AMAZE SUBMISSION

Joint Standing Committee on the NDIS's inquiry into the provision of Assistive Technology under the National Disability Insurance Scheme

September 2018

Contents

Summary of Recommendations

Definitions that are inclusive of the needs of autistic people.

1. When defining AT for the purposes of the NDIS, the NDIA consistently adapt the WHO definition to refer to any device or system that supports individuals to perform tasks, build functional skills or enhance their independence and community participation.

Transparent, consistent and evidence based approach to funding AT for autistic people, including ensuring planners and assessors can guide and provide options to autistic people to best support their needs.

2. The NDIA, in collaboration with the Autism Advisory Group, develop guidelines on the:
    - types of AT funded by the NDIS to support the needs of autistic people, including evidentiary requirements for funding; and
    - interface between the NDIS and other Commonwealth and State based AT schemes, particularly the education system.
3. The NDIA provide training to planners, LAC's and AT Assessors on AT needs for autistic people, including the broad range of communication, motor development, sensory regulation and learning needs AT may support and the types of AT that may be funded.
4. The NDIA provide publicly available data on items that have been funded to provide guidance to planners, LACs, NDIS applicants and their families and/or carers on what is eligible for funding.
5. The NDIA conduct a review into the evidence base, safety and cost-effectiveness of commonly used sensory toys and devices.
6. The NDIA consistently fund appropriate training in the use of communication and other complex apps.

Future proofing to ensure that autistic people have access to the best supports for their needs that are cost effective

7. The Commonwealth/NDIA provide ongoing funding to undertake research to support the building of an evidence base of AT.
8. The NDIA develop transparent guidance on how the evidence of AT cost-effectiveness is assessed.

About Amaze

Amaze is the peak body in Victoria for autistic people and their supporters. Amaze is a not-for-profit organisation established in 1967 that represents around 55,000 autistic Victorians.

In 2015 Amaze launched its Strategic Directions to 2040 – a 25 year plan to achieve social impact where society respects every autistic person and they have real opportunities to participate and contribute. To achieve this, our three main goals are to:

- Increase community awareness and understanding of autism;
- Improve attitudes and behaviours towards people on the autism spectrum;
- Create more opportunities for people on the autism spectrum to participate and contribute to society in meaningful ways**.**

Amaze operates under a number of principles that guide our work and underpin our decision making. They are:

1. **Autistic People at the Centre** – We embody the motto "nothing about us without us". We act as a facilitator to ensure the voices and needs of autistic people and their families/supporters are heard in the wider world. We actively engage with autistic people and their supporters to inform our priorities, how our organisation is governed and operates, and how we design and deliver our activities. We actively work to improve attitudes and behaviours towards autistic people and their families/supporters.

2. **Collaboration and Partnership.** We recognise that we cannot achieve our social impact goals alone and so we actively seek out like-minded people and organisations as partners.

3. **Courage and Independence** – We condemn any discrimination and ableism used to stigmatise or invalidate the life experience of autistic people. Whilst we adopt a practice of partnership, the needs of autistic people and their families will always come first, and we will speak out and challenge any government or organisation's policy or practice that compromises autistic people.

4. **Evidence based** – We seek data and evidence to underpin decision making and we measure the outcomes of our work wherever possible. We advocate for greater collection of and accessibility to, data from public institutions that measure and track outcomes for autistic people and result in greater accountability.

1. Introduction

Amaze welcomes the Joint Standing Committee on the NDIS's inquiry into the provision of Assistive Technology (AT) under the National Disability Insurance Scheme (NDIS).

We are pleased that the NDIS has provided a mechanism for AT to be provided to autistic participants of all ages. AT can make a significant difference to the lives of autistic people by enhancing their social communication skills, fine and gross motor skill development, sensory and emotional regulation and in turn, increasing their social and economic participation.

However, we are concerned by the lack of clarity and transparency regarding the types of AT funded by the NDIS to support the needs of autistic people. We are also concerned that some people feel worse off under the NDIS compared to previous AT funding schemes for autistic people, in particular the Helping Children with Autism package.

Many autistic people have co-occurring disabilities, including a range of physical, psycho-social and intellectual disabilities. While our submission to this inquiry focuses on funding for AT under the NDIS to support the needs of participants that relate to their autism characteristics, we also recognise that our community is facing a range of challenges accessing AT (including significant delays and procedural frustrations) to support their physical and other needs.

2. Our engagement with autistic people and their families regarding their experiences accessing AT under the NDIS

Autistic people and their families and carers are at the centre of everything we do at Amaze. Accordingly, for the purposes of responding to your inquiry we conducted a survey of autistic people and their families and carers to hear their experiences and aspirations for obtaining AT under the NDIS.

