



## **Submission:**

## **A new National Disability Strategy – Stage 2 consultations**

**October 2020**

**To:**

National Disability Strategy Governance and Engagement Section  
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**This submission has been endorsed by the following organisations:**

Australian Association of Gerontology (AAG); Australian Federation of Disability Organisations (AFDO); Australian Rehabilitation and Assistive Technology Association (ARATA); Council on the Ageing (COTA) Australia; People with Disability Australia (PWDA); Blind Citizens Australia; Guide Dogs Australia; Limbs 4 Life; Multiple Sclerosis (MS) Australia; Polio Australia; Spinal Cord Injuries Australia; Spinal Life Australia; Vision Australia; Council on the Ageing (COTA) Victoria; Post-Polio Victoria; Bayside Polio Group.



## Contents

1. About the Assistive Technology for All Alliance .....	1
2. Introduction .....	1
3. Recommendations .....	2
4. What is assistive technology? .....	3
5. Assistive technology under the Convention on the Rights of Persons with Disabilities .....	4
6. Assistive technology under the Sustainable Development Goals .....	5
7. Ending age discrimination in Australian disability policy .....	5
8. Overview of primary funding streams outside the NDIS .....	9
8.1 The National Injury Insurance Scheme (NIIS) .....	10
8.2 The Commonwealth Continuity of Support Programme (CoS) .....	12
8.3 The aged care system .....	13
8.3.1 The Commonwealth Home Support Programme (CHSP) .....	13
8.3.2 Home Care Packages Program .....	13
8.4 State-based aids and equipment programs .....	15
9. Outcome areas proposed for the new National Disability Strategy .....	17
9.1 Rights protection, justice and legislation .....	17
9.2 Health and wellbeing .....	17
9.3 Inclusive and accessible communities .....	19
9.4 Economic security .....	21
9.5 Learning and skills .....	23
10. Government roles and responsibilities .....	25
11. Targeted action plans to drive implementation .....	28
12. Concluding comments .....	30
Appendix A: Conclusion and Recommendations from Report on the rights of older persons with disabilities, published by the Special Rapporteur on the rights of persons with disabilities in July 2019 .....	32
Appendix B: ARATA Assistive Technology Funding Map .....	34
References .....	35

## 1. About the Assistive Technology for All Alliance

The Assistive Technology for All (ATFA) Alliance is a national partnership of peak bodies and consumer representatives spanning the health, ageing and disability sectors. We have joined forces to advocate for the establishment of a national assistive technology program to meet the needs of people with disability who are excluded from the National Disability Insurance Scheme (NDIS).

The members of the ATFA Alliance and the consumers we represent believe that the lack of equity in Australia's disability support system is unjust and intolerable. That is why we have launched a public campaign to bring about equal access to assistive technology in Australia. The Assistive Technology for All campaign website can be accessed at <https://assistivetechforall.org.au/>.

We would like to thank Simon Kneebone for producing the cartoons included throughout this submission. Simon's website can be accessed at: [www.simonkneebone.com](http://www.simonkneebone.com)

## 2. Introduction

The ATFA Alliance is pleased to provide this submission to inform the second stage of consultations on the review of the National Disability Strategy. We recognise that the National Disability Strategy is a blueprint for the progressive realisation of the rights set out under the Convention on the Rights of Persons with Disabilities. As such, our submission will:

- Highlight the role that assistive technology plays in promoting, protecting, and upholding the rights of people with disability.
- Outline current gaps in the provision of assistive technology to people with disability who are excluded from the NDIS.
- Comment on the appropriateness of the six focus areas that have been proposed for the new National Disability Strategy.
- Outline a number of steps that must be taken to increase government accountability under the new National Disability Strategy
- Demonstrate the need for the new National Disability Strategy to include a targeted action plan to urgently address the assistive technology funding gap that exists for people with disability who are excluded from the NDIS.

To inform this submission, we held a focus group with 10 people with disability who had been excluded from the NDIS because they did not meet the age eligibility requirements for the scheme. Although older people with disability are the largest cohort to be excluded from the NDIS, it is worth noting that there are also an estimated 800,000 people with disability under the age of 65 who will not be eligible for the scheme. The recommendations made throughout this submission are intended to improve access to assistive technology for all people with disability who are excluded from the NDIS, irrespective of age.

Please note that the case studies provided throughout this submission are based on the needs and circumstances of real individuals. We have, however, altered some identifying details to protect the anonymity of those concerned. These case studies have been provided to demonstrate how the Australian Government is failing to uphold the rights of people with disability who are excluded from the NDIS and help to validate the discourse and recommendations proposed herein.

### 3. Recommendations

#### **Recommendation 1:**

The new National Disability Strategy must urgently abolish Australia's ageist approach to the provision of services and supports to people with disability and equitably promote, protect and uphold the rights of older people with disability in line with Australia's obligations under the Convention on the Rights of Persons with Disabilities.

#### **Recommendation 2:**

While we broadly support the six outcome areas that have been proposed for the new National Disability Strategy, we assert that the outcome area of personal support must be given higher priority. This is in recognition of the fact that personal supports such as assistive technology facilitate autonomy, safety and independence. They are key enablers for inclusion and participation which will help to deliver successful outcomes under each of the remaining priority areas that have been proposed for the new strategy.

#### **Recommendation 3:**

In the absence of a new National Disability Agreement, the Australian, State and Territory Governments must urgently fund and implement outcomes under the National Disability Strategy to clearly outline who will be responsible for funding assistive technology (including home modifications) for:

- People with disability who are over the age of 65 who do not meet the age eligibility requirements for the NDIS.
- People with disability who are under the age of 65 who do not meet the eligibility requirements for the NDIS.

#### **Recommendation 4:**

The new National Disability Strategy must clearly identify funding arrangements and responsibilities associated with each individual component of the assistive technology journey, including:

- Skilled assessment and referral
- Equipment trials and demonstrations
- Equipment customisation

- Purchase/installation of customised aids, equipment and home modifications
- Specialised training
- Equipment maintenance and repairs.

#### **Recommendation 5:**

The new National Disability Strategy must establish a framework to drive nationally consistent outcomes across service systems to ensure all people with disability have equitable access to the assistive technology they need.

#### **Recommendation 6:**

The new National Disability Strategy must include a funded action plan to provide urgent and equitable access to assistive technology for people with disability who are excluded from the NDIS.

#### **Recommendation 7:**

The new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program to streamline access and provide equitable support to people with disability who are excluded from the NDIS. This program should:

- Harmonise existing state-based assistive technology programs and those operated by not-for-profit organisations. This would streamline access and drive nationally consistent outcomes for consumers while reducing administrative burden on governments
- Be aligned with the NDIS Assistive Technology Strategy to address the inequity between the support that is provided under the NDIS and other service systems
- Be driven by key performance indicators relating to the timely provision of equipment, in line with the aspirations of the NDIS Participant Service Guarantee.

## **4. What is assistive technology?**

1. 'Assistive technology' is an umbrella term that is used to describe any aid, piece of equipment or home modification that helps someone overcome the impact of disability.
2. According to the World Health Organization:  
*"Assistive devices and technologies are those whose primary purpose is to maintain or improve an individual's functioning and independence to facilitate participation and to enhance overall well-being. They can also help prevent impairments and secondary health conditions."*<sup>1</sup>
3. Assistive technology can take many forms, such as:
  - A ramp to enable someone to enter and exit their home without support
  - A rubber stall to help someone turn the pages of a book
  - A walking frame to assist with balance and mobility
  - A cane to assist someone who is blind or vision impaired to move around safely and independently

- A wheelchair to promote mobility and independence
- Voice dictation software to enable someone with limited dexterity to use a computer
- A prosthetic limb to enhance balance, mobility, and functionality
- A splint to overcome lost muscle strength and enable someone to walk safely and independently
- An electronic communication device to help someone who cannot use their voice to communicate their thoughts.

## 5. Assistive technology under the Convention on the Rights of Persons with Disabilities

1. According to the Attorney General's Department, the National Disability Strategy:

*"... is the mechanism to ensure that the principles underpinning the Convention are incorporated into policies and programs affecting people with disability, their families and carers."* <sup>2</sup>

In light of this fact, we wish to remind the Department of the critical role assistive technology plays in promoting, protecting, and upholding the rights set out under the Convention.

