



## ***Assistive Technology for All Alliance***

### ***Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability***

#### ***Rights and Attitudes Issues Paper***

**September 2020**

**To:**

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

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Brisbane Queensland 4001

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**This submission has been endorsed by the following organisations:**

Australian Association of Gerontology (AAG); Australian Council of Social Services (ACOSS); Allied Health Professions Australia; Australian Federation of Disability Organisations (AFDO); Australian Rehabilitation and Assistive Technology Association (ARATA); Carers Australia; Consumers Health Forum of Australia; Council on the Ageing (COTA) Australia; Every Australian Counts; People with Disability Australia (PWDA); AGOSCI Inc.; ATchat; Assistive Technology Suppliers Australia; Australian Orthotic Prosthetic Association; Australian Physiotherapy Association; Blind Citizens Australia; Guide Dogs Australia; Limbs 4 Life; Multiple Sclerosis (MS) Australia; Occupational Therapy Australia; Polio Australia; Spinal Cord Injuries Australia; Spinal Life Australia; Vision Australia; Council on the Ageing (COTA) Victoria; Bayside Polio Group; Independent Living Assessment; Indigo; LifeTec; Motor Neurone Disease (MND) Association of Victoria.



**AAG**  
Australian  
Association of  
Gerontology



**Allied Health  
Professions  
Australia**



Australian Federation of  
Disability Organisations



**arata**  
participation through technology



**Carers  
Australia**

**CHF** Consumers Health  
Forum OF Australia

**COTA**  
For older Australians



**Occupational  
Therapy** AUSTRALIA



**PEOPLE WITH DISABILITY  
AUSTRALIA**



Promoting Opportunities.  
Protecting Rights.  
For people aged 50+



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## 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 not covered by the National Disability Insurance Scheme (NDIS).

The members of the ATFA Alliance and the consumers we represent feel very strongly that the lack of equity in the current arrangements is unjust and intolerable. That is why we have launched a public campaign to bring about equal access to assistive technology in Australia. We have developed a website to support the campaign which includes information about the inadequacies of the funding streams that are currently available outside the NDIS. The Assistive Technology for All campaign website can be accessed at <https://assistivetechforall.org.au/>.

## 2. Introduction

The ATFA Alliance is pleased to provide this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Our submission has been drafted in response to the Royal Commission's 'Rights and Attitudes Issues Paper', published in April 2020 (The Issues Paper).

We are reassured by the Royal Commission's acknowledgement of the United Nations Convention on the Rights of Persons with Disabilities as a tool for governments to ensure that the rights of **all** people with disability are promoted, protected and upheld. Regrettably, the Australian Government continues to fall short of its obligations to people with disability in a range of different areas.

Our submission will focus specifically on the Government's failure to provide equitable access to assistive technology for people with disability who are not covered by the National Disability Insurance Scheme (NDIS). Our submission also highlights that systemic ageism is evident in current government policies and presents as an attitudinal barrier affecting older Australians' equitable access to assistive technology.

We trust that our comments will satisfy the Royal Commission's request for information that will help it understand the extent to which organisations and governments recognise, promote and safeguard the rights of people with disability in laws, policies and practices.

While the case studies provided throughout this submission are based on the needs and circumstances of real individuals, we have altered some identifying details in order 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 not covered by the NDIS.

### 3. Recommendations

#### Recommendation 1:

The Royal Commission recommend that the revised National Disability Agreement and National Disability Strategy:

- Clarify who will be responsible for funding assistive technology for people with disability not covered by the NDIS.
- Focus on measures that would harmonise existing state-based assistive technology programs and those operated by not-for-profit organisations to streamline access and drive nationally consistent outcomes for consumers.
- Put measures in place to ensure that all people with disability not covered by the NDIS have equitable access to the assistive technology they need.
- Include specific deliverables and performance indicators relating to the timely provision of assistive technology to people with disability not covered by the NDIS.

#### Recommendation 2:

- The Royal Commission recommend that State and Commonwealth Governments work together to develop a funded National Assistive Technology Program to provide equitable support to people with disability not covered by the NDIS as a matter of urgency.

### 4. What is assistive technology?

‘Assistive technology’ is an umbrella term that is used to describe any aid, piece of equipment or home modification that can help someone overcome the impact of disability or ageing.

Assistive technology can take many forms, such as:

- A home modification 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 people to walk safely and independently
- An electronic communication device to help someone who cannot use their voice to communicate their thoughts.

