



The Assistive Technology for All Alliance
Pre-Budget submission

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This Pre-Budget submission has been endorsed by the following organisations:

Council on the Ageing Australia, Australian Association of Gerontology, Every Australian Counts, National Disability and Carer Alliance, The Australian Federation of Disability Organisations, People with Disability Australia, Australian Rehabilitation and Assistive Technology Association, Occupational Therapy Australia, Assistive Technology Suppliers Australia, TAD Australia, Blind Citizens Australia, Leukodystrophy Australia, LifeTec, Council on the Ageing Victoria, Limbs 4 Life Australia, MS Australia, Polio Australia, Spinal Cord Injuries Australia, Vision Australia, Bayside Polio Group, Huntington’s NSW ACT, Independent Living Centre WA, MND Victoria, Parkinson’s Victoria, Post Polio Victoria



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1. **About *Assistive Technology for All***

Assistive technology (AT) plays a critical role in the lives of people with disability by facilitating independence and participation in everyday activities. Screen reading software, mobility aids, electronic communication devices and prosthetic aids are all examples of AT. Please note, detailed definitions of AT can be found in Appendix 1.

Assistive Technology for All is a national alliance of peak bodies and consumer representatives spanning the Ageing and Disability Sectors. Together, we are advocating for equitable access to AT for people with disability who are not eligible for the National Disability Insurance Scheme (NDIS).

2. **Introduction**

The *Assistive Technology for All* Alliance is pleased to provide this Pre-Budget submission to Treasury.

The comments provided focus on key areas that impact on access to assistive technology for older people with disability, many of whom are now forced to access the support they need under the aged care system.

The case studies are based on the needs and circumstances of real individuals; we have altered some identifying details to protect the anonymity of those concerned.

3. **Summary of Recommendations**

Recommendation 1:

That the Commonwealth Government either:

- Implement the medical and general accident streams of the National Injury Insurance Scheme (NIIS) to provide support to people of all ages who acquire disability through catastrophic injury.
- Or-
- Provide access to the NDIS for people of all ages who acquire disability through catastrophic injury.

Recommendation 2:

That the Commonwealth Department of Health co-fund the Information, Linkages and Capacity Building (ILC) stream of the NDIS so that older people with disability have timely access to disability-specific information and support and can access capacity building, early intervention and local area coordination services on an equitable basis with participants of the NDIS.

Recommendation 3:

That the Department of Health invest in strategies to build the capacity of aged care assessors to understand and respond to the unique needs of people with disability. This should include consideration of joint purchasing arrangements between the Commonwealth Department of Health and the National Disability Insurance Agency (NDIA).

Recommendation 4:

That the Commonwealth implement measures to ensure people with disability living in residential aged care can access funding for assistive technology to facilitate mobility, communication and participation in everyday activities.

Recommendation 5:

That an intergovernmental agreement is established to develop a funded national aids, equipment and assistive technology program, including agreement on the process and timeframes for implementing a national program. As an interim solution for the urgent needs of older people with disability (who are therefore ineligible for the NDIS), the Commonwealth Government should specifically fund aids and equipment for this group.

4. The Case for Increasing Access to Assistive Technology

1. Assistive technology helps facilitate social inclusion, economic participation and autonomy. The NDIS Assistive Technology Strategy states:

“AT (assistive technology) enables people with disability to live a better, more independent and more inclusive life. It enables people with disability to maximise their abilities at home, in the community and in the workplace, ensuring greater economic and social participation.”¹

2. In 2018, the National Aged Care Alliance (NACA) commissioned a review of the social and economic impacts of assistive devices. The review found that **significant savings** could be made in health and aged care by increasing investment in assistive technology. This is because providing people with disability with timely access to affordable assistive technology can:
 - Reduce the need for GP visits
 - Reduce demand for home care services
 - Reduce hospital admissions.
 - Delay entry to residential care. ²

The economic modelling that was undertaken as part of the review demonstrated that substantial cost offsets and downstream costs will be avoided if AT is introduced at the point of need. A link to NACA's 'Assistive Technology for Older Australians Research Report' is provided in Appendix 2.

