

Parliament of Australia
Joint Standing Committee on the National Disability
Insurance Scheme Inquiry
~ Assistive Technology ~

Submission from: Jane Tracy

My 33 year old son, Nick, is a participant in the NDIS. He is an energetic, socially engaged young man for whom relationships are centrally important in his life. Nick has an intellectual disability and cerebral palsy and is not able to use speech to communicate. He has always been a very resourceful communicator– using gestures, some key word sign, vocalisation, and visual cues in attempts to get his message across. He doesn't speak, but has always had a lot to say!

Until 5 years ago, Nick relied on family members, and others who knew him very well, to interpret his communications to others with whom he was trying to engage and share. This was OK when he was a preschool child and family were usually with him, but as his world expanded and he wanted to be more independent, his ability to make himself understood was very limited. This led to him often giving up, becoming more withdrawn, and often showing frustration and angry.

Five years ago we got him an iPad. It was quite unknown whether he would be able to use it, or be interested in doing so but we wanted to try. He took to it like a duck to water! It has given him an independence in communication, and in entertainment, that he had never had before. We have installed the App Proloquo2Go, and he also has photos he can show people. He now has the ability to make choices, express his opinion, demand attention, set the topic of conversation, join in socially, and exercise his choice and control through being able to ask for and about the things and people that are important to him. We have even added a Bluetooth speaker that he can wear around his neck so he can turn up the volume and 'shout' if he feels he is not being listened to or heard!

At the time we got the device, many (family, friends, therapists) thought that Nick would have difficulty using it, and that it would quickly get broken and so was not worth trying. I disagreed and so went ahead and, bought it for him anyway. I have always bought tough "tradie" cases for the iPad and taken out "AppleCare" insurance and we have had remarkably few problems. There has been a broken speaker and home button – both replaced under warranty, and two screen breakages requiring a trade in and, on one occasion, a new iPad.

Nick's cerebral palsy also affects his balance and ability to walk. He uses a wheeled walker for daily mobility and a wheelchair when he needs to go longer distances. Without these aids he falls frequently because of his balance, poor muscle coordination and weakness, and frequent seizures. Without his walking aids he is both severely limited in his mobility and is at high risk of falls and

consequent serious injury. For Nick therefore his mobility aids are essential for his daily life.

My recommendations relate to the recognition that Assistive Technology is often fundamental to people's ability to function on a day-to-day basis, and so provision, repair and replacement needs to be addressed as a matter of urgency in order that the person is supported in their function, independence and dignity. The timely provision, repair and replacement of essential equipment is a matter of respect for the population requiring these aids.

- **Expedite processes for equipment provision** so bureaucratic and system delays do not sabotage the opportunities for people with disability to communicate with those who share their lives; move around their homes and communities; and participate in and contribute to their communities.

Current delays for equipment are unacceptably long for many people.

- **Streamline the repair and replacement** of equipment that has been previously recommended/prescribed so just replacing or repairing something that works well does not require jumping through unnecessary hoops.

An urgent/emergency response must be available so people can have essential equipment repaired/replaced immediately.

- **Enable retrospective funding** for repair and replacement of equipment that has been previously recommended/prescribed and is working well. It may not be possible or practical to obtain approval in a timely way when essential equipment fails. The person should be able to repair or replace the equipment and be reimbursed.

There seems little point in having re-assessments and re-prescription/recommendation of products/equipment that the person concerned is happy with and has previously been shown to be fit for purpose.

An example is the failure of Nick's iPad. This has happened 6 or 7 times over the last 5 years – usually on a Friday or weekend! The family has immediately ensured the time without an iPad is minimized for Nick as we appreciate the feelings of frustration, powerlessness and dependence that he experiences when he loses his ability to communicate with others. Usually we have been able to return a functioning iPad to him within 24 hours. In the 5 years of having Nick's iPad, repairs have usually been done under warranty; only once have we had to purchase a new iPad.

- **Enable retrospective funding** for equipment that the person concerned has found to be effective, and has subsequently had approved through an appropriate therapist.

In our case, we tried a range of communication tools and devices. It was felt Nick would not manage an iPad, but I decided to buy one for him and try anyway. This was a great success. I would like to see a situation that enabled the person to be reimbursed for the cost of the equipment if it was found to be effective and then subsequently approved by a therapist. The therapy assessment and advice would ensure NDIS money is not wasted and that the item is a reasonable and necessary support for the person. A system that enabled this to occur may encourage people to use their own resources to explore possibilities, only requesting NDIS funds when a solution was effective and approved.