2. Article 4 of the Convention sets out the general obligations that are placed upon state parties to the Convention, including:

*"g) To undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost"* <sup>3</sup>

3. Article 19 of the Convention establishes the right of people with disability to live independently and be included in the community. It requires that:

*"b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community."* <sup>4</sup>

4. Article 20 of the Convention relates to personal mobility, noting that governments have a role to play in:

*"a) Facilitating the personal mobility of persons with disabilities in the manner and at the time of their choice, and at affordable cost;*

*b) Facilitating access by persons with disabilities to quality mobility aids, devices, assistive technologies and forms of live assistance and intermediaries, including by making them available at affordable cost;*

*c) Providing training in mobility skills to persons with disabilities and to specialist staff working with persons with disabilities;"* <sup>5</sup>

5. A 2009 study undertaken by the Department of Health Sciences at the University of Lund in Sweden, sought to analyse the assistive technology content of the Convention from a basic human rights standpoint. The final report from this study states:

*“It is concluded that a non-discriminatory interpretation of the provisions entitles all people with disabilities to a right to demand available and affordable assistive technology.”*<sup>6</sup>

6. A 2019 UN report published by the Special Rapporteur on the rights of persons with disabilities noted:

*“Discrimination on the basis of age is both a human rights violation and a root cause of many abuses affecting older persons with disabilities... differential treatment on the basis of age is often considered permissible, and older persons, including those with disabilities, therefore do not enjoy the same rights on an equal basis with their younger peers.”*<sup>7</sup>

Accordingly, when we reference the Convention, we acknowledge that it is intended to apply to all people with disability equally, irrespective of age.

## **6. Assistive technology under the Sustainable Development Goals**

1. We understand that the new National Disability Strategy will be a critical tool in ensuring Australia is on track to meeting the Sustainable Development Goals, which serve as a roadmap for global development efforts to 2030 and beyond.
2. We refer the Department to a paper entitled 'Assistive products and the Sustainable Development Goals', published in the Journal of Globalization and Health in December 2016. This paper demonstrates how the provision of assistive technology is critical to the equitable achievement of the 17 Sustainable Development Goals.<sup>8</sup>
3. This point has also been reinforced by the World Health Organization, who state:

*“Access to assistive technology is a fundamental human right, a legal obligation for all countries within the Convention on the Rights of Persons with Disabilities and a prerequisite for the full and equitable achievement of the Sustainable Development Goals.”*<sup>9</sup>

## **7. Ending age discrimination in Australian disability policy**

*“For the first time in my life I am the direct victim of discrimination because of my age and heritage, rather than the lifelong subtle discrimination I have experienced because of my disability. Discrimination now at the very hands of the Government.”* – Consumer with Post-Polio Syndrome

1. We remind the Department that the National Disability Strategy is fundamentally about promoting, protecting and upholding the rights of people with disability. With this in mind, we implore the Government to urgently end the current system of age discrimination that has been thrust upon older people with disability who are excluded from the NDIS.
2. The right to equality and non-discrimination is a fundamental human rights principle that is at the heart of the Convention on the Rights of Persons with Disabilities. We refer the Department to the obligations set out under Article 5 of the Convention, which says that states parties:

*“Recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.”*

*“Shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.”<sup>10</sup>*

3. As the Department will be aware, the NDIS is governed by the NDIS Act. Section 22 of the Act states that a person must be under 65 at the time of making an access request to satisfy the age eligibility requirements for the scheme.<sup>11</sup> As such, older people with disability now make up the largest cohort of people with disability to be excluded from the NDIS. This includes:
  - People who were born with or acquired disability early in life who had already turned 65 when the NDIS was rolled out in their area
  - People over 65 who acquire disability as part of the ageing process
  - People over 65 who acquire disability through catastrophic injury
  - People over 65 who acquire disability due to the chronic, progressive and/or degenerative nature of a pre-existing condition.
  - People who are diagnosed with a disease or condition which creates disability after they turn 65.
4. If older people with disability were receiving an appropriate level of support under other service systems, this age cut-off would not be so problematic. Regrettably, this is simply not the case.
5. When the NDIS was introduced, it was assumed that older people who were not eligible for the scheme would be able to access support from the aged care system. Regrettably, This arrangement has failed to provide older people with equitable access to the services and supports they need.
6. The aged care system is based around principles of frailty and ageing, lacks specialist disability expertise and is ill-equipped to provide timely and equitable access to assistive technology. This point was reinforced in findings from the Legislated Review of Aged Care, which recognised that the current arrangements prevent the optimal provision of assistive technology to people with disability who are over the age of 65.<sup>12</sup>
7. There are a number of state and commonwealth programs outside the aged care system that can subsidise the cost of assistive technology for people who are excluded from the NDIS. At present, however, none of these pathways provide equitable or appropriate access to assistive technology. Existing service gaps will be explored further in section 8 of this submission.
8. Older people with disability describe the current arrangements as “inequitable”, “discriminatory”, “dehumanizing” and “unfair”. One focus group participant noted:

*“The great inequity about all of this is that if you were just under 65 when the NDIS came over to your area, you could remain on it (after you turned 65). We now have increasing numbers of people over the age of 65 who are receiving funding under the NDIS. Then there are people who missed out by six weeks, six months or a couple of years.”*

One gentleman we spoke with, a 67-year-old man with paraplegia, has experienced this inequity first-hand. He turned 65 less than one month before the NDIS became available in his area. Had he lived a little further south where the scheme was rolled out earlier, he would have met the age eligibility requirements and would have been able to continue receiving services under the NDIS beyond his 65th birthday.

9. We have also been made aware of examples where individuals would have met the NDIS age eligibility requirements when the scheme was being rolled out, but had not been informed by health or government services that they would need to apply before their 65th birthday. By the time they became aware of the age eligibility requirements, they had already turned 65 and were thus excluded from the scheme. As one of our focus group participants noted:

*“Nobody rang me or sent me an email to say ‘you only have until you turn 65 to get onto the NDIS. You might want to think about it.’”*

10. We note that the Parliamentary Joint Committee on Human Rights had expressed concern with the age eligibility requirements set out under the NDIS Act from as far back as 2013. In its report on the NDIS Bill 2012, the Committee noted:

*“This assumes that the aged care system does or will deliver all the forms of assistance support required and is organised in accordance with the principles and operates in compliance with the obligations set out in the CRPD (Convention on the Rights of Persons with Disabilities) and the NDIS. While the incidence of disability may increase with age, the assumption that a person who has lived with disability for many years can transition without difficulty to a different system that may be organised around different principles deserves further examination.”<sup>13</sup>*

11. In its report on the NDIS Bill, the Parliamentary Joint Committee on Human Rights recommended that the age 65 cut-off under the NDIS be reviewed as part of the two-year review of the NDIS Act. Submissions to the two-year review of the NDIS Act closed in September 2015. When the Department of Social Services was questioned about its revision of the age 65 cut-off as part of this review, it was stated that this fell outside the terms of reference of the review and, as such, had not been explored. To-date, the Australian Government has still not undertaken a comprehensive review of the appropriateness of current arrangements for people with disability who are over the age of 65.
12. We submit that The Australian Government’s failure to provide equitable and appropriate access to assistive technology to older people with disability constitutes a breach of its obligations under the Convention on the Rights of Persons with Disabilities. The Convention does not place any limitations on which people with disability have the right to access support. Access to assistive technology is a universal right that must be equitably promoted, protected and upheld for all people with disability irrespective of age. We refer the Department to the Report on the rights of older persons with disabilities that was published by the Special Rapporteur on the rights of persons with disabilities at the United

Nations in July 2019 for further guidance on this matter. The conclusion and recommendations from this report are set out in Appendix A.

### **Case study 1: Graham and Aaron**

Graham and Aaron both have Motor Neurone Disease (MND). They have lived in the same regional community since childhood and played football together in the same premierships teams many years ago. They have maintained a close friendship over the years and still mix in the same social circles.

Graham is 66 years old. He is not eligible for the NDIS as he was unable to apply for the scheme before his 65th birthday. He has been assessed as being eligible for a level 4 home care package under the aged care system but was advised that he would need to wait 12-18 months for a suitable package to become available.

Graham has been forced to self-fund ramp access to his home and modifications to his bathroom in the meantime. Without these urgent modifications, he would not have been able to remain living in his own home. While he has received some support to subsidise the cost of these modifications through state funding, donations, and fundraising events, his out of pocket expenses have still been significant. His need to rely on charity is also inconsistent with the principles articulated under the Convention on the Rights of Persons with Disabilities.

Things have been much more straight-forward for Aaron, who is 64 years old and is able to access support under the NDIS. His NDIS plan has enabled him to access fully funded assistive technology, including bathroom modifications and ramp access to his home. He is also able to ask for his NDIS plan to be reviewed if his circumstances change and he feels that he no longer has enough funding available to meet his needs.