### 5. The role of assistive technology in safeguarding against abuse and neglect

1. The World Health Organization states:

*“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.”*

1

2. The timely provision of appropriate assistive technology facilitates mobility, communication and self-care. It ensures people with disability have the prerequisite tools necessary to uphold their rights, safeguard themselves against harm and act on any instances of abuse that do occur.
3. Without timely access to appropriate assistive technology, many people with disability are forced to rely on others for support. This increased dependency can contribute to heightened levels of carer stress.
4. Dependency on others and carer stress are both well documented risk factors for providing the precondition under which abusive relationships occur. <sup>2 3</sup> Research also shows that people with disability are 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>4</sup>
5. The timely provision of assistive technology also has the potential to delay entry to residential care by allowing people with disability to remain living independently in their own homes. Research by the Royal Commission into Aged Care Quality and Safety has shown that “Australians want the Government and community to assist older people to live well in their own homes for as long as possible”. <sup>5</sup>
6. The timely provision of appropriate assistive technology further maximizes the health and safety of people with disability by:
  - Improving health outcomes
  - Preventing secondary health conditions
  - Reducing the risk of falls
  - Reducing hospital admissions. <sup>6 7</sup>

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

1. Article 1 of the Convention states that the purpose of the Convention

*“... is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.”* <sup>8</sup>
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>9</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>10</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>11</sup>*

5. A 2009 study that was 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 study aimed to clarify the Convention's opportunities and limitations in relation to assistive technology. 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>12</sup>*

6. The critical role of assistive technology within the broader human rights context has also been reaffirmed by the World Health Organization, who has stated:

*“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>13</sup>*

## **7. The policy context surrounding assistive technology in Australia**

1. Article 33 of the Convention requires Governments to:

*“establish and designate a framework to promote, protect and monitor implementation of the Convention.”<sup>14</sup>*

2. To fulfill its obligations under Article 33, the Australian Government committed to developing a national disability strategy soon after it had ratified the Convention. 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>15</sup>*

3. In 2009, the National People with Disabilities and Carer Council undertook an extensive consultation process to inform the development of the new National Disability Strategy. The issues associated with access to assistive technology were well documented within the final consultation report. Entitled 'Shut Out: The Experience of People with Disability and Their Families in Australia', the report noted:

*“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>16</sup>

4. The concerns outlined in the 2009 Shut Out report were adequately captured in the final National Disability Strategy 2010-2020, which promised to dramatically improve access to personal supports such as assistive technology for people with disability across Australia. As such, the Strategy includes the following two outcomes:

*“A disability support system which is responsive to the particular needs and circumstances of people with complex and high needs for support.”*

*“Universal personal and community support services are available to meet the needs of people with disability, their families and carers.”*<sup>17</sup>

5. The National Disability Insurance Scheme (NDIS) was established in 2013 to progress Australia’s implementation of the Convention on the Rights of Persons with Disabilities and the National Disability Strategy.
6. The NDIS 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>18</sup> The Australian Government has also now committed to implementing an NDIS Participant Service guarantee. From July 2020, the guarantee will cut waiting times and improve access to services for NDIS participants; with a strong focus on improving timely access to appropriate assistive technology.<sup>19</sup>
7. While the NDIS forms an integral part of the disability policy landscape, it is only projected to provide individual support to around 10% of people with disability across Australia.<sup>20</sup>
8. Interactions between the NDIS and mainstream services are guided by the ‘Principles to Determine the Responsibilities of the NDIS and Other Service Systems’.<sup>21</sup> A Disabled People’s Organisations Australia working group, representing a number of disability organisations, in its 2019 report on Australia’s progress under the Convention on the Rights of Persons with Disabilities, observed:

*“... 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>22</sup>

9. The situation for people with disability who are not covered by the NDIS has been further exacerbated by outdated funding agreements between state and commonwealth governments. Funding responsibilities relating to specialist disability supports, for example, 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 shifted dramatically since the implementation of the NDIS. The agreement was reviewed by the Productivity Commission in 2018/19, with the process resulting in the development of an extensive report

outlining a number of recommendations to government.<sup>23</sup> These recommendations have still not been implemented.

