

NDIS Discussion Paper - Assistive Technology

<http://www.ndis.gov.au/document/1286>

To respond directly to the NDIA <http://www.ndis.gov.au/form/assistive---technology---discussion---paper---feedback---form> (Closing date for feedback is 28th February 2015)

Submitted Wednesday 11 Feb 2015

As an active member of the polio community and a consumer of a wide range of AT my main concerns with regard to the NDIS Discussion Paper are

- There are that there are lots of good statements re intention – but too few specifics with regard to implementation
- An inference that savings can be found by reducing the number of suppliers and range of equipment.
- That low need AT can be supplied from inexpert sources such as chemists and supermarket type business.
- The discussion paper has taken a system's management approach which suggests that assessment and identification of long term solutions that incorporate choice and tailored solutions will not be the first step in providing AT solutions.
- There seems to be little input from views of those with expertise in AT solutions and health who recognise the dangers of supplying 'off the shelf' equipment that often leads to equipment abandonment and under use due to associated pain and difficulty of use – e.g. low budget manual wheel chairs primarily only useful for patient transfer.

Members of the polio community have lived with equipment needs and supply in many cases for well over 60 years –we have lived experience of both supply and technological innovation. We are most concerned that the 1000's of polios (aged 64 or less) who will qualify for NDIS funding should not be disadvantaged by a system that is bounded by standardised equipment rather than tailored support and independence.

Productivity Commission Disability Care and Support¹ was very clear in its recommendation to provide tailored solutions however the discussion paper suggests a reduction in consumer choice, trialling and ongoing support, and suggests that 'cost-effectively' was interpreted as cutting costs.

The National Disability Insurance Scheme (NDIS) should have three main functions. It should:

- *cost-effectively minimise the impacts of disability, maximise the social and economic participation of people with a disability, create community awareness of the issues that affect people with disabilities and facilitate community capacity building. These measures should be targeted at all Australians*
- *provide information and referral services, which should be targeted at people with, or affected by, a disability*
- ***provide individually tailored, taxpayer-funded support, which should be targeted at people with significant disabilities who are assessed as needing such support (but excluding those***

¹ <http://www.pc.gov.au/inquiries/completed/disability-support/report>

people with newly-acquired catastrophic injuries covered by the National Injury Insurance Scheme

A scheme that is truly inclusive and cost effective will not be one bounded by gate keepers and burdensome process. The discussion paper has not placed enough emphasis on what has been learnt from the trial sites. The paper implies that many of the lessons' learnt at the trail site will be solved by managed procurement, but I believe the opposite will be the case. I have been given many examples of 'wait times' for therapists still being at the Barwon and other trail site. I have also heard of some simple tailored solutions being bogged down in process.

The approach of 'panel supply' based on 'contracts' with 'preferred suppliers' as a procurement model raises concerns that there will be pressure on many suppliers to maintain a range of product to maintain a customer base. I am concerned that any long term financial gain will be jeopardised by oversupply unworkable equipment.

It is suggested that items are to be purchased in bulk or on a 'preferred list' from a 'preferred supplier'. Talk to any longer term consumer of AT they will tell you about the abandoned stuff that is in their garage that just did not work for them -inappropriate wheel chairs both manual & power, pick up sticks, bulky walkers and crutches, transfer boards that only work in some environments and so on.

In the name of common sense I ask that tailored solutions are monitored by therapists who are not restricted by a range of suppliers, products lists or stuff sitting in warehouses committed to by the NDIA for supply.

The sales of some 'standardised' low cost items such scooters, walkers and bath chairs enable many of the local suppliers to stock a wider range of slower selling items such a pressure stockings, personal hygiene items that are not by any other main stream supplier's including chemists. The only stockists where I am able to buy my 'off the shelve extra wide- extra deep – lycra topped with a velco closure are Orthotists. So called specialist shoe stores don't stock shoes that are designed to accommodate bulky orthotics and different sized feet.

In Victoria we have experienced the damage done to the AT maintenance industry by the centralised supplied via SWEP. In theory a centralised system seemed a good idea, but in practice there is an extra layer of delay in communication between consumer, local supplier and local health provider. SWEP has not increased the number of recipients, nor has the system reduced 'wait times'. Repairs via Chemtronics work well in some areas, but delays in regional areas have still not been fully addressed. A further reduction in the number of suppliers would be only put further pressure on a system that is not working.

Innovation and cheaper product has seen an increase in personal hoist, motorise bed, and power-chair failures. It is all very well to argue that would be the case regardless of who the suppliers are, but if the business that supplies the equipment relies upon a localised client base, they are more likely to ensure that their reputation ensures repeat business.