### **Case study 2: David**

David has post-polio syndrome. The NDIS commenced roll out in his area 3 months after his 65th birthday and as such, he did not meet the age eligibility requirements for the scheme.

David requires the immediate use of a wheelchair, a lift chair and a shower chair as prescribed by an Occupational Therapist. He has applied for a home care package but has been told the waiting list is currently sitting at around 18 months. He has also attempted to access the equipment he needs through the Victorian aids and equipment program. He was told his needs were 'low priority', which meant he would be facing a similar waiting time under this program.

David and his wife have had to sacrifice their savings to purchase the specified equipment in the meantime as it was needed urgently. Had David been eligible for the NDIS, the equipment he needed would have been fully funded and he would have received it in a more timely manner.

### **Case study 3: Geoff**

Geoff is a polio survivor who lives in a residential aged care facility in Victoria. He uses a motorized wheelchair for mobility which now requires significant modification. It no longer meets his needs as he has experienced a progressive loss of function from the late effects of polio.

Unfortunately, there is still no dedicated funding available for assistive technology for people living in residential aged care in Victoria. Instead, there is an expectation that the aged care facility will fund and meet all of Geoff's needs. In reality though, the standard item the facility is required to provide is a manual wheelchair for mobility. This will not meet Geoff's requirements for seating and will not enable him to move around the facility independently. It will also prevent him from participating in social activities in the wider community.

It should be noted that many people managing the late effects of polio, like many others with physical disability, are forced to enter residential aged care at a younger age than other members of the community due to not being provided with the appropriate support. Unless significant home modifications are put in place, many are unable to meet basic care needs such as showering, dressing and mobility within the home. The economic reality of this will leave many people who are excluded from the NDIS with little choice but to move into residential care.

### **Recommendation 1:**

The new National Disability Strategy must urgently abolish Australia's ageist approach to the provision of services and supports to people with disability and equitably promote, protect and uphold the rights of older people with disability in line with Australia's obligations under the Convention on the Rights of Persons with Disabilities.

## **8. Overview of primary funding streams outside the NDIS**

Funding for assistive technology for people who are excluded from the NDIS is spread across multiple departments and not-for-profits at the state and commonwealth level. As such, the most appropriate pathway for accessing assistive technology remains very unclear to the consumer. The following sub-sections of this submission will set out the dominant funding pathways that were promised to provide support to people with disability who are excluded from the NDIS and highlight how these systems are falling short of people's needs.

## 8.1 The National Injury Insurance Scheme (NIIS)

1. The National Injury Insurance Scheme (NIIS) was intended to be rolled out alongside the NDIS to provide lifetime care and support to people who acquired disability through catastrophic injury. It was envisaged that the NIIS would cover catastrophic injuries caused by four types of accidents, including:
  - Motor vehicle accidents
  - Workplace accidents
  - Medical accidents
  - General accidents occurring in the home or in the community. <sup>14</sup>
2. Governments are yet to develop a national plan to guide the implementation of the four proposed streams of the NIIS across all states and territories. In the absence of an NIIS, many people who acquire disability through catastrophic injury are forced to access service systems that are ill-equipped to respond to their needs. One individual who has been affected by this issue is Chris English, who has recently appeared in the media to air his frustrations at the lack of support that is available to him. Chris acquired his disability through catastrophic injury at age 69. The newspaper article describing Chris' situation has been included below:

### **NDIS cut-off at 65 leaves older people with acquired disabilities in world of pain**

ABC Illawara, by Nick Rheinberger

Posted: 2 August 2019

Link: [www.abc.net.au/news/2019-08-02/quadruplegic-fights-discrimination-over-ndis-cut-off-at-65/11374748](http://www.abc.net.au/news/2019-08-02/quadruplegic-fights-discrimination-over-ndis-cut-off-at-65/11374748)

Chris English used to drive racing cars, but the only thing that he drives now is his electric wheelchair using his chin.

Mr English became a quadriplegic after he fainted and fell down some stairs last year.

"It happened on my 69th birthday," he said.

"I passed out for some reason, then woke up a few days later in an intensive care unit."

Mr English has had to give up his intricate work as a jeweller and his beloved garden, as well as his tireless work for the Kiama Lions Club.

But that is not the biggest problem.

Mr English and his wife, Bobbie, who is his full-time carer, said the real tragedy was that this accident happened at the age of 69.

If he was under 65, Mr English would have been eligible for an NDIS package worth more than \$100,000 a year, providing significant care and — most importantly — a sense of dignity.

But since he was over that age, he had to make do with an aged care supplement worth less than half that amount.

The couple said this was clearly a case of discrimination against older people with a disability.

"If Chris was 64 when this happened, he would have been eligible for the NDIS," Ms English said.

"And then it actually would have continued after he turned 65. But now we're capped at the maximum aged care subsidy, which might get us a carer for 60–90 minutes per day.

"I do everything else, with some help from the family. And there's no budget for respite care if I get sick."

Mr English said it did not make sense.

"Most accidents like this do happen to older people," he said.

### **Family and fundraising fills the gaps**

Mr English remains stoic about his condition, and his beloved Lions Club is keen to elect him as their president in the future.

But it is a struggle for his wife every day.

She is not only had to move from their home town of Kiama, they have had to turn to a fundraising website to get a suitable car to transport Mr English and his wheelchair.

If her husband's care becomes too much, the only option is to put him into a nursing home — and that is the last place Mr English wants to be.

"Before the accident, I didn't feel old," Mr English said.

"I've got nothing against aged care, but I want to be here at home."

This sense of unfairness has led Ms English to create a petition to "eliminate discrimination of older people with a disability".

Though she has had a sympathetic reception from her state member, Gareth Ward, who also happens to be the Minister for Disabilities, this is a federal issue, and Ms English hoped to travel to Canberra to present her argument to Stuart Robert, the Federal Minister for the NDIS.

### **NDIS cuts off at 65**

Mr Robert was unavailable for an interview with the ABC, and referred us to the Department of Social Services.

A spokesperson confirmed that "a person needs to have acquired their disability before the age of 65 and meet other eligibility criteria in order to be an NDIS participant".

"NDIS eligibility does however continue beyond age 64 for those who became NDIS participants before age 65," the spokesperson said.

"For those 65 and over, there is a range of supports available within the aged care system that can be accessed through My Aged Care, which may be suitable for older people with a disability."

While they wait for an audience with the minister, it falls to Ms English and family to take care of Chris.

They have now had to cut back on carers to five short mornings per week, and rely even more on family help.

That is taking a physical and mental toll.

"He's always been so sharp, with such an active mind," Ms English said.

"If they had their way, the Lions Club would take him to the local Driver Reviver van in the holidays so he could have a chat and keep telling them what to do."

## 8.2 The Commonwealth Continuity of Support Programme (CoS)

1. People who were excluded from the NDIS who were already receiving state-funded disability services prior to the roll out of the scheme were promised they would continue to access services under the Commonwealth Continuity of Support Programme (CoS).<sup>15</sup>
2. There are many people who have been excluded from the NDIS who are still not eligible for the CoS Programme, including:
  - People who had not been accessing state-administered specialist disability services prior to transition to the NDIS
  - People who were still on waiting lists for state-administered specialist disability services during transition to the NDIS
  - CoS Programme participants who transition into residential aged care.<sup>16</sup>
3. Even for those who do meet the eligibility requirements for the CoS Programme, the situation is very unclear. The 2019 Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities stated:

*“While the Commonwealth and State/Territory Governments have agreed to provide continuity of support through disability services outside the NDIS, in practice there is confusion and uncertainty about what services will continue to be provided and/or funded. Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government.”<sup>17</sup>*

4. Assistive technology is one area where ongoing boundary disputes have arisen between state and commonwealth governments. The 2019 edition of the CoS manual states:

*“... in the first instance, aids and equipment (including vehicle modifications) should be accessed through available State programmes.”<sup>18</sup>*

As will be demonstrated in section 8.4 of this submission, however, state-based programs are also currently falling short of people’s needs.

5. The federal Government has now announced that the "Disability Support for Older Australians" (DSOA) Program will replace the CoS Programme on 1 July 2021, stating:

*“The Government is committed to supporting vulnerable older people with disability aged 65 years and over (50 years and over for Indigenous people) who are not eligible for the NDIS. The DSOA will deliver specialist services to these older Australians. This funding will be more in line with the NDIS, and provide a more client-centred program. It will help to meet growing demand, from providers and consumers, for funding higher needs.”<sup>19</sup>*

While this sounds positive, the DSO Program will not close the assistive technology funding gap for the full breadth of people with disability who are excluded from the NDIS. This measure will only apply to the approximately 3,600 people who are

currently receiving support under the CoS Programme. The extent to which it will improve access to assistive technology for current CoS participants also remains unclear.