10. An example of the impact the current policy environment is having on service delivery can be seen by examining access to individual therapist support and advice, equipment trials and demonstrations. These services have historically been provided by Independent Living Centres (ILCs) in each state. NDIS participants now have the capacity to have these services funded through their individual funding package. It is critical that those not covered by the NDIS are provided with an equitable level of support. Unfortunately, however, state and territory governments have started to retract funding for Independent Living Centres since the implementation of the NDIS. Many of these Independent Living Centres have subsequently closed or are in the process of closing.<sup>24</sup>
11. Federal and state governments continue to place a strong emphasis on the NDIS as the sole solution to the provision of support to people with disability, irrespective of the fact that it constitutes a very small section of the disability service landscape. In doing so, they have failed to put appropriate measures in place to meet the needs of people with disability who are not covered by the NDIS. As noted in the Productivity Commission's 2019 review of the National Disability Agreement report:

*"the focus on the NDIS has taken all of the 'oxygen out of the sector' with limited attention placed on achieving better outcomes for people with disability in other areas, particularly for those not covered by the NDIS."*<sup>25</sup>

## **8. How is assistive technology funded for people with disability outside the NDIS?**

1. Funding for assistive technology for people who are not covered by the NDIS is currently spread across multiple state and federal government departments and not-for-profits, leading to widespread confusion and inequitable access for consumers. The Australian Rehabilitation and Assistive Technology Association (ARATA) has compiled a funding map of current funding streams in Australia, which is detailed in Appendix 1.
2. Inconsistencies between states and service systems mean that access and out of pocket expenses can differ greatly depending on an individual's age, level of disability, geographic location and which service system they are accessing. These are the same issues that were identified in the 2009 Shut Out report – the very issues that the National Disability Strategy had promised to address. 'The Shut Out' report 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>26</sup>

3. The NDIS now provides a national framework for the provision of assistive technology to people with disability, as was suggested in the Shut Out report. While this has removed or has started to close the gap in access to assistive technology for NDIS participants, the situation for those who fall outside the scheme has still not changed.

4. Most people with disability who are not covered by the NDIS will be eligible to receive some level of assistance under their state-based aids and equipment program, the Commonwealth Continuity of Support Program (CCOSP) or the aged care system. At present, none of these pathways provides equitable or appropriate access to assistive technology. Further information about the substantial shortfalls that exist under each of these systems is available via the Assistive Technology for All Alliance website - <https://assistivetechforall.org.au/>
5. In summary: long waiting lists, prohibitive co-payments and funding shortages mean that people not covered by the NDIS are still forced to:
  - Go without the assistive technology they need
  - Sacrifice their limited income to self-fund assistive technology
  - 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.
6. The Australian Government's failure to resolve the current issues surrounding access to assistive technology for people with disability who are not covered by the NDIS constitutes a breach of its obligations under the Convention on the Rights of Persons with Disabilities and the National Disability Strategy. These instruments do 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 whether they are eligible for the NDIS.
7. The current National Disability Strategy will expire this year and work on developing a revised strategy is already underway. In 2018, the Social Policy Research Centre undertook a review of the implementation of the current Strategy to inform this process. The final report from this review identified that a key priority of the revised Strategy should involve:  
*"... addressing the barriers experienced by people who do not receive NDIS packages."<sup>27</sup>*

#### **Recommendation 1:**

**The Royal Commission recommend that the revised National Disability Agreement and National Disability Strategy:**

- **Clarify who will be responsible for funding assistive technology for people with disability not covered by the NDIS.**
- **Focus on measures that would harmonise existing state-based assistive technology programs and those operated by not-for-profit organisations to streamline access and drive nationally consistent outcomes for consumers.**
- **Put measures in place to ensure that all people with disability not covered by the NDIS have equitable access to the assistive technology they need.**
- **Include specific deliverables and performance indicators relating to the timely provision of assistive technology to people with disability not covered by the NDIS.**

### ***Case Study: David (post-polio syndrome)***

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: Bob (Multiple Sclerosis)***

62-year-old Lyn has a 70-year-old husband named Bob who has been living with MS for the past 30 years. Because of the age eligibility requirements for the NDIS, Bob has had to turn to the aged care system to access support. Bob has been assessed as being eligible for a level 4 Home Care Package and has already been waiting 15 months for a package to become available. In this 15 months, Bob and Lyn have been forced to spend in excess of \$10,000 directly attributable to Bob's needs.

If Lyn was the one with MS, she would still meet the age eligibility requirements for the NDIS. An NDIS package would have provided greater access to the supports that were needed in this situation and Lyn and Bob would have been far better off.

### ***Comparative Case Study: Robert and Steve (above-knee amputees)***

Robert and Steve both have left above knee amputations resulting from aggressive infections. Robert is 67 years old and Steve is 56 years old.

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. After a fall or when he is feeling fatigued (because of the type of prosthesis he has been fitted with), Robert uses an old manual wheelchair which is weighty and quite difficult for him to push around.

