. It was necessary for me to resubmit the documents which had been provided to me by the occupational therapist and, which she had provided directly to the NDIA in March. I knew this because I had been copied into the relevant e-mail. This itself generated a delay, as staff of the NDIA send an e-mail reply to me asking whether I approved of the application being submitted. I queried why they thought it necessary to question me when I had been copied into the e-mail and, how it just didn't make sense for me to get all the trouble of finding somebody to write a report and then not approve of its submission. Heavens only knows when this matter will be resolved; likely I will have to be re-measured for a further new chair by the time the one on order shows up.

One wonders what this is really all aimed towards. In my less charitable moments I suspect bureaucrats and politicians alike set this scheme up with a mind to ensure that only the fittest or most stubborn would survive in making their claim for NDIS funding. Equally, it has occurred to me that the strain I have felt and that no doubt has been experienced by my family may well have taken otherwise happy and healthy years of the length of all our lives. Was that the intent of the NDIA? I am certain that this is the experience of many other people with disabilities and their families. This should be recognised for what it is: a form of abuse. And it is a form of abuse made all the more grievous by the fact that exactly the opposite was promised.

The NDIS has not made my life easier, simpler or better. It has not made my family's life easier, simpler or better. While we may have obtained certain pieces of equipment and support from it, all of these initiatives had to be started by us, we had to locate professionals to provide technical and other reports and, when NDIA staff found these documents inadequate, it again fell to me (and my mother) to prepare appeals and complaints. Such processes need to be measured not in the weeks or even months but years. The state-based system, even at its worst, could not be accused of doing things quite like this.

I think the Productivity Commission prepared a report on disability care from a fundamentally false premise. This asserted that disability care could be made an economically viable venture. Given that many people with disability are unemployed and on fixed incomes, this was always a fallacy. I would equally say that time has demonstrated the Productivity Commission's other apparent belief that the establishment of the NDIS would generate economic growth, a vibrant service system and, employment for people with disabilities, was also fundamentally flawed. I stand by submissions made to both the Productivity Commission and the pre-budget process pointing out these issues.⁸

If this committee wants to do something positive, it must start dealing with the reality of disability services and not the politically correct fairy tale presented by many advocates. The NDIS will never work and, is doing much harm. It is time to re-establish state-based services and to make sure that everyone who needs it gets a basic level (or minimum standard) of disability support. We should no longer build silos about who has significant disability and who does not. This could also allow planning meetings to become a voluntary feature of the NDIS, or whatever might succeed it. If there was a basic basket of services, then you would only need a planning meeting if you wanted specific additional services.

We also need to stop drawing a strict dividing line between health and disability. My cerebral palsy is as much a disability as it is a health problem. Cerebral palsy confines me to a wheelchair. It also restricts my mobility, means I wear spectacles, take medication for epilepsy and have circulatory difficulties. There can be no rational demarcation between what is health and what is disability. Under the old state-based system, two departments at the same level of government could more readily coordinate needs for people with disabilities who found themselves in either the health or disability system or both at once.

If you are thinking, when will he say something overwhelmingly positive about the NDIS, please do not hold your breath waiting. My experience with the NDIS has not been positive and, I am not going to sugarcoat it because some people say: "this NDIS is the only one we've got" or "we have to make

⁸ See Submission: Introducing Competition and Informed User Choice Into Human Services at https://www.pc.gov.au/_data/assets/word_doc/0006/209760/subpfr356-human-services-identifying-reform.docx as at 8 August 2019

See Pre-Budget Submission at https://consult.treasury.gov.au/budget-policy-division/2018-19-pre-budget-submissions/consultation/view_respondent?sort=excerpt&order=ascending&uuld=519819481 as at 8 August 2019

this work". I will not submit to that sort of argument because it is not true. We had an imperfect, sometimes frustrating, but ultimately salvageable state-run system. At least in New South Wales, we wantonly destroyed it. People with disabilities and their families are far worse off as a result.

Finally, the most soul-destroying part of the NDIS is that there is no vision. When I refer to no vision what is meant is that there is no plan for improvement on an individual or corporate level of the lives of people with disabilities or their families. The legislation makes disturbingly clear that the agency will not fund anything that improves a participant's physical functioning or could be described as cutting-edge science because of the scheme's essentially risk averse structure. This guarantees disability being perpetuated indefinitely. We can never hope of a world where the experience of disability goes the way of smallpox, whooping cough or polio. In all three examples, doctors and scientists have worked assiduously to eradicate these diseases from human experience through vaccination.

In some respects, this fight goes on, but many people are living healthy lives because of the researchers who have translated their discoveries into clinical practice. This takes testing, this takes risk, this takes hope and, it requires a vision that things can and should be better. The NDIS fails spectacularly to deliver anything like this and its proponents, as well as all of those who enacted it, should be condemned for consigning people to lifelong disability without hope of relief. This was my argument at a Sydney University conference on consumer involvement in health research and, the program, my paper and my presentation slides are attached as appendix 1.

Again, this is offered to show another serious flaw in the NDIS as well as an alternative vision of what could and should have been done. We should aim unreservedly and unapologetically for a world where disability, in all its forms, is no longer part of the human experience. We have the talented young scientists with the capacity to achieve this, if we fund and promote their work sufficiently. As a nation, Australia does not do that at all well. We must improve and, we must learn not to accept disability as a part of life. I may not live to see that day, but I will certainly do everything I can to bring it about sooner rather than later.

Recommendations:

1. That the Committee recommend the Commonwealth devolve disability services back to the states and territories;
2. That the Committee recommend that state-based providers of last resort be established, as recommended by the New South Wales Legislative Council;
3. That the Committee recommend that unnecessary silos in the NDIS be abolished. This would involve setting a minimum service standard that all people with disabilities would be entitled to and, dispensing with the concept of significant disability, as well as the need for individual planning unless a particular person sought additional services;
4. That the Committee recommend that state and federal governments re-evaluate the place of churches and charities in service provision, in light of the findings of inquiries like the McClelland Royal Commission into child abuse;

5. That the Committee recommend to all governments that drawing distinctions between health and disability is unhelpful and unproductive, particularly for people with disabilities, who must deal with both all of the time;
6. That the Committee recommend to state and federal governments that far more resources be committed to medical research and scientific enquiry, with the objective of eliminating all forms of disability and impairment from the human condition.

Yours faithfully,

Adam Johnston

8 August 2019