### **8.3 The aged care system**

Since 1 July 2019, all older people with disability who do not meet the age eligibility requirements for the NDIS or the Commonwealth Continuity of Support Programme have been required to access services from the aged care system.<sup>20</sup> There are two main programs that exist under the aged care system to provide support to people in their own homes. These are the Commonwealth Home Support Programme and the Home Care Packages Program.

#### **8.3.1 The Commonwealth Home Support Programme (CHSP)**

1. The Commonwealth Home Support Programme (CHSP) provides a range of entry-level services to support older people who require assistance at home.
2. The CHSP can provide up to \$500 of funding per person per calendar year for aids and equipment. While this cap can be increased to \$1,000 with appropriate supporting evidence from an occupational therapist, information about the cap increase is not always communicated to consumers.
3. Funding for assistive technology is provided under a service category entitled 'Goods, Equipment and Assistive Technology'. Unfortunately, not all aged care planning regions are funded for this service type under the CHSP. Even in regions where funding is available, it still may not be available for all types of assistive technology that are required by people with disability.<sup>21</sup>
4. The CHSP manual states:  
  
*"The CHSP is not designed to replace existing state managed schemes which provide medical aids and equipment (e.g. Medical Aids Subsidy Scheme). CHSP service providers are encouraged to access these state and territory aids and equipment programs where appropriate."*<sup>22</sup>
5. While this implies that consumers can access support through state-based assistive technology programs instead of using the limited funds available under the Commonwealth Home Support Programme, there is no national consistency in how this applies. Furthermore, as will be demonstrated in section 8.4 of this submission, existing state-based aids and equipment programs are currently falling well short of people's needs.

#### **8.3.2 Home Care Packages Program**

1. The funding available under the Commonwealth Home Support Program falls significantly short of the needs of many people with complex and high needs for support, which means they are usually forced to try and access services under a Home Care Package instead. The Home Care Packages Program provides support to older people with complex needs to help them stay at home.

2. There are four levels of annual funding available under the Home Care Packages Program which are set at pre-determined levels. Home Care Packages differ from the NDIS in that the amount of funding allocated is not determined by a person's individual needs. The four pre-determined funding levels are as follows:
  - Level 1: \$8,927.90
  - Level 2: \$15,705.95
  - Level 3: \$34,174.95
  - Level 4: \$51,808.10 <sup>23</sup>
  
3. Many older people with disability with complex and high needs for support are assessed as eligible for either a level 3 or 4 package. Unfortunately, the waiting list to receive one of these packages currently sits at around 12-18 months. As a result, 19,000 Older Australians per year are being forced into residential care because they can't access the support they need to stay at home.<sup>24</sup>
  
4. While NDIS participants have access to fully funded aids and equipment and are not required to make any financial contribution towards their care and support needs, people accessing the Home Care Packages Program are required to pay a range of different fees, including a daily basic fee and an income-tested care fee.<sup>25</sup>
  
5. Older people with disability can have significant difficulty funding the aids, equipment and home modifications they need out of a home care package. The limited funds available mean that people with disability are often forced to trade off one vital service to be able to afford another. If someone needed a new power-assisted wheelchair to be funded in a particular calendar year, for example, this could leave them with little to no funding left over to cover the costs of attendant care support, home maintenance or any of the other services they may require.

**Case study 4: Lyn**

A polio survivor, Lyn, is waiting on a Level 4 Home Care Package. Lyn requires a range of assistive technology, and also daily assistance in her home. While she currently has equipment, it will need replacing in future as well as regular maintenance and repair. The equipment she currently requires includes:

Wheelchair	\$18,000
Shower chair	\$1,680
Ceiling hoist	\$8,861
Corset	\$800
<b>TOTAL COST</b>	<b>\$29,341</b>

If the above equipment were to be purchased under her Level 4 package, this would leave \$20,909 remaining (equal to just over \$57 per day). This amount is required for daily care in her home (including operation of the hoist in/out of bed and showering), maintenance/repair

of the equipment and all other expenses she may have. With administration fees for a Level 4 package likely to be around \$11,000, there is very little available funding remaining.

Lyn was offered a Level 2 Home Care Package in the meantime, valued at \$15,000 per year. This would have been inadequate for her care needs, only covering assistance with operation of the hoist in/out of bed and showering for 3 days a week (leaving her in bed for the other 4 days) and would offer absolutely no allowance for assistive technology.

Had Lyn been eligible for the NDIS, the aids and equipment she urgently required would have been discussed in her planning meeting. The package of funds allocated for the next 12 months would be calculated around these needs so that she would have access to an appropriate level of support.

#### **8.4 State-based aids and equipment programs**

1. Despite there being an assumption that an individual's assistive technology needs can still be dealt with at the state level, existing state-based aids and equipment programs currently fall well short of people's needs.
2. Key policy and program issues can be summarised as follows:
  - Most state-based programs remain grossly underfunded. There has been no commitment to growth to keep up with the increasing costs of assistive technology. Using Queensland as an example, we know that funding for the state-based Medical Aids Subsidy Scheme (MASS) has not been increased since 2008. In fact, funding for the scheme has actually decreased because there is an expectation that it will no longer service people who are eligible for the NDIS. We know that aids and equipment programs in other states have followed similar trends.
  - People accessing state-based programs are still expected to make a significant, and often prohibitive, financial contribution towards the cost of their assistive technology.
  - Many people accessing state-based programs continue to be plagued by long waiting lists. This prevents them from accessing support when they need it most; with a person's assistive technology needs often having changed significantly between the date of prescription and receipt of the technology that has been recommended.
  - People accessing state-based aids and equipment programs do not have the same level of choice and control that is afforded to participants under the NDIS. There are a range of approved products that can be funded under each program. As such, not all equipment that is required by people with disability can be funded.
  - People living in residential aged care are unable to access assistive technology under existing state-based aids and equipment programs. There is currently no other pathway available to provide people living in care with the specific equipment they need.

- Some state-based programs prevent people from accessing funding if they are already in receipt of, or on the waiting list for a home care package.<sup>26</sup> As demonstrated in section 8.3.2 of this submission, however, home care packages do not provide people with timely or appropriate access to assistive technology.

#### **Case study 5: Sandra**

Sandra is a 38-year-old woman who lives in Victoria. She has an incomplete spinal injury as a result of a horse riding accident she was involved in several years ago.

Sandra spent her first 3 and a half years post-spinal injury without NDIS funding after being rejected for the scheme several times. She relied largely on hand-me-down assistive technology, including a second-hand walker from a friend's Mum and an old manual wheelchair from a friend with footrests taped on with gaffa tape. These solutions did not meet her needs and she found herself not joining in on social activities, outings with her family or doing any hobbies because she was so exhausted after getting around at work.

Sandra couldn't afford the allied health services she needed to learn to use her mobility equipment appropriately. This led to misuse and fatigue. She also had to pay for all repairs and maintenance on her assistive technology herself. This often meant that she went long periods without being able to get around while she saved up for the repairs that were needed.

Sandra received funding for her intermittent (single use) catheters through the Victorian State-Wide Equipment Program and the Federal Continence Aids Payment Scheme. She was unable to access funding for the self-lubricating catheters that best met her needs though, and had to make do with a cheaper model instead. She suffered from frequent urinary tract infections as a result.

After several rejections, Sandra was eventually accepted onto the NDIS. As an NDIS participant, she can finally afford the mobility supports she needs to achieve her work and personal life goals. She also now has a catheter that better meets her needs and her health has improved as a result.

Sandra worked out that she had been paying about \$30,000-\$40,000 per year out of her own pocket for assistive technology and related allied health supports before she was accepted into the NDIS. In order to meet these costs, she was required to go without other services and supports. She needed to make ends meet and cut down in other areas of her and her family's life.

Sandra knows how the systems outside the NDIS are failing people with disability, because she's experienced things from both sides. While she is grateful for the fact that she now has better access to services under the NDIS, she knows there are many people who are still excluded who cannot get the help they need.