3. Without access to assistive technology, many people with disability are forced to rely on others for support. This is concerning when considering that:
 - Dependency on others is one of the key factors that has been shown to increase peoples' risk of being subjected to violence, abuse, neglect and/or exploitation.
 - Research demonstrates that people with disability are less likely to report abuse or take steps to leave an abusive relationship in instances where they are heavily reliant on their abuser for support.
 - Without access to the appropriate mobility and communication aids, people may not have the functional capacity to report any instances of abuse that do occur.^{3 4}

When people with disability are forced to rely on family and carers, the impact extends well beyond the person with disability themselves. It can impact on the physical and mental health and wellbeing of carers and reduce their capacity to be social and economic participants. In the context of older people with disability, they will often receive informal support from an ageing family member whose capacity to assist with the necessary tasks may be somewhat limited. One gentleman who had already been waiting 830 days for an appropriate home care package, wrote:

"my wife has had surgery and requires further procedures including fitting of back brace for a serious back injury and is unable to give me the level of care I require."

5. Background and Policy Context

It is important for the Treasury to understand how older people with disability came to be filtered into the aged care system, and what gaps still exist in meeting their needs. We have provided some brief points below to help clarify the current arrangements:

1. The National Disability Insurance Scheme (NDIS) is designed to provide lifetime care and support to people with permanent disability. It commenced trial in 2013, with national rollout commencing in 2016.⁵
2. The design and implementation of the NDIS was informed by the Productivity Commission's 2011 Inquiry into Disability Care and Support. The terms of reference for this inquiry indicated that the scheme was: *"intended to cover people with disability not acquired as part of the natural process of ageing."*⁶

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 be eligible for the scheme.⁷ As such, **older people with disability now make up the largest cohort of people 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 progression of a pre-existing condition.
4. The NDIS has the capacity to fully fund the assistive technology that is needed by younger people with disability, irrespective of how or where their disability was acquired. Funding pathways that are available to people outside the NDIS, however, do not provide an equitable level of access.
5. Federal and state governments continue to place a strong emphasis on the NDIS as the sole solution to the provision of services and supports to people with disability. In doing so, they have not put appropriate measures in place to meet the needs of the 90% of people with disability who are not eligible for the NDIS.⁸
6. The current situation has been perpetuated by outdated 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. This process resulted in the development of an extensive report that outlined a number of recommendations for government. These recommendations have still not been implemented.⁹
7. Interactions between the NDIS and mainstream services are guided by the 'Principles to Determine the Responsibilities of the NDIS and Other Service Systems'.¹⁰ A 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."¹¹

8. The need for resolution of the ongoing boundary issues between Commonwealth and State and Territory Governments was also identified in the Legislated Review of Aged Care; which recognized that current arrangements prevent the optimal provision of assistive technology to people with disability who are over the age of 65.¹²

6. Overview of Primary Funding Streams Outside the Aged Care System

Funding for assistive technology for older Australians is currently spread across multiple departments and not-for-profits at both the state and commonwealth level. As such, the most appropriate pathway for accessing assistive technology remains very unclear to the consumer.

In 2018, the Australian Rehabilitation and Assistive Technology Association developed a map of existing funding streams for assistive technology in Australia. A copy of this Funding Map is attached as Appendix 4.

This section of our submission sets out the dominant funding pathways that were promised to provide support to people with disability outside the NDIS and highlights how these systems are falling short of people's needs. This will help clarify why older people with disability are now forced to access the assistive technology they need under the aged care system.

6.1. The Commonwealth Continuity of Support Program (CCOSP)

1. People who do not meet the age eligibility requirements for the NDIS but 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.¹³
2. There are many older people with disability whose needs are still not being met under this program, including:
 - People who had not been accessing state-administered specialist disability support prior to transition to the NDIS.
 - People who were still on waiting lists for state-administered specialist disability services during transition to the NDIS¹⁴
 - Program participants who transition into residential aged care.
3. For those who are eligible for and are able to access support under the Commonwealth Continuity of Support Programme, the situation is still very unclear. The 2019 Shadow Report to the United Nations Committee on the Rights of Persons with Disabilities states:

“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.”¹⁵

4. Irrespective of the current confusion surrounding the implementation of the program, it seems that it is still not likely to create a funding pathway for assistive technology. The 2019 edition of the CCOSP manual, for example, states:

“...in the first instance, aids and equipment (including vehicle modifications) should be accessed through available State programmes.”¹⁶

Case Study: Ruth

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 the Commonwealth Continuity of Support 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.

