



Dear Committee,

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.

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, research obtaining quotes by an allied health professional [1 to 5 hours at \$172.00 per hour]
- report by allied health professional [1 hour at \$172.00]
- trial of equipment if required [delivery/shipping fees, assessment by allied health professional 1-hour x \$172, assessment by participant/carer “informal support”]
- 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 (which 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 like a wheelchair. 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 in contradiction to the much applauded “choice and control” and carer time and money, informal supports, again drawn on.

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 use 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 being required. 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.

Simplifying the process for low / risk low cost AT would free up resources for the assessment of more expensive and complex equipment. Nobody questions that a rigorous process is required for the selection of a \$50 000, motorised wheelchair, however, a \$1500 custom made orthotics should be straight forward, especially as this type of equipment tends to the ongoing. In all instances the process needs to be timely as the impact of delays huge to the person experiencing the delays.

The NDIA is obsessed with managing two types of AT related risk:-

1. The Risk of injury to a participant from the use of AT
2. The Risk of wasting money, either in the purchase of the wrong piece of equipment or the purchase of equipment or the equipment not being “reasonable and necessary”

The NDIA does not consider the risk:-

3. The risk to a participant caused by delays in receiving vital AT
4. The Risk of wasting money due to the costs associated with the assessment and reassessment of AT applications.

A Cost–benefit analysis (CBA), considering the costs associated with assessment, reassessment and administration (point 4) in regard to the risk of wasting money on the purchase of AT deemed not “reasonable and necessary” (point 2) may reveal it is a better business case to accept the risk and therefore cost of point 2.

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. Long waiting times for AT applications is adding to this stress. There is no way of tracking AT applications, calls to the NDIA only result in being on hold for long periods of time and having to retell the story yet again to another stranger.

People are suffering unnecessarily and taxpayer money is being wasted on ridiculous bureaucracy.

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

Sincerely,

A solid black rectangular box used to redact the signature of the author.