

To whom it may concern

Thank you for this review.

We have had our plan since May 2019. It has made a big difference to my life as a carer, and our son now has a consistent routine each day and some supports which he did not have previously. While it seems to be working for us, I still have some concerns regarding the scheme.

Please consider the following comments in your review.

Our first contact with NDIA was not positive. The phone went unanswered on many occasions, and when it was, the tone was condescending.

People with disabilities are told they are not defined by them: You are a *person* with Down syndrome; a *person* with quadriplegia. It would seem that under the NDIS, particularly at the planning stage, the labels are very much in place with requests for more information to prove said disability. I would also refer you to stories of people who have been denied NDIS funding because they are 'not disabled enough.'

The scheme is more complicated than it needs to be. I have been an unpaid carer for twenty years (a whole other issue which I hope will be addressed in future commissions). Every support and service our son had before NDIS, I sourced myself. (I don't believe the previous system was as broken as the Productivity commission would have us believe.) As a carer I thought I could operate as I had been, sourcing our son's requirements, but now because of the complicated processes, the task of ordering his continence aids went from a simple phone call and same week delivery, (with MASS and CAPS) to a three week saga involving two follow-up phone calls and chasing invoices to be signed off.

The NDIS needs to be a HEALTH scheme, not an insurance scheme. We are not wrecked cars which need to be assessed (which is how I felt going into the planning meeting). We are people with ongoing needs for support and management into the future.

My suggestion for improvement: Each participant receives a purple card which operates like a Medicare card. It is then presented to the service provider who can be paid promptly from the participant's funds and the participant receives their service/requirements without delay.

It seems to me that this review is assessing the NDIS as it has become, rather than seeking any reform. I would ask that you listen to participants and their families and find ways to simplify the process for those of us who are already burdened by their caring roles, or their impairments.

Thank you.

Raelene Purtill