6.2. 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.¹⁷
2. Presently the NIIS is only available in Queensland, with no determination made at present as to whether this scheme will be rolled out nationally.
3. The NIIS, if properly implemented, would have provided an avenue to accommodate the specialist needs of any older people who acquire disability through catastrophic injury into the future. At the time of writing this submission, however, the medical and general accident streams of the NIIS had still not been implemented.
4. In the absence of a National Injury Insurance Scheme, older people who acquire disability through catastrophic injury are forced to access support under the aged care system. This system does not provide equitable support and lacks specialist disability expertise.
5. 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

Chris English used to drive racing cars, but the only thing that drives now is his electric wheelchair using his chin. Mr English became a quadriplegic after he fainted and fell down some stairs last years. "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."

Recommendation 1:

That the Australian Government either:

- **Implement the medical and general accident streams of the National Injury Insurance Scheme (NIIS) to provide support to people of all ages who acquire disability through catastrophic injury.**
- **Or-**
- **Provide access to the NDIS for people of all ages who acquire disability through catastrophic injury.**

6.3. State-based aids and equipment programs

1. Despite there being an assumption that an individual's assistive technology requirements 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 and there has been no commitment to growth to keep up with the increasing costs of assistive technology.
 - Older people accessing state-based programs are expected to make a significant and often prohibitive financial contribution towards the cost of their assistive technology.
 - Older 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.
 - The extent to which governments intend to continue funding state-based aids and equipment programs beyond full roll out of the NDIS remains unclear.

- People living in residential aged care are unable to access assistive technology under existing state-based aids and equipment programs. There is no other pathway available to provide people living in care with the specific equipment they need. This can have a very negative impact on the mobility, participation and overall health and wellbeing of the individual.
- Some state-based programs have traditionally prevented people from accessing funding if they are already in receipt of a level 3 or 4 home care package. In some states these exclusions now appear to have been broadened even further. In some states, for example, program guidelines prevent older Australians from accessing funding for assistive technology if they are already on a waiting list for another government-funded service, such as a level 1 or 2 home care package. There is concern that further restrictions may be imposed through the potential integration of the Commonwealth Home Support Programme and the Home Care Packages Programme.¹⁸

Case Study: 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 required 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.

Case Study: Two people living with an above knee amputation – state-based Artificial Limb Scheme Funding and the NDIS support differences

Robert and Steve have left above knee amputations. Both underwent an amputation due to an aggressive infection. Robert is 67 years old and underwent an above knee amputation in 2010. Steve is 56 years old and underwent an above knee amputation in 2011. As Robert is only eligible for his state-based Artificial Limb Scheme he does not have appropriate access to supports, assistive technology or home modifications. By contrast Steve has an NDIS Plan with access to an array of reasonable and necessary funded supports.

Robert uses a mechanical knee unit which provides no safety and consequently he experiences regular falls. In addition, he has a very basic prosthetic foot which does not provide energy return and

leads to fatigue. Robert has no choice over the type of prosthesis he receives. After a fall or due to feeling fatigued because of the type of prosthesis he has been fitted with, Robert uses an old wheelchair which is weighty and quite difficult for him to push around. Up until last year Robert worked full-time however the impact of the regular falls on his body has led to him reducing his working hours to part-time.

Robert has minimal home modifications because he would need to self-fund these, and he is not in the 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) - which increases his level of fall risk.

Steve was funded for a Microprocessor Knee Unit (MPK) and multi-axis prosthetic foot in his first NDIS Plan two years ago. Being fitted with an MPK prosthesis has enabled Steve to return to full-time work and he has never experienced a fall due to the technology and safety that this knee unit provides him with. In addition, all bathroom modifications made in his home have 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, and on a daily basis he walks his dog on the beach for exercise.

