Submission
No 232

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

Name: Ms Natalie Atherton

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Natalie Atherton,

Hon Greg Donnelly MLC
 Chair
Portfolio Committee No. 2 – Health and Community Services
NSW Parliament
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Dear Hon Greg Donnelly MLC,

I am the parent and carer of a 15-year-old daughter with severe intellectual disability (nonverbal and incontinent). I welcome the opportunity to provide information to the inquiry hoping it will improve the implementation of the NDIS, my observations and experiences are from the view point of a parent carer. The NDIS is a much needed and ambitious program of social change, however, the needs of the individual are as important as the goals of the whole.

My submission will focus on the following areas:

1. Lack of capability within the disability community (people with a disability and their carers) to successfully navigate a very complex system and the need for support services and advocacy to ensure people are able to lead successful lives under the new system.
2. The Assistive Technology and Home Modifications component of the scheme in NSW is overly bureaucratic, does not represent value for money and most importantly is not meeting the needs of people with a disability (PWD).
3. The annual planning process is stressful and complex.

The core NDIS values of "choice and control" are of upmost importance. They are principles that all members of our society aspire to and most achieve. However, it is not enough to simply give disempowered people a pot of money and a complex set of rules and regulations, that are constantly changing, and expect them to flourish. Some PWD and their carers have existed for decades, sometimes a life time, of being told what to do, what they can and can't do, and when to do it. To successfully manage the NDIS one needs to :-

- be literate,
- learn a new bureaucratic language,
- have the interpersonal skills to communicate to a planner or LAC effectively,
- coordinate and present documentation,
- source and manage services providers,
- manage budgets, pay invoices and keep financial records.

While support coordination funding is provided to assist with organising NDIS plans and upskilling participants it is frequently provided on a short-term basis, not explained to participants what it is for, and taken away from people during plan reviews from people who did not use it because they didn't know what it was for. LAC are also meant to assist participants in sourcing and organising service providers and equipment but again they are frequently unavailable and do not have the knowledge and experience required.

Long term funding and strategies are need to build capacity in these areas. Different strategies are needed for different people; online training resources, peer to peer mentoring, group workshops, in some cases long term one to one assistance and independent advocacy. Long term supports are required, paying for some to complete a two-hour online course and not providing any follow support is not going to work.

Assistive Technology is a broad term used to describe equipment from modified cutlery to electric wheel chairs. The process for applying for assistive technology is long, bureaucratic, expensive and frustrating. While there is provision for low tech low risk purchases under $500, and it is reasonable and necessary for expensive equipment to be fully assessed before purchase, the process for equipment in the $500 to $2000 range is ridiculous. Currently the process requires: -

- an assessment by an allied health professional [1 to 5 hours at $172.00 per hour]
- report by allied health professional [1 hour at $172.00]
- completion and submission of complex application form [participant/carer and health professional 1-hour x $172 (participant/carer time is not measured as is considered informal support)]
- multiple calls / emails to NDIS to check progress [usually participant/carer "informal support" can take hours]
- once approval is granted time spend with supplier fitting, modifying, arranging installation / delivery, learning to use, etc. [usually participant/carer "informal support" can take hours]
- approval is not granted go back to allied health professional and look for alternate solutions to unresolved problem and start process again.

In summary it can cost minimum 3 hours of allied health time at $172.00 per hour, in total $516.00 to apply for a piece of equipment that is $800.00 and the application maybe rejected. Please see the below examples for illustration:

> *Example 1: The parent of a 14-year-old boy with a chromosomal syndrome resulting in a severe intellectual disability, short stature and heart malformation (with results in fatigue) require a wheel chair or stroller for family and community outings. He is able to walk but fatigues and may need to have a short nap to recover. The family is planning a holiday and wish to have the device available to them for the holiday. Mum is well organised and with many months to spare and the assistance of an occupational therapist selects and applies for a special needs stroller with a backrest that partially reclines, approximately $2000. Special needs strollers, are designed for larger, older children, do not look "babyish" and are designed to use hours at a time but not to sit in all day every day. The request is denied. Therapist is shocked, as the boy has out grown a "normal" stroller and the family is now limited to what activities they can participate in. A second application is submitted, and is denied on the grounds that it is not appropriate for a 14-year-old boy to be in a "stroller". A wheelchair with a similar reclining back rest starts at $10 000. With the family holiday fast approaching, mum purchases a second hand "stroller" of eBay for $800 and pays for it herself. Over $500 has been spent in reports, the NDIS dictated what equipment was suitable and carer time and money, informal supports, again drawn on.*
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> *Example 2: A 15-year-old girl with a chromosomal syndrome, severe intellectual disability and very low muscle tone requires specialist orthotics in her shoes. These need to be assessed and replaced every 12 to 18 months. The girl required an intensive early intervention program to get her walking and many people with the same condition us a wheelchair. Without the orthotics in her shoes she experiences pain, difficulty walking and difficulty*

> *standing in a stable position that allows her to use her hands in a functional way. Every year the planner agrees the orthotics are reasonable and necessary, however, the family is still required to submit an assistive technology request, costing $500 in paper work for orthotics that cost between $800 to $1200 and can take 3 to 6 months for an approval. With limited communication, increasing pain and limited exercise during the waiting period lead to escalation in self-harm behaviours.*

The Assistive Technology system should be simplified, a possible amendment maybe: purchases under $3000, recommended in writing by an allied health professional (including a quote), for people on List A (https://www.ndis.gov.au/operational-guideline/access/list-a.html) should be able to be approved by the planner and funding allocated as part on the planning process, without further approval. Alternately, compile a list of low tech / low risk assistive technology under $3000 that can be approved by planners or purchased using core funding by self-managers. People wishing to purchase special needs stroller and orthotics are not doing so to wrought the system or infantise their child.

The annual planning process has become the disability sector's version of the "HSC". There is incredible pressure on parent/carers to fully and competently represent the person in their care. There is no room for error, no preview of the plan, no recourse if you forget something, no guarantee you will get what the planner agrees to in the meeting, no control over the planner you are allocated, and the review process is dysfunctional. Parent and carers spend days preparing for meetings collating allied health reports and doing research. Parents and carers generally do the best they can for their PWD, however, planner inconsistencies, bureaucracy and a dysfunctional review process are resulting in added stress for families that are already under a huge amount of stress and heartache.

As a carer I am time poor, I hope my submission will make a small contribution to improving the system for all.

Sincerely,

Natalie Atherton