

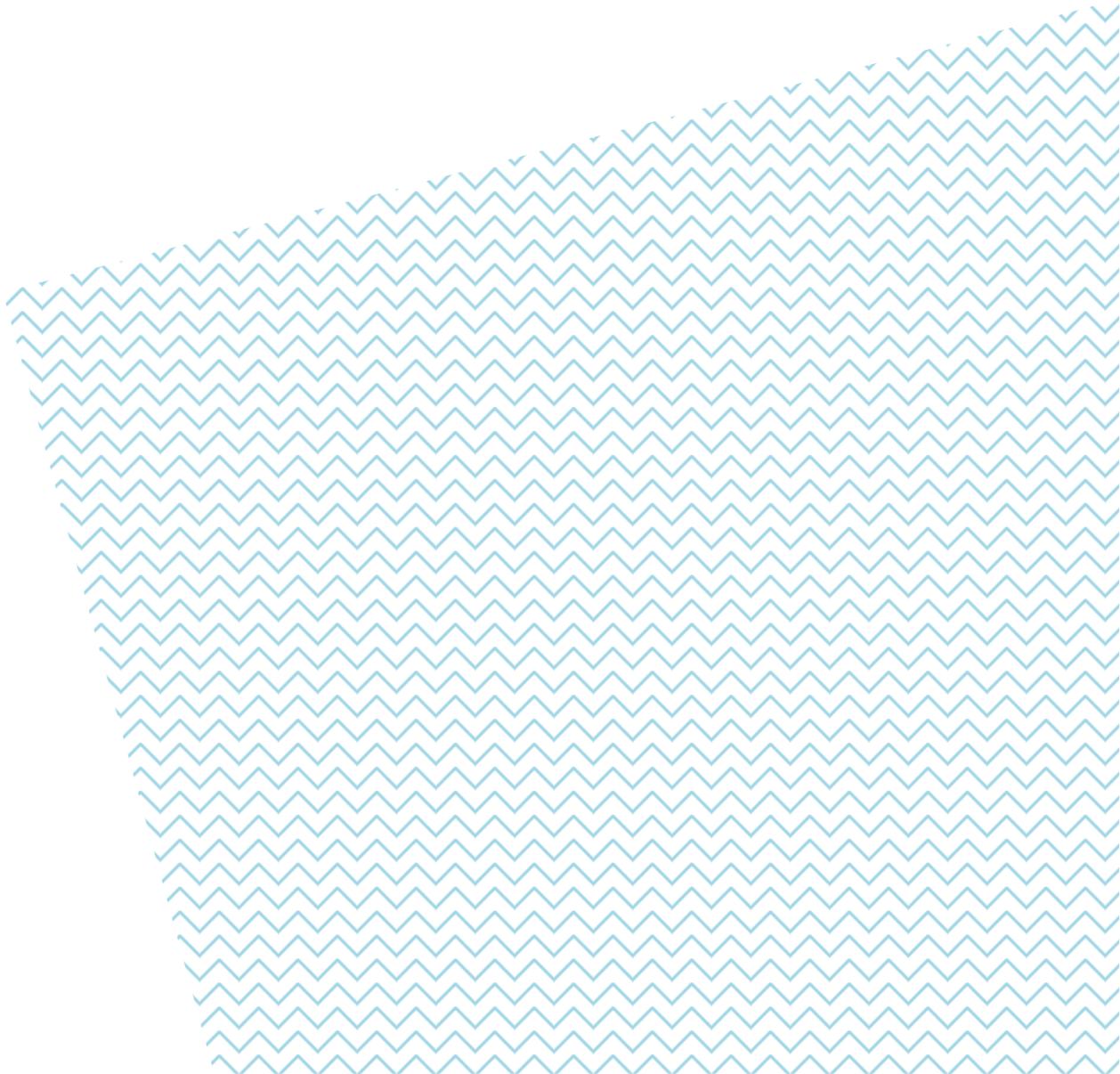


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Department of Accounting & Melbourne Disability Institute

# **Assistive Technology (AT) for All: Exploring the benefits and challenges of timely access to AT when ineligible for the NDIS.**

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## Executive Summary

Assistive Technology (AT) plays a vital role in supporting the lives of Australians with ABS figures showing more than 2.3 million individuals with a disability use some form of AT. Access to an AT is however challenging for those with a need but for age or other reasons are ineligible for National Disability Insurance Scheme support for obtaining necessary AT.

The purpose of this report is to investigate the impacts of challenges to timely access to AT for individuals who are ineligible for NDIS support. Through a survey of 92 such individuals, this report documents the widespread potential positive impacts of AT, and the consequent negative economic, social and wellbeing impacts of challenges to timely access.