Steve's NDIS plan enabled him to trial a variety of prosthetic devices to determine which one best meets his needs. He has been able to exercise choice and control over both the assistive devices he uses and the service providers (allied health) he selects.

7. Barriers to accessing assistive technology under the aged care system

- From 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 access services from the aged care system, under either the Commonwealth Home Support System (CHSP) or a home care package.
- Since the Commonwealth has taken over responsibility for funding the aged care system, assistive technology has been continuously underutilized and underfunded.¹⁹
- Current issues relating to the supply of assistive technology will be highlighted throughout the following subsections of our submission.

7.1. The Commonwealth Home Support Programme cannot fund high cost aids and equipment that may be required by people with disability

1. The Commonwealth Home Support Program (CHSP) can provide up to \$500 of funding per person per calendar year for aids and equipment. This cap can be increased to \$1,000 with appropriate supporting evidence from an Occupational Therapist.²⁰ Anecdotally, however, we know that information about the cap increase is not always communicated to consumers.

2. Funding for assistive technology is provided under a service category entitled 'Goods, Equipment and Assistive Technology'. Under this service category, the sub-category of assistive technology includes communication aids, support and mobility aids, self-care aids, medical care aids, reading aids, car modifications and other goods and equipment. Not all aged care planning regions, however, 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.²¹
3. There is still a great deal of confusion between the role of State and Commonwealth Governments in this area. As an example, the Commonwealth Home Support Programme 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."*²²

While this implies that consumers can access support from state-based assistive technology programmes instead of using the limited funds available under the Commonwealth Home Support Programme, there is no national consistency in how this applies and the extent to which it is happening remains unknown. Due to the fact that the Commonwealth Home Support Programme only provides minimal funding for assistive technology, most people with permanent and profound disability will need to access funding under a home care package.

7.2. There is a lack of support available to help older people with disability navigate the current service system

1. The aged care system is complex and confusing for many older people to navigate.
2. The needs of people with permanent and profound disability differ greatly from those of the average older person. Despite this fact, there is still no tailored information available to help older people with disability navigate their options and access the support that best meets their needs.
3. Federal and state governments continue to inject significant amounts of money into projects that are designed to help younger people with disability understand how to navigate the NDIS. Regrettably, however, there has been no information provided to older people with disability to inform them about My Aged Care as it relates to the specialist support needs of people with disability.
4. ILC (Information, Linkages and Capacity-building) is a component of the NDIS that sits outside of the arrangement for individually funded packages of supports. Its role is to provide information, linkages and referrals to all people with disability to connect them to appropriate disability, community and mainstream supports. In reference to older people with disability, the ILC Policy Framework states:

"People with disability who are over the age of 65 years will access information and referral or benefit from community capacity building, however, they will likely gain most of their supports

from the aged care system. The NDIS and aged care interface arrangements should be complementary and ILC should support people to access the most appropriate services and supports.”²³

5. Local Area Coordination is the centrepiece of the ILC system. Local Area Coordinators work directly with people with disability at the community level to provide them with information and referral services that are tailored to their needs. The ILC policy framework states:

“LAC will not be confined to those only with an IFP (Individually Funded Package). LAC will also be available to people with disability who need support but who do not have or are not eligible for an IFP, and to their families and carers.”²⁴

6. It was originally assumed that Local Area Coordinators would play a key role in connecting older people with disability with specialist supports that are appropriate to their needs. At present, however, Local Area Coordination agencies are only providing services to NDIS participants; as they are being inundated by NDIS-related tasks such as planning and support coordination.

Recommendation 2:

That the Commonwealth Department of Health co-fund the Information, Linkages and Capacity Building (ILC) stream of the NDIS so that older people with disability have timely access to disability-specific information and support and can access capacity building, early intervention and local area coordination services on an equitable basis with participants of the NDIS.