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 has access to an array of fully-funded reasonable and necessary supports under his NDIS Plan as 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 multi-axis prosthetic 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.

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 he has been fitted with is well-suited to his individual needs. He has also been able to return to full-time work.

#### ***Case Study: Amir (spinal cord injury)***

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

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. Had Amir been eligible for the NDIS, his chair would have been fully funded.

## **9. Older people with disability: falling through the cracks**

1. The issues paper states that the Royal Commission is considering the multi-layered experiences of people with disability of different ages.
2. Australia's disability policy landscape is inherently ageist and fails to uphold the rights of older people with disability.
3. The implementation of 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>28</sup> As such, older people with disability now make up the largest cohort of people with disability who fall outside the NDIS. This includes:

- People who were born with or acquired disability early in life but 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.
4. Older people with disability who are excluded from the NDIS are negatively impacted in a range of different areas. Some of these impacts include:
- Reduced access to community life where there are opportunities for friendships and activities that promote health and wellbeing
  - Deteriorating health caused by longer periods spent indoors (at times in bed) and with reduced stimulation and exercise
  - Experiencing health outcomes that have serious, sometimes fatal consequences. Not only are people's lifestyles being compromised, their lives are being compromised.
5. The Parliamentary Joint Committee on Human Rights had expressed concern with this arrangement 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>29</sup>
6. The ATFA Alliance has also been made aware of incidents 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 could apply. By the time these individuals became aware that they could access the scheme, they were already over the age of 65 and no longer met the age eligibility requirements set out under the NDIS Act. Had these people been informed that they could only make an access request for the scheme prior to their 65<sup>th</sup> birthday, they would now be receiving a more appropriate level of support than that which is available to them under other service systems. These examples suggest that there may be many other older people with disability throughout Australia who missed out on an opportunity to join the scheme at a time when their age would not have been a barrier.
7. The age cut-off that exists under the NDIS would not be so problematic if older people with disability were being provided with equitable access to assistive technology under other service systems. Regrettably this is not the case.
8. Current arrangements have forced many older people with disability to turn to the aged care system in an attempt to access the support they need. Australia's 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 was reinforced in the 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>30</sup>

9. 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 and the National Disability Strategy. The Government's stance on this matter goes against the principles of equality and non-discrimination that underpin international human rights law and must be addressed as a matter of urgency.

#### ***Case Study: Geoff (Polio survivor)***

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 not covered by the NDIS with little choice but to move into residential care.

#### ***Case Study: Ruth (Multiple Sclerosis)***

Ruth is a 68-year-old woman with Multiple Sclerosis. Until recently, she had been receiving support in her own home under the Commonwealth Continuity of Support Programme. A recent change in circumstances has led Ruth to move into residential care and as such, she is no longer eligible to receive support under this programme.

Ruth's powered wheelchair is very old and is no longer meeting her needs. She has been looking for avenues to access funding for the purchase of a new wheelchair, but she has been told that there is nothing available. This situation is negatively impacting upon Ruth's comfort, mobility, independence and participation in everyday activities. If Ruth was under 65, she would have been eligible to access support under the NDIS and her new wheelchair would have been fully funded.

**Case Study: Lyn (Polio survivor)**

Lyn is a polio survivor. She is ineligible for the NDIS as she is over 65 and does not meet the age eligibility requirements for the scheme. She is waiting on a Level 4 Home Care Package under the aged care system which is valued at \$50,250 per year.

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. It will also require regular maintenance and repair. The equipment she currently needs includes:

|               |          |
|---------------|----------|
| Wheelchair    | \$18,000 |
| Shower chair  | \$1,680  |
| Ceiling hoist | \$8,861  |
| Corset        | \$800    |
| -----         |          |
| TOTAL COST    | \$29,341 |
| -----         |          |

If the above equipment were to be purchased under a Level 4 package, this would leave \$20,909 remaining (equal to just over \$57 per day). Lyn needs this funding to cover daily care in her home, including operation of the hoist in/out of bed and showering. It will also need to cover maintenance/repair of her equipment and all other disability-related expenses she may incur. Administration fees for a Level 4 package are likely to equate to around \$11,000. This means there will be very little funding left over to meet Lyn's needs.

Lyn has been told that it will be quite some time before a level 4 Home Care Package will become available. She 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. It only would have covered assistance with operation of the hoist in/out of bed and showering for 3 days a week, which would force her to remain in bed for the other 4 days. A level 4 package would also 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 have been calculated around these needs so that she would have access to an appropriate level of support.