The survey (open from 4 September 2018 to 13 September 2018) was completed by 42 people, of which 15% were autistic people (including 10% that were autistic and cared for an autistic person) and 85% were family members or carers of one or more autistic person(s).

Our survey responses demonstrate that there are significant inconsistencies, and a high lack of awareness regarding to the types of AT that may be funded under the NDIS for autistic people. The findings from our survey are discussed in detail below.

3. Defining AT for the purposes of the NDIS

The NDIS utilises the World Health Organization (WHO) definition of AT, which is 'any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed'.

One of the core objectives of the *NDIS Act* 2013 is to build the independence and social and economic participation of people with disability. The NDIA’s AT strategy identifies its vision as “[t]o build an empowering, sustainable and consistent approach to ensuring NDIS participants have choice of and access to individualised technology solutions that enable and enhance economic and community participation”. Under the NDIS Price Guide, it is stated that AT in the Capital Supports category includes “aids or equipment supports that assist participants to live independently or assist a carer to support the participant.”

We would therefore query whether, in the context of the NDIS, the WHO’s definition of AT unduly restricts AT to devices or systems that support task performance only. For example, there are a range of existing and emerging types of AT that over time can support the learning of skills to enhance sensory and emotional regulation, fine motor skill development, a range of social interactions (for example job interview skills) and generally help build a participant’s independence. In addition, augmentative and alternative communication devices may be used for a range of purposes, not only as a replacement for spoken language, but to build verbal and alternative functional communication skills and to support emotional regulation and behaviour management.[1] These skills do not necessarily link directly to task performance.

Recommendation 1.

When defining AT for the purposes of the NDIS, the NDIA consistently adapt the WHO definition to refer to any device or system that supports individuals to perform tasks, build functional skills or enhance their independence and community participation.

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[1] Iacono T, Trembath D, Erickson S, 2016. The role of augmentative and alternative communication for children with autism: current status and future trends. *Neuropsychiatric Disease and Treatment* 2016:12 2349–236.

4. Transparency regarding types of AT funded under the NDIS

Feedback we have received from the Victorian autism community (through our Autism Information Adviser service, NDIS Community Engagement Project and NDIS and AT survey) suggests a significant lack of understanding among NDIS applicants, participants, planners, Local Area Coordinator's (LACs), and AT assessors regarding the meaning of AT and the types of AT that may be funded by the NDIS for autistic people.

AT and NDIS survey findings

Among the 42 respondents to Amazes AT and NDIS survey, 63% reported that they currently have an NDIS for themselves or a family member/person they care for. Of these responders, only 62.5% had applied for AT funding in one or more of their NDIS plans, with the remainder unsure of their eligibility or what they could apply for. Feedback we received included:

"I was told I couldn't apply for assistive technology"

"We explored it in the NDIS plan but with little information available on what we could apply for and our planner did not explore it with us"

Of the responders who are yet to enter the NDIS but hope to in the future, only 57% reported that they would apply for AT, with the remainder unsure of their eligibility. Feedback included:

"I find it hard to get information on who is eligible (for AT). Some people say he is other[s] say no he isn't".

The Commonwealth government has committed to ensuring that no-one is worse off under the NDIS, compared with previous schemes. However, the Helping Children with Autism (HCWA) scheme provided a more flexible and individualised approach to applying for AT for children under 7 years of age. Under the HCWA scheme, the types of AT that could be applied for were much broader (particularly for sensory regulation, such as trampolines and climbing equipment), up to 30% of HCWA funding could be used to purchase AT (recognising differing individual needs) and required only a report from an allied health professional.

While the NDIA Assistive Technology & Consumables Code Guide, AT Operational Guidelines, NDIS Price Guide and NDIS AT Complexity Level Classification Document provides guidance about the types of AT that may be funded, this guidance is focused mainly on AT to support the needs of people with physical disabilities. There is little guidance on AT supports for people with cognitive disabilities such as autism.

Autistic people and their families/carers do not have access to clear and consistent information regarding the types of AT that are available under the NDIS (particularly Level 1, low risk items) to support their needs. Given 29% of NDIS participants identify autism as their primary disability, clear guidance on their eligibility to apply for AT is urgently needed.

Reports to our NDIS Community Engagement Project team include that many planners, LACs and AT assessors do not appear to understand the AT needs of autistic people, the types of AT that may best support a wide range of communication, sensory and other needs. This lack of understanding is undermining the choice and control of autistic participants to access the types of AT they need to engage in daily tasks and enhance their social and community participation.