7.3. Cost benefits of joint purchasing arrangements with the NDIS

1. An approach that may go some way to providing a solution to the high cost of AT, is to consider joint purchasing arrangements between sectors.
2. The NDIS Assistive Technology Strategy, October 2015, stated on page 6, under the heading, ‘2.1.2 Emerging technologies in aged care and health sectors’:

“There are common needs in the disability, health and aged care sectors. Solutions in one sector can often be used across the other sectors. The aged care and health sectors are large and growing. As they continue to grow they will attract increasing amounts of investment, leading to more innovation and more emerging technology solutions. There is opportunity for the Agency to: (1) embrace technological developments in the aged care and health sectors; (2) collaborate with stakeholders in these sectors; and (3) to co-invest in AT with aged and health care bodies.”²⁵

3. Further to this, the National Aged Care Alliance position paper on Assistive Technology for Older Australians, June 2018, makes the following suggestion, under the heading ‘Cross-sector work and other opportunities’:

“The deployment of AT within the NDIS may provide the aged care sector with models of efficiency and effective delivery of personalised AT services once maturity of the NDIS scheme is reached. A national AT scheme with the NDIS may allow greater economies of scale for procurement and development of innovation. This is particularly so in the case of technological solutions that may be higher in capital cost but have a longer life, provide better consumer outcomes and/or reduce future costs in other care settings, such as acute hospital services or residential aged care. NDIS data on AT may also provide good evidence to inform practice and aged care decisions and, in some cases, offer opportunities to deliver specialised services not commonly found within the ‘aged care’ system.”²⁶

The ATFA Alliance supports this approach, leading to the following recommendation:

Recommendation 3:

That the Department of Health invest in strategies to build the capacity of aged care assessors to understand and respond to the unique needs of people with disability. This should include consideration of joint purchasing arrangements between the Commonwealth Department of Health and the National Disability Insurance Agency (NDIA).

7.4. Older people cannot access assistive technology in a timely manner

1. As at 30 June 2019, there were 119,524 people still waiting for a home care package. This included:
 - more than 3,000 people who were not receiving any assistance at all, despite having been deemed eligible for a package.
 - 47,462 people who had been offered a lower level package until they were able to be provided with a package at their assessed level.
 - 68,900 people who were being provided with support under the Commonwealth Home Support Programme while waiting for a home care package to become available.²⁷
2. Whilst the Federal Government has announced an additional 34,000 Level 3 and 4 packages over four years,²⁸ people with disability who are over 65 are further disadvantaged in accessing the assistive technology they need due to this blowout in waiting times. Careful consideration must be given to the provision of assistive technology as an early intervention measure; particularly when older people are still on a waiting list to receive support.
3. This situation can negatively impact upon families and carers as well as consumers with disability. In reference to this issue, one gentleman told us the following:

“Today marks 916 days since I was assessed Level 4 Age Care Package, during that time I have missed out on necessary services to enable me and my wife who also has significant disability to live meaningful and productive lives. There is absolutely no argument that Aged people with profound disabilities have been seriously disadvantaged by the present system. If the Aged

Care Ministry does not get its act together we are going to end up with more people in homes at a greater cost to the Government, or maybe they are waiting for us to die.”

4. The Australian Government has now promised to develop an NDIS Participant Service Guarantee. The Guarantee will:

“set new standards for the time it takes for key steps in the NDIS process. This means there will be shorter, agreed timeframes for people to receive a decision on whether they will be covered by the NDIS, for them to get an NDIS plan and to have their plan reviewed.”²⁹

The government has stated that the guarantee will have a particular focus on people with disability who require access to assistive technology. This service guarantee should be replicated for people with disability accessing the aged care system to provide an equitable level of support.

Case Study: Lyn

62-year-old Lyn has a 70-year-old husband Bob who has been living with MS for the past 30 years. Because of the rules in place with NDIS, Bob can only access My Aged Care, which doesn't give the same amount of assistance as the NDIS. Presently Bob has been waiting 15 months for any action/assistance on his approved aged care level 4 application. In that 15 months they have spent in excess of \$10,000 directly attributable to Bob's needs.

In this case if Lyn was the one with MS, she would get an NDIS package and their life and wallet would be a whole lot better off!

Case Study: Margaret

67-year-old Margaret, diagnosed with Parkinson's 11 years ago, lives at home with her husband Kevin. Her need for assistance has increased significantly in the past 2 years. It's now 18 months that she's been waiting for a level 4 package. The current level 2 package does not meet her complex and increasing needs, resulting in added emotional and financial stress for all the family.