**Comparative case Study: Graham and Aaron (two men living with MND)**

Graham and Aaron both have rapidly progressive Motor Neuron Disease (MND). They have lived in the same regional community since childhood and played football together in the same premiership 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 65<sup>th</sup> 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. He was told that he could access a lower level of support under a level 2 package in the meantime but would still need to wait 9-12 months to receive this. He wasn't sure whether he would accept this offer as he feared he would be worse off under a level 2 package. This is because he would have had to pay full fee for all of the services he had already been accessing at a subsidised rate; including home nursing, community allied health, home cleaning, personal care and in-home respite.

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: Margaret (Parkinson's disease)***

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 has chosen to live in her own home with Kevin but requires the appropriate supports and services to make this possible, safe and sustainable. They're 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. They both retired earlier than planned due to Margaret's increasing disability and dependence on Kevin's assistance.

## **10. The ultimate solution: A National Assistive Technology Program for people with disability not covered by the NDIS**

1. The ATFA Alliance believes that the issues identified throughout this submission would be best resolved through the establishment of a harmonised and nationally consistent assistive technology program to support people with disability who are not covered by the NDIS.
2. 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.
3. The establishment of a national assistive technology program also has the potential to reduce demand in other areas such as acute health and aged and community care, which would in turn minimize downstream government costs. This is because improving access to assistive technology has been shown to:
  - Improve health outcomes
  - Prevent secondary health conditions
  - Reduce the risk of falls
  - Reduce hospital admissions
  - Incur fewer costs relating to caregivers and long-term care
  - Reduce reliance on carers, and therefore minimise risk of potential exposure to violence, neglect and abuse
  - Delay entry to residential aged care.
4. 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 the 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.
5. 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
  - The provision of high and low-cost aids and equipment
  - Training to enable participants to use assistive technology safely and effectively
  - Maintenance and repair of assistive technology.
6. 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.
7. 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 2:**

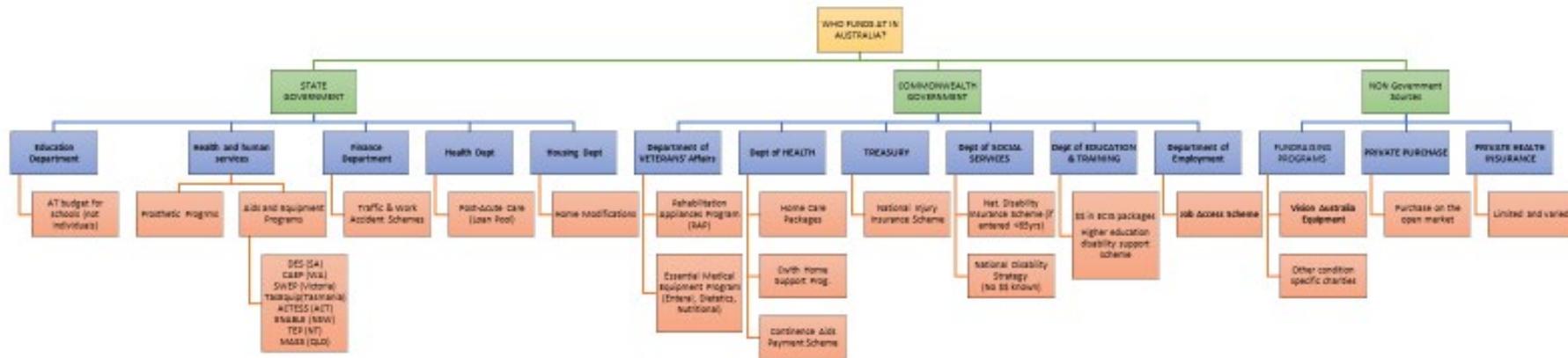
**The Royal Commission recommend that State and Commonwealth Governments work together to develop a funded national assistive technology program to provide equitable support to people with disability not covered by the NDIS as a matter of urgency.**

## **11. Concluding comments**

Thank you for providing The Assistive Technology for All Alliance with an opportunity to submit evidence to inform the Royal Commission's investigations. It is essential that all people with disability have access to the assistive technology they need to promote safety, independence and participation in everyday life. It is our hope that the Royal Commission process will help to shine a light on the inequity and injustice that currently exists for people with disability who are not covered by the NDIS and seek to remedy this situation through its recommendations to Government.

If you require further information in relation to any of the points that have been raised within 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 1: 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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