## 9. Outcome areas proposed for the new National Disability Strategy

1. While we broadly support the six outcome areas that have been proposed for the new Strategy, we submit that the area of personal support must be given higher priority. This is because personal supports such as assistive technology are key enablers that allow people with disability to exercise their rights in all areas of life. As one of our focus group participants noted:

*“What we’re talking about here is just basic needs. It’s nothing special. It’s just the basic supports that we need to help us live a normal life.”*

2. Without timely access to personal supports such as assistive technology, the Department cannot expect to achieve significant change under the other outcome areas that have been proposed for the new National Disability Strategy. As stated by the World Health Organization:

*“Assistive technology enables people to live healthy, productive, independent, and dignified lives, and to participate in education, the labour market and civic life. Assistive technology reduces the need for formal health and support services, long-term care and the work of caregivers. Without assistive technology, people are often excluded, isolated, and locked into poverty, thereby increasing the impact of disease and disability on a person, their family, and society.”<sup>27</sup>*

3. We have provided further commentary on the relationship between assistive technology and the other proposed outcome areas for the Strategy under the following subsections of this submission.

### 9.1 Rights protection, justice and legislation

1. The current National Disability Strategy lists the following policy directive under the outcome area of ‘Rights protection, justice and legislation’:

*“People with disability to be safe from violence, exploitation and neglect.”<sup>28</sup>*

2. The timely provision of appropriate assistive technology helps to ensure people with disability have the prerequisite tools necessary to uphold their rights, safeguard themselves against harm and act on any instances of abuse that may occur.
3. Without timely access to appropriate assistive technology, many people with disability are forced to rely on other people for support. This increased dependency can contribute to heightened levels of carer stress. This is problematic when considering that dependency and carer stress are both well documented risk factors for providing the precondition under which abusive relationships occur.<sup>29 30</sup>
4. Research shows that people with disability are also less likely to report abuse or take steps to leave an abusive relationship when they are still heavily reliant on their abuser for support.<sup>31</sup>

### 9.2 Health and wellbeing

*“It’s hurting my back because I don’t have the right brace.” – Consumer with Post-Polio Syndrome*

*“If we don’t have the equipment we need to stay mobile, this can have an enormous impact on our health.” – Consumer with spinal cord injury*

1. Research shows that improving access to assistive technology can:

- Improve health outcomes
- Prevent secondary health conditions
- Reduce the risk of falls
- Reduce hospital admissions.
- Delay entry to residential care.<sup>32 33</sup>

These points were all validated during the focus group we held to inform this submission.

1. Many assistive products facilitate mobility and help people with disability to remain physically active. These products play a critical role in maintaining good health, as we know that sedentary behaviour is linked to poorer health outcomes.<sup>34</sup>

As one of our participants stated:

*“Without assistive technology, I can’t even get out of bed.”*

2. It becomes even more important for people to maintain their mobility as they age, with some estimates suggesting that around half of the physical decline associated with old age can be attributed to physical inactivity.<sup>35</sup> Providing people with disability with timely access to the assistive technology they need can therefore help facilitate healthy ageing.

3. Several of our focus group participants spoke about their fear of becoming socially isolated as a result of not having access to the assistive technology they needed, with one participant noting:

*“You get secluded and you isolate yourself. If you don’t get the equipment you need you stay at home.”*

It is worth noting that social isolation and loneliness have been linked to a range of health problems, including mental illness, emotional distress, suicide, dementia, problems with sleep, high blood pressure, lowered immunity and premature death.<sup>36</sup>

4. Mental health was another recurring theme, with one participant revealing that her diagnosis of mental illness had been exacerbated by concerns associated with how she would continue to pay for the assistive technology she needed. Several participants agreed that the current lack of access to assistive technology had impacted on their level of motivation, with one consumer stating:

*“You get worn down. You get cynical. You just don’t want to try anymore because you don’t want to get knocked back yet again.”*

5. A number of participants spoke about being at increased risk of accident or injury as a result of not having access to appropriate assistive technology. One consumer

noted that he'd had one of the wheels fall off his wheelchair while he was in the middle of an online meeting. Another spoke about having to manufacture her own hoist because she could not access funding for a proper one, which posed a significant safety risk.

6. We note that the Australian Government has set a target to ensure there are no people with disability under the age of 65 entering residential aged care by 2022.<sup>37</sup> The 2020-21 budget also includes \$10.6 million for The Younger People in Residential Aged Care Strategy to help keep younger people with disability out of aged care.<sup>38</sup> While we strongly support these initiatives, it is disappointing that the Government is not taking proactive steps, such as the timely provision of individualised assistive technology, to prevent people with disability who are over the age of 65 from having to unnecessarily enter residential aged care as a system of last resort. It is ageist and discriminatory to assume that anyone's life is of less value just because they happen to be over 65.

#### **Case study 6: Margaret**

*Other relevant outcome area:*

- *Rights protection, justice and legislation*

67-year-old Margaret was diagnosed with Parkinson's Disease 11 years ago. She lives at home with her husband Kevin and her need for assistance has increased significantly in the past 2 years.

Margaret has been assessed as being eligible for a level 4 Home Care Package under the aged care system. She has now been waiting 18 months for a level 4 package to become available, but has been granted access to a level 2 package in the meantime. The level 2 package does not meet Margaret's complex and increasing needs, resulting in added emotional and financial stress for her and her family.

Margaret's immediate need is a powered adjustable bed, which would assist her to safely get in and out of bed, reduce carer strain and stress, help with swallowing of saliva/less coughing, reduce the risk of aspiration-related pneumonia (a leading cause of death in Parkinson's), and improve much needed sleep for both Margaret and Kevin. Margaret also needs a powered lift chair that would assist her to stand up from a sitting position, placing less physical strain and dependence on Kevin. Margaret and Kevin are unable to self-fund the bed and chair as they have already paid for other essential equipment and services that the aged care system has not been able to provide.

### **9.3 Inclusive and accessible communities**

*"Being able to get out of your home and being able to socialise is really difficult." – Consumer with spinal cord injury*

*"Not having access to assistive technology can stop us from doing what we want to do" – Consumer who is blind*

1. The current National Disability Strategy lists the following policy directive under the outcome area of inclusive and accessible communities:

*“Increased participation of people with disability, their families and carers in the social, cultural, religious, recreational and sporting life of the community.”*

2. We submit that this objective cannot be achieved unless people with disability are provided with appropriate access to the assistive technology they need. This was recognised in the 2019 ‘Right to opportunity’ report that was developed after the first round of consultations to inform the development of a new National Disability Strategy. The report stated:

*“Access to aids and assistive technology was seen as a major issue and crucial for improving access in the community, and the inclusion of people with disability in community activities.”* <sup>39</sup>

3. Our focus group participants cited several examples where they had been cut off from their communities as a result of not having access to the assistive technology they needed. Alarming, one consumer had been left completely housebound for 6 months in the absence of the critical equipment she required to leave her home.
4. Participants also felt that there was a disconnect between the aspirations of the NDIS and other service systems. They noted that people who were eligible for the NDIS were able to have assistive technology funded to help them meet their individual goals and increase their participation in community activities. It was agreed that the same opportunities were not afforded to those who were excluded from the scheme, with one participant noting:

*“We have to fight tooth and nail for the bare basics we need to survive. We can’t access funding for other things that would help us do the things we want to do and improve our quality of life.”*

As an example, we spoke to a prosthetic user who enjoyed ice skating, rollerblading and cycling for social and physical health and wellbeing. He explained that he could only access funding for a walking foot which did not offer the appropriate dynamics for these activities. If he could not find a way of funding an appropriate prosthesis himself, he would have been forced to give up these activities altogether.

#### **Case study 7: Amir**

*Other relevant outcome areas:*

- *Rights protection, justice and legislation*
- *Health and wellbeing*

Amir is in his early 70s. He sustained a level C4 spinal cord injury 42 years ago and needs a new power drive wheelchair to help him get around. His chair is his primary mobility device and he cannot access his community without it. He needs to sit in it for most of the day, so it has to be customised to provide him with an appropriate level of autonomy and comfort and prevent potentially serious or fatal pressure wounds from developing. As such, he needs a chair with

customised seating, power seat functions and customised chin control. The chair he needs has been priced at \$32,000.

Unfortunately, Amir is only eligible to access a subsidy of around \$15,000 under the Queensland state-based aids and equipment program (Medical Aids Subsidy Scheme). This leaves him with an out of pocket expense of around \$17,000 which he cannot afford.