Her immediate urgent 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. They have been on a waitlist for a suitable powered bed for 12 months. Margaret has also been waiting for 16 months for 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.

7.5. Funding packages do not currently meet the needs of many people with disability

1. Funding packages that are provided under the Home Care Packages Programme are set at pre-determined levels and are not built around the individual needs of each consumer.
2. This model does not address the complex support needs that many people with permanent and profound disability may present with. The limited funds available mean that many people with disability are forced to trade off one vital service to be able to afford another. Their funding package simply isn't designed to be able to accommodate all of their individual needs for support.
3. Many older people with disability accessing support under the aged care system are still struggling to cover the purchase of the aids and equipment they need. In many instances, however, the individual will also require specialized training to enable them to use the specified equipment safely and independently. In some instances this training will also need to be extended to informal carers, such as family members.
4. Prior to the roll out of the NDIS, agencies who specialized in assistive technology training received block funding from government. This enabled them to provide training to clients on a needs basis, usually at no cost to the individual. Under the NDIS, however, this block funding model has been replaced by a market-driven approach. Organisations have set hourly rates for services, such as assistive technology training, based on the prices outlined in the NDIS price guide. Many service providers are now quoting the same prices for non-NDIS participants, irrespective of the fact that they may not have enough funding available under their Home Care Package to cover the costs.

Case Study: Lyn

A polio survivor, Lyn, is waiting on a Level 4 Home Care Package, 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 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 |

TOTAL COST \$29,341

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.

Case Study: Laura

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

Laura wants to be able to use her computer independently again. As she can no longer read print, she will need to learn how to navigate the computer using specialised text-to-speech software. Not only will she have to learn how to use the software itself, but she will also need to learn how to navigate the computer using only her keyboard as she is no longer able to track the mouse pointer on the screen.

A blindness service provider has quoted Laura \$180 per hour to provide the training she needs, which aligns with the NDIS price guide. Laura wants to be able to send and receive emails, use the internet, manage her personal documents and order her groceries online.

Because she is completely new to the use of screen reading technology, it may take quite a few hours of training to enable her to meet these goals. 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.

Case Study: Two people living with MND – differences between support through the Aged Care system and the NDIS

Mr A and Mr B are friends, have lived in same regional community since childhood and have played football together in same premiership teams many years ago, and have maintained close friendship over the years. They still mix in the same social circles. Both Mr A and Mr B have rapidly progressive MND.

Mr A is 66 years old and was diagnosed with MND in late 2018 and accesses his supports through My Aged Care (MAC). Mr B is 64 years old and diagnosed with MND in late 2017. Mr B accesses his funds for supports through the National Disability Insurance Scheme (NDIS).

Mr A does not have appropriate access to supports, services, assistive technology or home modifications. By contrast Mr B has an active NDIS plan with ongoing and quick access to supports as funded in his NDIS Plan.

Mr A has chosen to self-fund a ramp access to his home and bathroom modifications. Without these things he could not remain at home. By contrast, Mr B has an active NDIS Plan with ongoing and quick access to funded supports.

Mr A's assistive technology is provided from MND association through limited state funding and funds raised through donations and fundraising events. Mr B, on the other hand, has access to fully funded assistive technology as assessed by allied health professional and bathroom modification and ramp installation to his home.

Mr A has been assessed through MAC for home care package (HCP) level 4 and has been advised of long wait times for this of 12 – 18 months. Mr A feels he will be dead prior to HCP level 4 being available. Mr A has been advised that a level 2 HCP wait time less, between 9 – 12 months. However, he is not sure if offered a level 2 HCP, while awaiting a level 4 HCP, he would take it as he fears he would be worse off financially. All services including home nursing, community allied health and disability supports such as home cleaning, personal care and in-home respite would be at full fee if he takes a package, rather than the current subsidised rate. This makes him feel he would be worse off to accept a level 2 HCP.

Mr B's situation differs significantly due to him being in receipt of an NDIS Plan. Through his Plan, Mr B has a choice of service providers such as in-home disability support, community access support, and allied health support. Mr B also has the opportunity for his NDIS plan reviewed at least annually or as his needs change. Mr B is now on his second NDIS plan.