There are a large number of occupational therapists and physios employed by suppliers that provides some confidence that their customers are not exposed to the dangers of inappropriate unsupported AT solutions. Good AT suppliers insist upon working with customers' health specialists and repeat referrals depend very much upon their reputation to provide good service in a timely and efficient manner. We need local suppliers and local support to maintain our economy and our independence.

The discussion paper almost refers to mentors as an innovation. Whilst in principle 'AT mentors' can add a dimension of peer support, my experience cautions me against those who can't see beyond personal solutions – *it works well for me so it will work well for you*. 'AT mentors' supported by health experts is something that should be explored. I would suggest that this mentorship would work best if limited in instance and presented in group sessions where the opinions of others are most likely to be expressed.

I am sure it will agree that not all mentorship is helpful. There will be many personal details known by therapists that would not be relayed to mentors. I would consider that I have a good knowledge of what is available in AT, and have spent years on AT committees, reviewing uses, learning out new product – but I am not a therapist and I don't have the skills to advise others.

A few years ago stance control was found to be very successful for people who in many cases could barely stand up without complex supports. A 'mentor' suggested that stance control might work for me, he cautioned me though that it did not work for everybody. I was excited; my thought was that stance control would mean that I would not require a power wheelchair. The cost about the same as a power chair \$12,000 to \$20,000 for both legs. It took 12 months of assessment and monitoring to ensure that there would have been long term value for me with such an investment. I was extremely disappointed when it was learnt during the process that I lacked the muscles to safely activate the controls.

In reality I was extremely fortunate – I didn't spend the money, but a friend of mine did after receiving advice from two orthotists and a rehab specialist. Although her assessment process and training all were positive, she found after she had been using stance control for several months that she only has the muscular endurance to manage it for short periods at a time. This possibly may have been due to the progressive nature of her individual late effects of polio. My point being that great caution needs to be taken with complex AT – our bodies are not all the same and damage from disease and/or injury varies from person to person.

I spent 12 months researching my last power-wheel chair to ensure that it would work for me and that I would be able to resume my community activities independently. I worked with an occupational therapist who has over 20 years of experience working with polio damaged bodies. In an effort to save money we considered 6 standard power chairs and trailed three at my home, before it was agreed that the one that best suited my independence and long term needs was to customise a light weight hybrid power-chair-(J3 back and custom made cushion).

My light weight power-chair provides the independent freedom for me to maintain an active role in the community in the areas of disability solutions, AT and aged care. I have a medium sized 4x4 with a drop down tail gate that enables me to roll my wheel-chair in and out independently. I can walk it up a step or two and most importantly I travel independent of carers and maintain a high level of self-respect.

Tailored solutions require knowledgeable suppliers with commitment to their industry and accredited prescription to ensure sustainable outcomes. It is essential that equipment be locally supported and trialled. As a member of the polio community I am well aware of the differing levels of support required by individuals with progressive and chronic conditions.

People who live with the late effects of polio make up the largest single physical disability group in Australia.² There are over 10,000 of us who rely upon power-wheelchairs, scooters and specialist orthotics for mobility. There are a further 30,000 in Australia who manage a

² HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH AND AGEING, page 5 Friday, 30 March 2012

wide variety of chronic and restrictive symptoms that can be best managed by the use of tailored AT solutions. There are very few off the shelf solutions that work for people who live with the late effects of polio.

As a consumer, in the last 5 years I have purchased , four sets of custom made leg braces, 8 pairs of extra wide / extra deep shoes, 2 sets of elbow crutches, one set of smart crutches , four walking sticks, a walker, a manual wheelchair and a power wheelchair. I also receive respiratory support from a BiPAP via the Victorian Respiratory Support Service. The items that I currently use are custom made leg braces (requiring 3 monthly safety review) and a walking stick with a flexi foot for transfers, a pickup stick and long shoe horn to help with self-dressing and a power wheelchair.

On behalf of my younger friends who manage a life of changing needs from Late Effects of Polio, Multiple Sclerosis, Motor Neurone Disease, Cerebral Palsy and like neurological conditions – please don't sell our needs short by a one size 'almost fits all' solution from an anonymous base of suppliers. We deserve to know who provides our care and we need to know who to turn to when things go wrong.

Yours Sincerely,

Peter Willcocks
0431 117 950
pgwillcocks@gmail.com

You have permission to publish and distribute this letter, and I would be most willing to discuss this further should the opportunity arise