**From:** Adam Johnston <adamdj1@optusnet.com.au>
Sent: Tuesday, 13 July 2021 1:27 PM
To: AGENCYPOLICY <AGENCYPOLICY@ndis.gov.au>
Cc: 'DRC Submissions' <DRCSubmissions@royalcommission.gov.au>
Subject: Response to consultation paper- Home and Living

Cc: Disability Royal Commission

Dear Sir,

As a middle-aged man living with cerebral palsy, your consultation paper frightens me. Firstly, you rule out (on page 4) 24 hour or 1:1 support. Yet, throughout the document you keep referring to an ordinary life at home. This rationale begins to fall apart when you consider that if we were enjoying an ordinary life, for starters, we would not be disabled.

Secondly, you refer to notions of independence. All people are interdependent to a certain extent. Would NDIS participants need care or an NDIS Agency if we were truly independent? No, we would not. Before you suggest that disability support services or assistive technology make independence possible, this is true only while such things remain available. If a service provider fails to show up or a piece of equipment breaks down, the NDIS participant could find themselves left in a bed, on a toilet or stuck in a bath to name but a few possible predicaments. Therefore, I reject your notion that what the NDIS provides is an ordinary life or independence.

‘Independence’ for those of us disability is a notion mediated by an absolute dependance on others, which would be foreign to the 80 percent or so of people who do not experience disability. It is also a factor governed by the reliability of other people and the vagaries of their lives, which I do not control. I can have no or little notice of such things, before any number of the predicaments mentioned above (or others) apply. It is time to see the phrase ‘independence’ for the cruel fiction that it truly is. Also, in the time of COVID, it has become clear to all people that true independence and freedom relates to the capacity to travel from your home at will. Many people with disability did not enjoy such freedoms prior to COVID. Even in my own case, accessing services was one thing – contorting your own life, engagements, and ablutions around when ‘the next provider/care worker will show up (we hope)’ is something requiring military planning and a strong physical constitution. These days, I eat lunch and morning tea in the mid-afternoon, so one can avoid shitting one’s pants before the 4:00pm toilet service.

If the NDIA wants to tell me this is ordinary life and I am independent, then go ahead. I will simply ask you to justify your stance, pointing out that a good marker of ordinary life is those 80 percent of people not experiencing disability. These people also probably don’t have to think much about ‘siloed lives.’ For those of us with disabilities, the State/Federal service dance remains, even in the age of the NDIS. Why could the Agency not make our lives easier and, where it finds an application more akin to another State, Federal or non-government service, sort out those arrangements through its own Memorandums of Understanding, rather than leaving us the participants and our families to sort out the mess?

Equally, I found it amusing how you said you would not pay for house extensions. When families are available you are only too happy to deem them informal care to reduce plan budgets, so where is the consistency? Indeed, my first Plan (another thing the 80 percent of people living ordinary lives are not required by law to make) is memorable for the two fat, bombastic women from Uniting who came to my home and attempted to throw my mother out of our living room, on the premise that they only wanted to talk to me. When I pointed out that my mother Sally was (and remains) my lifelong principal carer, this was her house, every decision made about me affected both of us and that I would not continue without her, they were suitably chastened. It is little wonder that Uniting dropped the word ‘care’ from its name. And if many of the staff in the NGO sector also dropped a few hundred kilos they would feel a lot healthier and, I would feel much safer when they dealt with me. The Uniting experience also made me wonder if the NDIA and its partners have carried a bias against the family unit? You will use its presence to reduce outlays, try to divide its members but never spend in the cause of family maintenance. Uniting, a supposedly Christian organization (at least originally) is prepared to go along with this in the name of maintaining its funding as a LAC and planning body. After all, maintaining an adherence to faith would obviously have damaged Uniting’s bottom line.

Finally, I have never met a LAC or Linkage Service who does more than give me a list of phone numbers to ring, or emails to send messages to which may never be answered. My mother is still very much the one who makes up for what others do not do and, is the one who still fills the breach when others (who are being paid) do not attend. She and I both work, with a range of paid and voluntary commitments we both like to keep. In pre-COVID days we would cancel some services if I had a full day out. Mum and I would attend to my toileting requirements early in the morning, so I could make a full day without problems and, she can do a day’s work without worrying about me too much. I have learnt to eat and drink in increasingly measured ways, so as not to upset a digestive system which is more problematic with age.

I am fortunate that Mum maintains a physical fitness regime likely to tire women half her age, knowing full well that she does it for my benefit. Yet, we have carers and support agencies hinting that only if only Mum retired from work, we rose later in the morning or retired to bed earlier in the evening, staff would be easier to find. Who is being served here and is everything really run for provider convenience? I think so and have said to Mum more than once that I think the NDIS would be happy if we rose at 12 noon and were back in bed by 1:00pm; at least then I won’t inconvenience care workers, unless they are at lunch. With some, you are forced to conclude they are always at lunch even when they are working. In summary, the NDIS cannot claim to be delivering an ordinary life at home or anywhere else. Until you are prepared to fund and facilitate functional improvements (see attached and [https://www.onlineopinion.com.au/view.asp?article=20903](https://aus01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.onlineopinion.com.au%2Fview.asp%3Farticle%3D20903&data=04%7C01%7CAGENCYPOLICY%40ndis.gov.au%7C2b38e13fbb9b4bf134dc08d945ae31af%7Ccd778b65752d454a87cfb9990fe58993%7C0%7C0%7C637617442293331682%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C2000&sdata=IgRW607JNjL0vwk2Mc2jJ9SG7FKWfE%2BlAQTaYnTlO1w%3D&reserved=0)) it is impossible to believe you are serious about people with disability having an ordinary life or independence. What is offered in the consultation paper does not go anywhere near it.

Regards



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