INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

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Submission to the Inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in NSW

NSW Parliament

To whom it may concern,

I am a current NDIS participant who is very unhappy with my NDIS journey to date. I was diagnosed with Multiple Sclerosis in 1990 at the age of 20. Until early 2014, I did not require much support apart from that provided by family/friends during active relapses. Since this time my disabilities have worsened and my functional ability declined. Thus, I have required supports, but have received none and was told (by GPs, Neurologists, allied health workers, the MS Society etc. etc.) to "wait for the NDIS". The NDIS rolled out officially in my area in July 2016.

I finally received my first plan on 27/10/2016. I then spent the next 13 months (and 4 'reviews') attempting to get errors/oversights/unreasonable decisions made in this first plan rectified.

I then requested a change of circumstances review in April 2018. This was primarily because I had moved (into a home in October 2017 that had been awaiting a project home company to build since I first engaged them in 2013). After finally ascertaining what NDIA process I needed to follow, as well as submitting all types of reports and documentation, then following up the NDIS on repeated and numerous occasions, I received an email & form letter on 25 June 2018 stating they were "pleased to let me know" that my NDIS Plan has been approved. This plan and communication did not address the specifics of my review request, rejected much of my requests, provided little meaningful explanation of what had/hadn't been approved, contained several "planner oversights" and has rejected Assistive Technology/minor home modifications recommended by an NDIS registered Occupational Therapist. In an email from the planner, they have suggested I instead install a piece of assistive technology I do not need, and cannot be safely used unless in a wheelchair (which I am not!).

I am a person with a disability who requires supports now. The delays, process issues, bureaucracy, lack of knowledge, lack of ownership, and on many occasions unprofessional and superior attitude of some NDIA employees, means I experience unreasonably long delays in obtaining the supports I require, not just because they're "nice to have" but just to function and be safe.

My experience has been largely unsatisfactory, and caused me unnecessary stress and hardship. How a scheme could have been rolled out to a group of vulnerable people, that is so alarmingly ill thought out, ill equipped and inconsistently executed terrifies me. In my opinion it has none of the basics. Things like User Documentation, tested and documented procedures for all users, forms, education and training for NDIA staff/contractors, providers and participants /carers. Basics.

What follows are some key unsatisfactory elements of the scheme I have experienced:

- Inadequate knowledge of decision-making employees of the participant or their disabilities.
- Inconsistently applied judgements and operating guidelines that argue with themselves.
- Attitude of NDIA staff condescending & judgemental. It doesn't inspire confidence in their ability to do the job or that they are acting without bias.
- Ridiculously long processing times supports/assistive technology/ home modifications etc. are requested based on current (and often long unmet) needs.
- Inadequate/non-existent communication between the NDIS planner/LAC and participant regarding their plan, or plan review a review request, when finally assigned, and finally processed after an excessive amount of follow up on the participants part, is inadequately "answered" with a form letter (that doesn't address any of the specific requests of the review form) and a new plan, which doesn't use the same terminology that is used in the form letter. Nor does this written communication use terms that are consistent with the portal. This has always in my experience resulted in even further delays (in working out what has or has not been granted from the review request) and therefore even further delaying addressing any errors/discrepancies/inadequacies. There is no process to adequately inform the participant of the detailed results of their review.
- No processes are documented for participants. I can't meet the NDIA's requirements if they don't tell me what they are! Processes aren't documented or transparent to PWDs, are vague and nebulous. Website, LAC's and NDIA employees give conflicting information.
- A complaints process that channels back through the same inadequate system and processes that you are complaining about is a waste of time.

• Long and unreasonable delays for equipment/home mod requests. Both times I've requested such supports, I've supplied all required professional reports, only to have them denied, without adequate explanation, or advice on the next steps I should take. Just saying in a form letter than you can "request a review of a reviewable" decision, (another lengthy broken process that last time took six months to process). During these periods without the required supports, I am being placed at risk of injury, not to mention poor quality of life. This is a failure in duty of care. It also has further social ramifications for my children and husband.

I have tried many avenues to resolve my concerns: my local federal member, my LAC, the NDIS contact centre, requests for escalation, advocacy supports, the MS Society. Most have been unhelpful and simply channelled me back through a complaints process that is governed by the same agency that I have a complaint about! There is no circuit breaker.

There is no impartial watchdog.

Furthermore, the scheme has been rolled out and other disability services simultaneously cut (i.e. advocacy, transport, block funding etc.) with little or no transition periods.

I am well positioned in that I can self-advocate. Many cannot.

I am happy to speak further on any of these matters in the hope that this scheme can be fixed.

Sincerely,

Jacqui Funnell