7.6. People living in residential care cannot access appropriate funding for assistive technology

1. Older people living in government-funded residential aged care facilities are unable to access support through state-based aids and equipment programmes.
2. It is generally expected that any aids or equipment will be provided by the residential aged care facility. This arrangement continues to leave many older people with disability without the support they so critically need.

Case Study: Geoff

Geoff, a polio survivor, lives in residential aged care. His motorized wheelchair requires significant modification due to progressive loss of function from the late effects of polio. As there is no funding in Victoria for assistive technology for people living in residential aged care, there is an expectation that the aged care facility will fund and meet all his care needs. The standard item they would be required to provide, to replace his wheelchair when it cannot be further modified, is a manual wheelchair for mobility. This will not meet his requirements for seating, and will not enable him to move independently around the facility or participate in social activities in the wider community outside his residential facility.

It should be noted that many people managing the late effects of polio, like many others with physical disability, enter residential aged care at a younger age than the wider community. 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 leaves people with little choice but to move to residential care where sadly their intellectual and social needs are often left unmet as they are in a much younger age bracket than the majority of their co-residents.

Recommendation 4:

That the Commonwealth implement measures to ensure people with disability living in residential aged care can access funding for assistive technology to facilitate mobility, communication and participation in everyday activities.

8 The ultimate solution: A National Aids and Equipment Program for older people with disability

Assistive Technology for All ultimately believes that the issues identified throughout this submission would best be resolved through the establishment of a harmonised and nationally consistent assistive technology program to support people with disability who are not eligible for the NDIS. This approach would **simplify the current funding arrangements** while providing older people with the technology they need to lead better quality lives and maintain their connection in the community. It also has the potential to reduce demand in other areas such as acute health and community care, which in turn would **minimize downstream government costs**.

The programme would:

- Seek to harmonise existing state-based AT 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. At present, access and out of pocket expenses for the provision of AT differ depending on your age, level of disability, geographic location and which service system you access.
- 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.

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 AT safely and effectively.
- Maintenance and repair of AT.

To be eligible for the programme, 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.

Eligibility for the programme 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 5:

That an intergovernmental agreement is established to develop a funded national aids, equipment and assistive technology program, including agreement on the process and timeframes for implementing a national program. As an interim solution for the urgent needs of older people with disability (who are therefore ineligible for the NDIS), the Commonwealth Government should specifically fund aids and equipment for this group.

9 Concluding statement

It is essential that older people with disability have access to the support they need to lead full and active lives.

It is our hope that both of the Royal Commission processes currently underway will help to shine a light on the inequity that exists between people with disability who are under 65 years and those who are over the age of 65 and seek to remedy this situation through recommendations to Government.

In the meantime, we seek the implementation of the recommendations of this Pre-Budget submission that will largely address the specific issue of meeting the assistive technology needs of older Australians.

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 and can be contacted by phone on (03) 9655 2140, or by email at LHenley@cota.vic.org.au

Appendix 1: Assistive Technology Definitions

1. Assistive technology comprises products and services used to provide assistive solutions that, combined with opportunities for use in desired occupations, across multiple environments, and enable individuals' functioning and participation.³⁰
2. Assistive products include any product especially produced or generally available, used by or for *persons with disability for participation*, to protect, support, train, measure or substitute for *body functions /structures and activities*, or to prevent *impairments, activity limitations or participation restrictions (AS/ISO 9999 page 3)*. Examples of AT include wheelchairs, prostheses, walking sticks, hearing aids, visual aids, and specialized computer software and hardware that increase mobility, hearing, vision, or communication capacities.^{31 32}
3. Assistive technology services include any service that directly assists an individual in the selection, acquisition, or use of an assistive solution. Sometimes known as 'soft technologies', these include providing information and assessment, identifying and trialling assistive solutions, purchasing and customising the solution and ensuring ongoing and effective use, maintenance and review.³³