#### **9.4 Economic security**

*“We are now being asked to work longer than ever before – well over 65. But there’s no support available to help us to do this.” – Consumer with lower limb amputation*

*“I want to keep working. I’m prepared to go and work. With the right assistive technology I can do all of the things that are necessary and give myself longevity in work. With this support I can contribute and keep paying my taxes. But they don’t want to know me.” – Consumer with Post-polio syndrome*

1. The current National Disability Strategy lists the following policy directive under the outcome area of economic security:

“Increase access to employment opportunities as a key to improving economic security and personal wellbeing for people with disability and their families.”

2. All Australians have the right to remain in paid employment for as long as they choose, including Australians with disability. In 2018, the Australian Bureau of Statistics highlighted that 13% of the workforce was comprised of people aged over 65 - evidence of the fact that many Australians are exercising their right to work well into their later years. This figure will most likely increase as the population ages and peoples’ retirement intentions continue to change.<sup>40</sup>
3. Regrettably, we have spoken to several older people with disability who have been forced to give up work as a result of not having access to the assistive technology they’ve needed. We have also spoken to consumers who are currently in the workforce, but feel that they will be left with no choice but to retire early if the current funding landscape does not change.
4. As demonstrated in the case studies included throughout this submission, many people with disability who are excluded from the NDIS are forced to self-fund the assistive technology they need – often at considerable expense. This erodes peoples’ finances, meaning they have less money to spend on other things that are important for their socio-economic wellbeing and quality of life.

#### **Case study 8: Dennis**

*Other relevant outcome areas:*

- *Rights protection, justice and legislation*
- *Health and wellbeing*
- *Inclusive and accessible communities*

Dennis is a 70-year-old man of proud Aboriginal heritage. He has lived with a physical disability since the age of 3 when he contracted Polio. Dennis has carved a successful professional life for himself in commercial radio and broadcasting. He still works part-time in radio and has every intention of continuing to do so for as long as he can.

Dennis was 63 years old when the NDIS Act was passed. He was hopeful and excited that he would be able to benefit from this new scheme. His only need was to be able to access the modern braces, training and ongoing support that have become available for people with post-polio syndrome.

Advice from specialists had confirmed that Dennis was a perfect candidate for a new brace developed by Ottobock called the C-Brace. This brace promised to restore Dennis' quality of life and enable him to remain mobile and active. It has been proven to reduce falls and decrease joint and back pain for many polio survivors. It also provides the user with the ability to walk up and down stairs which is something Dennis cannot do with his current locked/stiff leg designed brace.

Dennis did not immediately sign up for the NDIS when it became available in his area, although he was under 65 and would have been eligible for the scheme at this time. It wasn't until he had undergone an operation that was designed to surgically straighten and lengthen his affected leg in readiness for the new brace, that he found out the brace would not be funded under the NDIS due to his age. Dennis had never been informed that there was an age limit on the services provided under the NDIS and that he would need to opt into the scheme before his 65th birthday. As a result, he missed out on the opportunity to access the scheme at a time when his age would not have been a barrier.

The C-Brace costs \$80 000 and cannot be funded under the NSW state-based aids and equipment program or the aged care system. This leaves Dennis to rely on a 'straight leg' brace or wheelchair, with continuing deterioration of his joints and severe back pain. As Dennis' condition continues to deteriorate, so too will his quality of life and capacity to work.

Dennis knows of several Australian polio survivors under the age of 65 who have had the C-Brace fully funded under the NDIS. He has seen the difference the new brace has made for these people and is frustrated that the Government will not allow him to access the same opportunities. Dennis says it is unfair that funding bodies currently expect older polio survivors to walk around with the older locked/stiff leg systems and endure the pain that comes with them, including joint and back pain and an increased risk of falls. He feels stripped of his dignity as he is told he is too old to be helped.

### **Case study 9: Robert and Steve**

*Other relevant outcome areas:*

- *Rights protection, justice and legislation*
- *Health and wellbeing*
- *Inclusive and accessible communities*

Robert does not meet the age eligibility requirements for the NDIS. He has had to access support under his state-based Artificial Limb Scheme which does not provide him with appropriate access to assistive technology. He has no choice over the type of prosthesis he receives and currently uses a mechanical knee unit which is not suited to his individual needs. This compromises his safety as it results in regular falls. He also has a very basic prosthetic foot which does not provide energy return and leads to fatigue. His endurance levels are poor due to the physical effort required to drive the prosthesis and he is mentally fatigued as he needs to concentrate with every step he takes to prevent his foot from rolling on a stone or crack in the pavement – also potentially leading to falls.

Robert has made minimal modifications to his home because he would need to self-fund them and he is not in a financial position to do so. Consequently, he only uses a board across his bath for personal washing and does not have grip bars in the wet areas (bathroom, toilet). This further increases his risk of falls.

Up until last year, Robert worked full-time. Unfortunately, the regular falls he experiences have had a significant impact on his body and he has had to reduce his work hours to part-time as a result.

By contrast, Steve is 61 years and has access to an array of fully funded reasonable and necessary supports under his NDIS Plan. This is because he is several years younger than Robert and meets the age eligibility requirements for the scheme. The NDIS has enabled him to trial a variety of prosthetic devices to determine which one best meets his needs. He was subsequently funded for a Microprocessor Knee Unit (MPK) and energy storing foot in his first NDIS Plan two years ago. All of the home modifications Steve has needed have also been funded through his NDIS Plan, including a ramp at the rear of his home and a fixed set in his now accessible shower.

Steve is able to lead an active lifestyle with his wife and two children because he has had access to the appropriate assistive technology to facilitate this. And unlike Robert, he has never experienced a fall because the knee unit prevents him from falling. Steve continues to work full time.

### **9.5 Learning and skills**

The current National Disability Strategy places a strong emphasis on lifelong learning from childhood through to adulthood. While many older adults want to learn new skills, they

may sometimes require the use of specialized assistive technology to facilitate their participation in educational activities.

### Case study 10: Laura

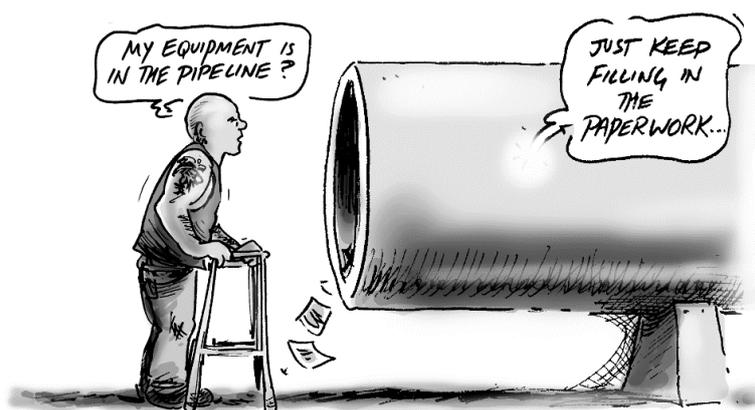
*Other relevant outcome areas:*

- *Rights protection, justice and legislation*
- *Inclusive and accessible communities*

Laura is 70 years old and has retinitis pigmentosa, a condition which causes progressive vision loss. Up until recently, Laura had quite good usable vision. Over the past 12 months though, her remaining vision has deteriorated to the point where she can no longer read print.

Now that Laura is retired, she is interested in taking up a few short courses that are offered by the University of the Third Age and her local community college. Because she can no longer use screen magnification though, she has no way of accessing course information or taking notes.

Laura wants to learn how to navigate her home computer and iPad using specialised text-to-speech software so she can complete the courses she is interested in. She wants to learn how to send and receive emails, navigate the internet and create and edit documents using this new software. Because she is completely new to this technology, it may take quite a few hours of training to enable her to meet these goals. A blindness service provider has quoted Laura \$180 per hour to provide the training she needs, which aligns with the NDIS price guide. As a recipient of a level 2 home care package, she is unable to afford this training as this would force her to go without other vital forms of support. Whether or not she could even have this training funded out of her Home Care Package also remains unclear.



### Recommendation 2:

While we broadly support the six outcome areas that have been proposed for the new National Disability Strategy, we assert that the outcome area of personal support must be given higher priority. This is in recognition of the fact that personal supports such as assistive technology facilitate autonomy, safety and independence. They are key enablers for inclusion and participation which will help to deliver successful outcomes under each of the remaining priority areas that have been proposed for the new strategy.