We are also hearing inconsistent advice regarding whether the following types of AT may be, or have been funded by the NDIS: iPads, smart watches, GPS devices and equipment and devices to support motor development and sensory regulation. It is also unclear whether the NDIS is funding text to speech/reading pens or devices (such as Dragon Dictation and Claro Reader) for autistic participants that find visual processing overwhelming or tiring when reading off hard copy or a screen.

AT and NDIS survey findings

Of our survey responders that have an NDIS plan or care for someone with an NDIS plan, 62.5% reported they had applied for funding for AT in one or more NDIS plan, yet only 35.7% reported that they were successful in receiving funding for AT in one or more plan.

Responders reported applying for and receiving funding for the following types of AT in one or more AT plans: weighted blankets, communication aids, visuals, apps for iPads, sensory pillow, fiddle toys. Similarly, respondents that hoped to become NDIS participants (or support a person they care for to access an NDIS plan) in the future, predominantly responded that they would seek to apply for iPads and communication apps, tablets, smartphones and laptops. They also reported they would seek to apply for speech to text apps, text to speech apps and reading pens, communication apps such as Proloquo2go and other learning apps.

Respondents that had applied for funding for AT in an NDIS plan, reported that their application had been rejected for the following types of AT (the reasons respondents were given for their applications being rejected are included in brackets below):

- iPad ("*Don't fund iPads", "..it's a high risk item*")
- Speech device ("*We are currently trialling different types*")
- Dyslexia assistive pen ("*Not enough evidence that it would benefit, despite dyslexia diagnosis*)
- Sensory aids & equipment such as scooter board, weighted blanket, body sock, pressure vest, exercise ball ("*All sensory aids and items refused on the basis that NDIS does not fund sensory resources*").
- Sensory "toys" weighted blankets, head phones to block out noise

One respondent further noted that the *"NDIA seem to have amounts/$ limits they apply to plans rather than funding a specific amount when provided a list*".

Of the responders who did receive funding for AT, 75% received funding for Level 1 low risk/low cost items. Of these respondents, 75% reported that they had a somewhat limited understanding of what they could purchase with this funding.

There is also evidence that while respondents were seemingly automatically funded for Level 1 AT in their first plan, they were not automatically funded for AT in their second plan and planners/LACs did not raise the question of AT with participants or their carers during the planning meeting. Feedback included:

"First son got $1000 specifically for a weighted blanket. Second son got $500 for 'low cost AT' but no specified items. Both kids got no AT money on second plan".

"Money automatically given in first plan. Had I had enough time to think I would have asked for specific items".

We understand that determinations of whether particular types of AT may be funded will depend on the individual circumstances of participants, that what may be reasonable and necessary for one participant may not be for another. However, a consistent approach is required in relation to the types of AT that are eligible to be funding under the NDIS. For example:

- **iPads**: Greater clarity is required regarding the funding of iPads and/or other tablets and devices.

  Our understanding is that iPads are generally considered mainstream devices and are not funded under the NDIS. However, we would urge the NDIA to review this position and consider funding iPads in circumstances where dedicated iPads (as distinct from family iPads or iPads otherwise used for entertainment and other purposes) are the most cost-effective option to support communication apps.

  The funding of a communication app can often not be separated from the need to fund a dedicated iPad or tablet to operate the app, the two are inextricably linked for the app to function and be fit for purpose. Some evidence based communication devices, such as Proloquo2go are only compatible with iPads and are recommended to be used on a dedicated iPad only.[2] It is not appropriate to fund communication apps such as Proloquo2go and suggest that families simply add them to the family iPad which has a range of other purposes, users and uses.

  There is also evidence that the funding of dedicated iPads and other tablets (with communication apps) may be more cost-effective than funding other Speech Generating Devices (SGDs). For example, iPads have been found to be more effective at supporting social communication than SGDs, whilst also being a fraction of the cost of many SGDs. In addition, iPads are smaller, have more natural sounding voices, have longer battery life, are more portable and are easier and cheaper to have repaired if damaged.[3]

- **Sensory and playground equipment:** We receive very mixed feedback (as demonstrated by our survey) regarding the types of sensory devices and equipment that are funded by the NDIS. We understand that playground equipment is generally not funded by the NDIS (with the exception of swings in some limited circumstances).

  We urge the NDIA to review its position in relation to playground equipment and consider funding this type of equipment (including swings, slides, trampolines and climbing equipment) were evidence is provided by an allied health professional of the need for a particular piece of equipment to support safe sensory regulation (i.e. to provide appropriate proprioceptive input and limit unsafe climbing).