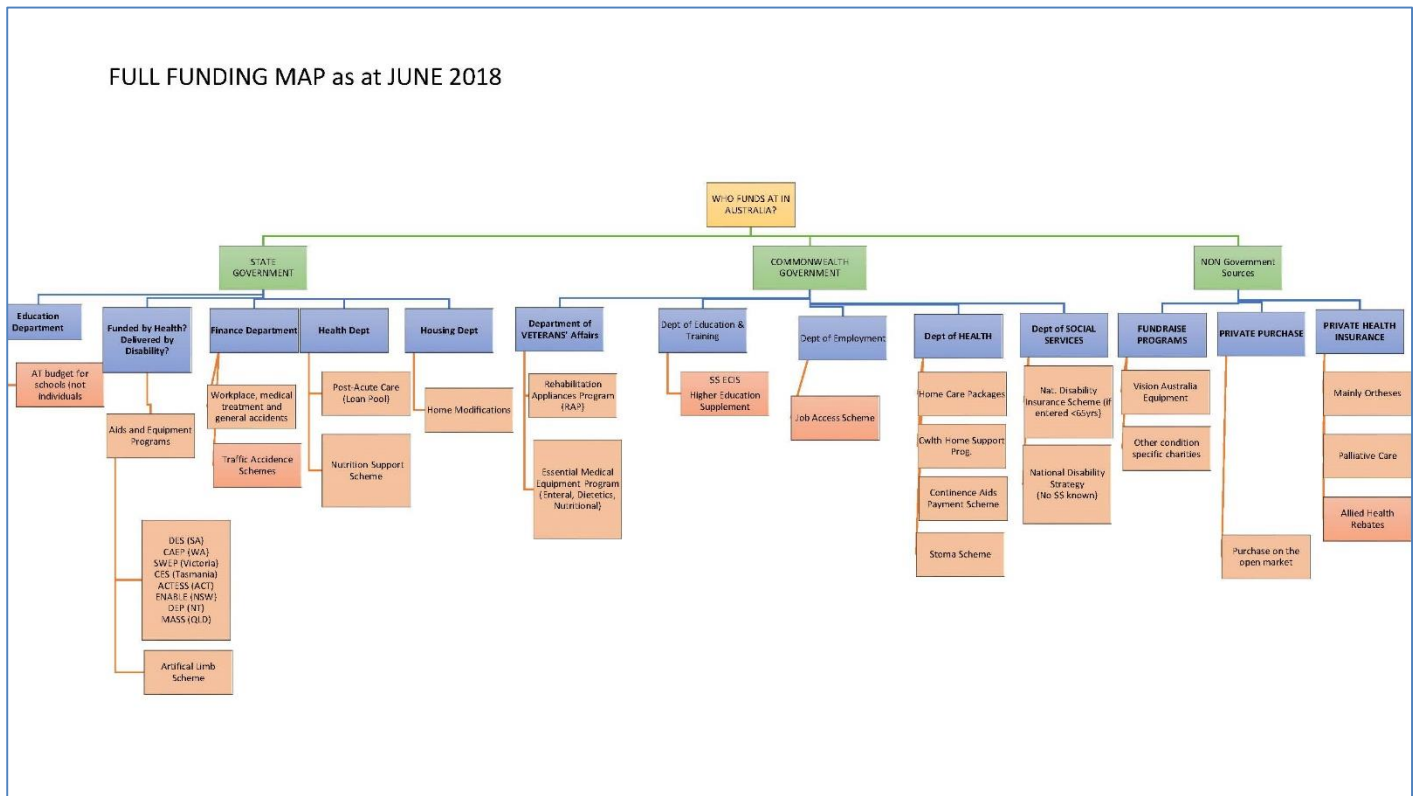
Appendix 2: Assistive Technology for Older Australians Research Report (NACA)

This Position Paper can be downloaded from the National Aged Care Alliance (NACA) website - https://naca.asn.au/wp-content/uploads/2018/11/NACA_Assistive_Technology_for_Older_Australians_Position_Paper-1-June-2018.pdf

Appendix 3: Improving the interface between the aged care and disability sectors, discussion paper (NACA)

This Discussion Paper can be downloaded from the National Aged Care Alliance (NACA) website - <https://naca.asn.au/wp-content/uploads/2018/11/Improving-the-Interface-Between-the-Aged-Care-and-Disability-Sectors.pdf>

Appendix 4: Assistive Technology Funding Map (ARATA)



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

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