## 10. Government roles and responsibilities

1. We strongly support the need for greater clarity around the roles and responsibilities of State and Commonwealth Governments, particularly in relation to people with disability who are excluded from the NDIS. This includes:
  - People with disability over the age of 65 who do not meet the age eligibility requirements for the scheme
  - Approximately 800,000 people with disability under the age of 65 who may not satisfy the other eligibility requirements for the scheme.<sup>41</sup>
2. As noted in the Department's position paper, funding responsibilities relating to specialist disability supports were previously set out under the National Disability Agreement. This agreement has not been updated since 2009, despite the fact that the funding landscape has changed dramatically since the implementation of the NDIS. This has resulted in significant service gaps for people with disability who are excluded from the scheme – particularly in the area of assistive technology.
3. We refer to the Productivity Commission's 2020 report on the Review of the National Disability Agreement, which recommended that the Australian, State and Territory Governments develop and enter into a new National Disability Agreement by the beginning of 2020.<sup>42</sup> It is our understanding that the Department has no intention of entering into a new Agreement and is instead seeking to capture Government roles and responsibilities under the revised National Disability Strategy.
4. The Department's position paper states that the new Strategy will:
  - Link to relevant publicly available information which summarises the role of the NDIS and outlines the roles and responsibilities that have already been agreed between governments.
  - Link to the Principles to Determine the Responsibilities of the NDIS and Other Service Systems and accompanying Applied Principles and Tables of Service (APTOS).<sup>43</sup>
5. We submit that it is not enough to simply refer to existing documents that do not provide an appropriate level of clarity in relation to funding arrangements and responsibilities. In reference to the Principles to Determine the Responsibilities of the NDIS and Other Service Systems, for example, the 2019 Civil Society Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities noted:

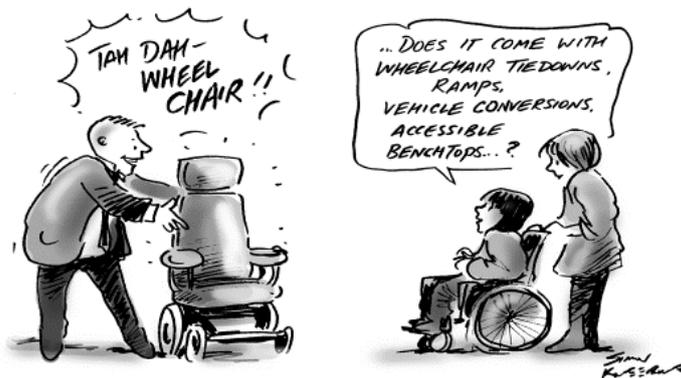
*"... the Principles are subject to interpretation and lack clarity. This is resulting in boundary issues and funding disputes, which can lead to reduced or no access to services for people with disability not eligible for the NDIS."*<sup>44</sup>
6. In 2017, the Productivity Commission recommended that prior to full roll out of the NDIS, all governments clarify the services they intend to provide to people with disability beyond those delivered through the scheme. A similar recommendation was made by the Joint Standing Committee on the NDIS in 2018. To-date, however, state and territory

governments have published very little information to clarify what services they will continue to provide to people with disability who are excluded from the NDIS.<sup>45</sup>

In reference to this fact, the 2019 Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities stated:

*“While the Commonwealth and State/Territory Governments have agreed to provide continuity of support through disability services outside the NDIS, in practice there is confusion and uncertainty about what services will continue to be provided and/or funded. Some disability supports are not being provided because of unclear boundaries about the responsibilities of the different levels of government.”<sup>46</sup>*

7. The Productivity Commission’s 2020 report on the Review of the National Disability Agreement recommended that:  
*“To facilitate greater clarity in responsibilities, governments should articulate and publish which programs they are rolling into the NDIS and how they will support people with disability who are not covered by the NDIS. They should also undertake a comprehensive gap analysis, with the new NDA outlining responsibilities for addressing any gaps.”*
8. While we accept that the Department does not wish to enter into a new National Disability Agreement, there is still a significant amount of work that needs to be undertaken to clarify funding arrangements and address existing service gaps for people with disability who are excluded from the NDIS. To this end, the new National Disability Strategy must clearly outline who will be responsible for funding assistive technology (including home modifications) for:
  - People with disability over the age of 65 who do not meet the age eligibility requirements for the NDIS
  - People with disability under the age of 65 who do not meet the eligibility requirements for the NDIS.
9. The new National Disability Strategy must also consider funding arrangements associated with each individual component of the assistive technology journey, including:
  - Skilled assessment and referral
  - Equipment trials and demonstrations
  - Equipment customisation
  - Purchase/installation of customized aids, equipment and home modifications
  - Specialised training.
  - Equipment maintenance and repairs.
10. Finally, the new National Disability Strategy must establish a framework for driving equitable outcomes across service systems to ensure all people with disability have access to the support they need. It is discriminatory and unjust, for example, to expect a 70-year-old to make a \$17,000 contribution towards the cost of a wheelchair that a 64-year-old would receive under the NDIS free of charge (see case study 7).



### Recommendation 3:

In the absence of a new National Disability Agreement, the Australian, State and Territory Governments must urgently fund and implement outcomes under the National Disability Strategy to clearly outline who will be responsible for funding assistive technology (including home modifications) for:

- People with disability who are over the age of 65 who do not meet the age eligibility requirements for the NDIS.
- People with disability who are under the age of 65 who do not meet the eligibility requirements for the NDIS.

### Recommendation 4:

The new National Disability Strategy must clearly identify funding arrangements and responsibilities associated with each individual component of the assistive technology journey, including:

- Skilled assessment and referral
- Equipment trials and demonstrations
- Equipment customisation
- Purchase/installation of customised aids, equipment and home modifications
- Specialised training
- Equipment maintenance and repairs.

### Recommendation 5:

The new National Disability Strategy must establish a framework to drive nationally consistent outcomes across service systems to ensure all people with disability have equitable access to the assistive technology they need.

## 11. Targeted action plans to drive implementation

*“We need less fragmentation. There’s a lot of fragmentation at the moment. The Government could streamline access to services to make the system better for everyone.” – Consumer with spinal cord injury*

1. We advocate the need for a targeted action plan to guide the provision of assistive technology for people with disability who are excluded from the NDIS. This matter requires urgent attention, as Issues relating to the provision of assistive technology to this cohort have remained outstanding since the current Strategy was introduced a decade ago.
2. In 2009, the National People with Disabilities and Carer Council undertook an extensive consultation process to inform the development of the current National Disability Strategy. The issues associated with access to assistive technology were well documented within the final consultation report, which noted:

*“There are currently multiple aids and equipment schemes operating across the country. Many submissions argued that a nationally coordinated and funded equipment scheme would eliminate existing inequities and ensure portability across jurisdictions.”<sup>47</sup>*

3. The NDIS has reduced fragmentation and streamlined access to assistive technology for eligible people with disability. The situation for those outside the scheme, however, remains unchanged. Funding for assistive technology for people who are excluded from the NDIS is still spread across multiple state and federal government departments and not-for-profits, leading to widespread confusion and inequitable access. We refer to the assistive technology funding map that has been developed by the Australian Rehabilitation and Assistive Technology Association, located at Appendix B. We note that the Department of Health recently commissioned Australian Health Care Associates to undertake a comprehensive review of assistive technology programs in Australia. While the final report from this review represents an updated source of data on current assistive technology programs, it is still not in the public domain.<sup>48</sup>
4. The 2009 consultation report that was developed to inform the current National Disability Strategy also referenced a number of other barriers to accessing assistive technology, stating:

*“Lack of availability or lengthy waiting periods forces people with disabilities and their families into purchasing aids and equipment themselves, often at considerable expense. When beyond the budget, people with disabilities are forced to go without for extended periods of time. Either way, the quality of life of people with disabilities and their families is significantly compromised. Submissions also discussed difficulties with fitting, adjustments, modifications and repairs. Some noted that even when available, equipment is not always suitable.”<sup>49</sup>*

5. The NDIS has gone a long way to resolving these issues for the 10% of people with disability who are eligible for the scheme. It is underpinned by a dedicated assistive technology strategy and has the capacity to fully fund the assistive technology that is needed by

people with disability, irrespective of where or how their disability was acquired.<sup>50</sup> The Australian Government has also now committed to implementing an NDIS Participant Service guarantee to cut waiting times and improve access to services for NDIS participants; with a strong focus on improving timely access to appropriate assistive technology. As demonstrated throughout this submission, however, the situation for people with disability who are excluded from the NDIS has not improved. In many respects, access has actually been further complicated as a result of outdated funding agreements and boundary disputes between state and commonwealth governments.