Notable findings include:

- Evidence of no meaningful difference in need between those who have acquired AT and those who are still seeking to acquire AT. Suggesting that challenges to timely access are not simply due to the prioritisation of individuals with greater need.
- Lack of funding commensurate with the costs of AT, together with wait times in acquiring AT continue to challenge the individuals ineligible for NDIS support.
- While the some are able to “self-fund” (e.g., by drawing on personal or family resources), others are left with unmet needs and/or are required to draw more heavily on informal supports or other funded formal supports.
- Acquiring an AT appears to not only lead to social and wellbeing benefits for the individual with a disability, but also leads to reduced need to draw on informal or other funded supports.

The survey combined both quantitative measures and self-reports of lived experiences of the challenges and benefits involved in acquiring AT for individuals ineligible for the NDIS. While no single study can be definitive, the data gathered in this study suggests that calls for improving access to AT for individuals with a disability that are ineligible for the NDIS are warranted, and merit further consideration by policy makers.

## 1. Introduction

This project was funded through the Melbourne Disability Institute Community-Based Research Scheme. The scheme meets the research needs of community organisations by providing research support and evaluation for advocacy and other programs that are making a difference in the lives of people with disability, their families and carers. The evaluation team come from the University of Melbourne's Department of Accounting.

Assistive Technology (AT) plays a vital role in supporting the lives of Australians. As of 2018, an estimated 4.4 million people, or 1 in 6 people in Australia live with a disability (Australian Bureau of Statistics [ABS], 2019). Over half of Australians with a disability (53.1% or 2.3 million of 4.4 million) use some form of AT to assist with their daily functioning, improve their independence, and increase their participation in social and economic life (ABS, 2019). AT in this study is defined broadly as "any products, equipment, instruments, or software that help a person with disability function and participate in society. They are sometimes also referred to as 'aids and equipment', 'medical appliances', or 'medical devices'."<sup>1</sup>

This report provides evidence on the impact of challenges in gaining timely access to AT for individuals with a disability that are for age or other reasons ineligible for the National Disability Insurance Scheme (NDIS). Two main research questions are explored:

- What are the social and economic benefits of providing timely access to AT?
  - The goal here is to provide evidence as to why individuals excluded from the NDIS should be supported in getting timely access to AT.
- What factors limit individuals from gaining timely access to AT?
  - The goal here is to document challenges that are impeding timely access, with a view to informing policy and practices that may address these challenges.

Exploring these research questions provides evidence that there are considerable positive social and economic impacts associated with gaining access to AT, and doing so in a timely manner. While no single study can be definitive, and the sample of respondents was not particularly large or necessarily comprehensive, the data gathered in this study suggest that calls for improving access to AT for individuals with a disability that are ineligible for the NDIS are warranted and merit further consideration by policy makers.

## 2. Methodology & Data Collection

To explore the research questions, a survey was developed<sup>2</sup> and distributed through the Assistive Technology for All alliance (ATFA). The survey specifically examined individual's AT needs, the benefits AT could provide them, their experiences in gaining funding and access to AT, and asked a series of questions relating to the impact AT has already had, or is expected to have, on their lives. Respondents were also given the opportunity to explain in their own words what gaining access to AT has meant, or would mean to them, and how it has, or is expected to, change their lives.

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<sup>1</sup> This definition was crafted in order to convey clearly the meaning of AT to our survey participants. It is drawn on definitions and conceptualisations of AT from WHO (2002), Desmond et al (2018) and NDIS (2022).

<sup>2</sup> A full copy of the survey questions is available in Appendix 1.

The survey instrument was developed in collaboration with the ATFA to ensure questions were framed in a manner to not cause distress to survey respondents. Support information was made available to all respondents in case reflecting on their experiences did cause any distress. The study received ethics clearance from the University of Melbourne’s Office of Research Ethics and Integrity.

Respondents to the survey were screened to ensure they; either require, are actively seeking, or have recently acquired AT, are not on an NDIS plan, and provided consent to participate in the study. Individuals were able to complete the study themselves, or have a support person complete the study on their behalf.

Respondents were instructed that they were able to skip responding to a question if doing so would cause them distress. All respondents were provided with information for support services if they experienced any distress while completing the survey.

Throughout this report descriptive statistics are presented and supported by self-reported accounts of the lived experience of respondents to facilitate the interpretation of the statistical data.

**Table 1 - Access to AT**

	Already acquired AT	Received funding for AT, but not yet acquired AT	Waiting or have not yet applied for AT funding	Total Respondents
<b>Percentage of Respondents</b>	43.5%	3.2%	53.2%	92

As indicated in Table 1, respondents to this survey included a mix of those who have already acquired AT, and those who have not yet acquired AT. Those who have already acquired AT were asked about their experiences applying for funding and sourcing their AT, and the impact that AT has had on their life. Those who have not yet acquired AT were asked about any experiences they may have had in applying for funding and sourcing their AT, and the impact they expect AT will have on their life.