  It should also be recognised that it is not only children that would benefit from this equipment. There are some autistic adults who would benefit extensively from being able to access this type of equipment at home to support their sensory and emotional

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[2] For more information, see www.assistiveware.com

[3] King A, Brady K, Voreis G, 2017. It's a blessing and a curse": Perspectives on tablet use in children with autism spectrum disorder. *Autism & Developmental Language Impairments* https://doi.org/10.1177/2396941516683183, 2017.

regulation (particularly given the difficulties adults have accessing this type of equipment in public playgrounds and safety issues).

We would also encourage the NDIA, in collaboration with the Autism Advisory Group, to provide greater clarity and consistency regarding the funding of sensory toys and devices to support sensory regulation and fine and gross motor skill development. As a first step, a review should be conducted into the types of sensory toys and devices that are evidence based, safe and cost-effective.

- **GPS devices**: While the AT strategy identifies GPS devices (and smartphones) as fundable AT under the NDIS, feedback we have received is inconsistent, with many participants reporting that their request for a GPS device was rejected. Clarity regarding the funding of GPS devices is urgently needed, including ongoing investment in research into their efficacy and diverse needs of users (no one type of GPS device can suit all purposes and needs, privacy issues can also arise).

Greater clarity and transparency is also required regarding the interface between the NDIS and other Commonwealth or State based AT schemes. For example, there are a range of AT items that may be used in the home and in other settings, including education settings and it remains unclear who is responsible for funding these items.

Recommendation 2.
The NDIA, in collaboration with the Autism Advisory Group develop guidelines on the:
- types of AT funded by the NDIS to support the needs of autistic people, including evidentiary requirements for funding; and
- interface between the NDIS and other Commonwealth and State based AT schemes, particularly the education system.

Recommendation 3.
The NDIA provide training to planners, LAC's and AT Assessors on AT needs for autistic people, including the broad range of communication, motor development, sensory regulation and learning needs AT may support and the types of AT that may be funded.

Recommendation 4.
The NDIS provide publicly available data on items that have been funded to provide guidance to planners, LACs, NDIS applicants and their families and/or carers on what is eligible for funding.

Recommendation 5.
The NDIA conduct a review into the evidence base, safety and cost-effectiveness of commonly used sensory toys and devices.

5. Funding training in use of some types of AT

We are concerned that training is not generally being funded to support participants and their families to use complex AT. Without appropriate training, the use and cost-effectiveness of funded AT can be vastly undermined. None of our survey responders reported receiving funding for AT in their NDIS plans.

We therefore urge the NDIA to review its approach to funding training for complex AT and ensure a transparent and consistent approach is taken by planners, LACs and AT assessors. In particular, if funding is provided for a communication app, funding must also be provided for a parent/carer and relevant others (including education providers, employers, etc.) in how to use it. This training needs to be ongoing to ensure its use is sustainable and evolves to meet the evolving needs of the user.

Recommendation 6.
That the NDIA consistently fund appropriate training in the use of communication and other complex apps.

6. Building the evidence of AT cost-effectiveness

As recognised in the AT strategy, AT will continue to evolve and change. For example, it is likely virtual reality will overtake a range of existing AT to support autistic people to learn and practice a range of social exchanges, entering new environments, practice attending job interviews etc.

We welcome the NDIA’s commitment under the AT strategy to stay up to date with developments in the AT market, foster its growth and development in Australia and monitor risks/unforeseen consequences.

However, it remains unclear exactly how the NDIA assesses the evidence base for emerging AT in this rapidly growing market. How are planners, LACs and AT assessors and participants kept up to date with the types of AT that are considered evidence based? How is the evidence assessed? Greater transparency is required in these regards for planners, LAC’s, AT assessors and participants.

The NDIA must also not focus only on increasing the supply of effective AT under the AT strategy, but also ensure that it is cost-effective AT that is being developed. Currently it appears that apps, sensory equipment and other AT to support the needs of people with disability is significantly more expensive than mainstream equivalents.

Recommendation 7.
The Commonwealth/NDIA provide ongoing funding to undertake research to support the building of an evidence base of AT.

Recommendation 8.
The NDIA develop transparent guidance on how the evidence of AT cost-effectiveness is assessed.

7. Closing

We thank you again for the opportunity to provide this submission. We look forward to reviewing your findings and recommendations.

If you have any questions or we can provide further information, please contact Braedan Hogan, Amaze’s Manager, Public Affairs and NDIS Transition on (03) 9657 1650 or via email at braedan.hogan@amaze.org.au.

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