6. In summary, long waiting lists, prohibitive co-payments and funding shortages mean that people who are excluded from the NDIS are still forced to:
  - Go without the assistive technology they need
  - Self-fund assistive technology, often at significant personal cost
  - Trade off one service over another
  - Continue using outdated or inappropriate aids which are not fit for purpose
  - Go without access to individual therapist support and advice, equipment trials and demonstrations
  - Go without suitable training to enable them to gain the maximum benefit from their assistive technology.
7. We assert that the above issues would best be resolved through the establishment of a harmonised and nationally consistent assistive technology program to support people with disability who are excluded from the NDIS. This approach would simplify current funding arrangements while providing people with the technology they need to lead better quality lives and maintain their connection in the community.
8. A national assistive technology program would:
  - Harmonise existing state-based assistive technology programs and those operated by not-for-profit organisations. This would streamline access and drive nationally consistent outcomes for consumers while reducing administrative burden on governments
  - Be aligned with the NDIS Assistive Technology Strategy to address the inequity between the support that is provided under the NDIS and other service systems
  - Be driven by key performance indicators relating to the timely provision of equipment, in line with the aspirations of the NDIS Participant Service Guarantee.
9. The program would need to be adequately funded to cover:
  - Skilled assessment and referral, particularly in complex cases where an individual's capacity can quickly diminish or change
  - The provision of high- and low-cost aids and equipment
  - Customisation
  - Training to enable participants to use assistive technology safely and effectively
  - Maintenance and repair of assistive technology.
10. To be eligible for the program, participants would need to:
  - Have a disability or long-term health condition that affects activities of daily living
  - Have a disability or long-term health condition that is non-compensable

- Not be eligible for the NDIS.
11. Eligibility for the program would not be impacted by:
- The age of the applicant
  - The applicant being on a waiting list or in receipt of (non-NDIS) services such as those provided under the aged care system.

**Recommendation 6:**

The new National Disability Strategy must include a funded action plan to provide urgent and equitable access to assistive technology for people with disability who are excluded from the NDIS.

**Recommendation 7:**

The new National Disability Strategy must prioritise the establishment of a funded National Assistive Technology Program to streamline access and provide equitable support to people with disability who are excluded from the NDIS. This program should:

- Harmonise existing state-based assistive technology programs and those operated by not-for-profit organisations. This would streamline access and drive nationally consistent outcomes for consumers while reducing administrative burden on governments
- Be aligned with the NDIS Assistive Technology Strategy to address the inequity between the support that is provided under the NDIS and other service systems
- Be driven by key performance indicators relating to the timely provision of equipment, in line with the aspirations of the NDIS Participant Service Guarantee.



**12. Concluding comments**

Thank you for providing The Assistive Technology for All Alliance with an opportunity to submit feedback to inform the development of a new National Disability Strategy for 2020 and beyond. It is essential that all people with disability have access to the assistive technology they need to facilitate their full and effective participation in the community and exercise their rights. As noted

throughout this submission, the current Strategy has failed to improve access to assistive technology for people with disability who are excluded from the NDIS. It is our hope that the revised Strategy will establish a framework to drive equitable outcomes across service systems to ensure all people with disability have access to the assistive technology they need into the future.

If you require further information in relation to any of the points that have been raised throughout this submission, please contact Assistive Technology for All Alliance Coordinator, Lauren Henley. Lauren works in the role of Policy Officer at Council on the Ageing Victoria. She can be contacted by phone on (03) 9655 2140, or by email at [LHenley@cota.vic.org.au](mailto:LHenley@cota.vic.org.au).

## **Appendix A: Conclusion and Recommendations from Report on the rights of older persons with disabilities, published by the Special Rapporteur on the rights of persons with disabilities in July 2019**

Note: The full report can be downloaded from: <https://undocs.org/en/A/74/186>

Older persons with disabilities encounter significant barriers to the exercise of their rights owing to the intersection between ableism and ageism. Such barriers include stigma and stereotypes; discriminatory laws and practices; denial of autonomy and legal capacity; institutionalization and lack of community support; violence and abuse; and lack of adequate social protection. Many of these human rights violations are frequently regarded as normal and rendered invisible to Governments, deepening the circle of discrimination and exclusion of older persons with disabilities.

The Convention on the Rights of Persons with Disabilities represents an opportunity to shed light on the multiple and intersecting forms of discrimination experienced by older persons with disabilities and to take action to ensure that older persons with disabilities enjoy all their human rights on equal basis with others. The effective application of a rights-based approach at the intersection between older age and disability needs to be accompanied by a paradigm shift with respect to society's perception of ageing and older persons. While impairment might be a normal aspect of ageing that should be embraced as part of human diversity, discrimination and social exclusion are not.

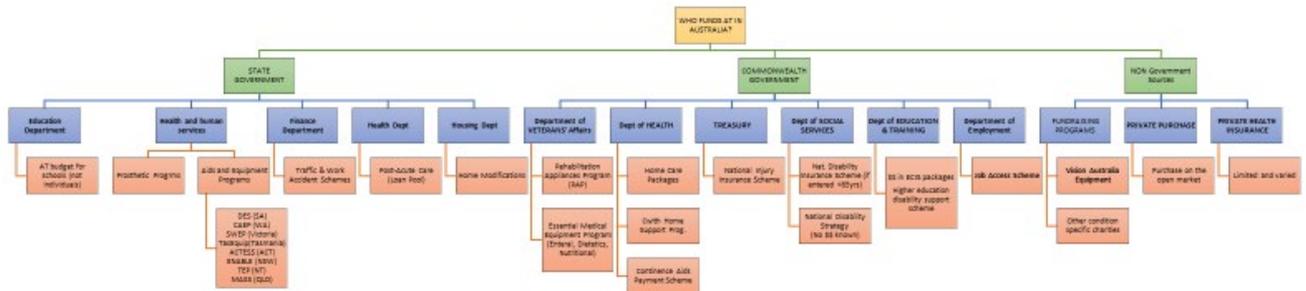
States have an international obligation to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all older persons with disabilities, including by reviewing their legal and policy frameworks; prohibiting discrimination on the basis of age and/or disability; ensuring access to rights-based community support; improving the accessibility of the physical environment, transportation and information and communications; guaranteeing access to justice; promoting participation in decision-making; fostering capacity-building and awareness-raising; and mobilizing resources for the implementation of these measures.

The Special Rapporteur makes the following recommendations to States with the aim of assisting them in realizing the rights of older persons with disabilities:

- (a) Conduct a comprehensive review of laws with a view to abolishing or revoking all laws and regulations that directly or indirectly discriminate against older persons with disabilities;
- (b) Prohibit by law all forms of discrimination on the grounds of disability and age, as well as on the basis of the intersection between both grounds, and guarantee to older persons with disabilities equal and effective legal protection against discrimination on all grounds;

- (c) Mainstream the rights of older persons with disabilities into all disability and ageing-related policies and programmes in order to ensure that the concerns and needs of older persons with disabilities are adequately addressed;
- (d) Ensure a human rights-based approach to disability and ageing in the design, implementation and evaluation of all disability- and ageing-related policies and programmes;
- (e) Integrate a gender perspective into all disability and ageing-related policies and programmes, addressing the intersectionality of discrimination faced by older women with disabilities;
- (f) Design comprehensive and inclusive social protection systems so that disability is mainstreamed into all programmes and interventions, and ensure access to specific programmes and services for older persons with disabilities;
- (g) Design and implement support systems so that older persons with disabilities have access to rights- and community-based support and services that are available, accessible, adequate and affordable;
- (h) Ensure that independent authorities effectively monitor all public and private facilities and programmes providing services to older persons with disabilities to prevent all forms of exploitation, violence and abuse;
- (i) Guarantee access to justice and effective remedies for all older persons with disabilities, and ensure that adult protection services and programmes are inclusive of and accessible by older persons with disabilities;
- (j) Adopt strategies to ensure the direct participation of older persons with disabilities in all processes of public decision-making that directly or indirectly concern them;
- (k) Implement awareness-raising programmes designed to combat stereotypes, prejudices and harmful practices against older persons with disabilities, and change the societal perceptions regarding disability and ageing;
- (l) Collect comparable disability- and age-disaggregated data on the situation of older persons with disabilities to adequately monitor the implementation of the Sustainable Development Goals;
- (m) Mobilize resources to increase the access of older persons with disabilities to support services and social protection, ensuring that all investments are inclusive of them.

## Appendix B: ARATA Assistive Technology Funding Map



A larger size of this Funding Map can be found on the Australian Rehabilitation and Assistive Technology Association (ARATA) website – [www.arata.org.au/access-&funding/funding-your-at/](http://www.arata.org.au/access-&funding/funding-your-at/)

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