The 92 respondents in this study had an average age of 59.8, with a median age of 68.0. 57.6% of respondents were aged over 65, falling outside the eligibility criteria of the NDIS based on their age. The remainder of the respondents fall outside the eligibility criteria of the NDIS for a variety of other reasons, notably it appears that ineligibility does not appear to be a driven by lack of need.

### 3. Results & Discussion

#### 3.1. Gaining access to AT creates a widespread impact

Providing access to AT can have a considerable widespread positive impact in helping people to access the everyday facets of life, such as independent living, and other everyday services.

**Table 2 – AT benefits everyday life**

<i>What impact has gaining AT had/would access to AT have on your opportunity to access the following?</i>	Little to no impact	A slight impact	A moderate impact	A great impact	An extreme impact
<b>Independent living</b>	3.5%	7.0%	14.0%	29.1%	46.5%
<b>Transport services</b>	12.8%	15.4%	16.7%	15.4%	39.7%
<b>Education</b>	32.7%	21.8%	10.9%	16.4%	18.2%
<b>Employment</b>	41.8%	12.7%	5.5%	14.5%	25.5%
<b>Recreation</b>	6.0%	8.3%	15.5%	28.6%	41.7%
<b>Everyday services</b>	9.9%	9.9%	9.9%	23.5%	46.9%

Table 2 shows over 75% of respondents indicated AT has had, or is expected to have, a great or extreme impact on their opportunity to access independent living. Over 70% of respondents indicated AT has had, or is expected to have, a great or extreme impact on their opportunity to access recreation and everyday services. Impacts on accessing independent living and transport services are also considerable, as over 50% of respondents indicated a great or extreme impact for each measure.

Outcomes relating to employment were heavily dependent on whether the individual was still employed. Of the 21 respondents that indicated they engage with employment in some form, 66.7% indicated that gaining access to AT has had, or is expected to have a moderate impact or greater on their opportunity to access future employment.

Comments from the below respondents indicate how AT can help individuals better access and participate in daily life.

*“[AT] would give me independence to go out by myself for shopping, visiting, social and community activities.” (Female, 69)*

*“Improved quality of life, [a] decreased risk of hospitalisation, [and] allow to stay living at home and not need to move into a nursing home.” (Male, 76)*

**Table 3 – AT Economic Impacts: The need for carers and formal supports**

<i>What improvement has the AT you have acquired/expect to acquire had on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>My need for carers and support workers</b>	31.4%	15.7%	12.9%	25.7%	14.3%
<b>The amount of money I spend on carers and support workers</b>	35.1%	17.5%	14.0%	21.1%	12.3%
<b>The likelihood of self-purchasing AT in the future</b>	25.3%	9.3%	21.3%	21.3%	22.7%
<b>My need for professional medical assistance</b>	26.8%	16.9%	25.4%	16.9%	14.1%
<b>My overall financial situation</b>	31.1%	5.4%	14.9%	20.3%	28.4%

Table 3 provides evidence that gaining access to AT also has the potential to impact meaningfully on an individual’s economic situation. Particularly, over 56% of respondents indicated that gaining access to AT has had, or is expected to provide a moderate to extreme reduction in the likelihood of self-purchasing further AT in the future. 63.6% of respondents indicated that gaining access to AT has had, or is expected to have a moderate to extreme improvement on their overall financial situation.

AT also has the potential to provide an extreme improvement in an individual’s quality of life, particularly around their social interactions, and mental health and wellbeing.

**Table 4 – AT improves social and mental wellbeing**

<i>What improvement has the AT you have acquired/expect to acquire had on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>Family relationships</b>	15.0%	6.3%	17.5%	30.0%	31.3%
<b>Friends relationships</b>	12.2%	8.5%	22.0%	24.4%	32.9%
<b>Mental health &amp; wellbeing</b>	5.6%	6.7%	18.0%	20.2%	49.4%
<b>Community engagement</b>	7.8%	14.4%	11.1%	21.1%	45.6%
<b>Social engagement</b>	9.3%	10.5%	12.8%	18.6%	48.8%

Responses from Table 4 indicate that gaining access to AT can greatly impact an individual's personal mental health and wellbeing, and their engagement with friends, family, and the broader community. An improvement in mental health and wellbeing especially is associated with gaining access to AT, as 49.4% of respondents rated an extreme improvement on their mental health and wellbeing, and over 87% of respondents rated a moderate or greater improvement on their mental health and wellbeing from the AT they have acquired or expect to acquire. Gaining access to AT was also associated with an improvement in community and social engagement, as 77.8% of respondents indicated a moderate or greater improvement on their community engagement, and 80.2% of respondents indicated a moderate or greater improvement on their social engagement.

The ability of AT to help an individual feel integrated within the community, and actively engage in relationships with family and friends is demonstrated through the experiences of this respondent:

*"I have a severe chronic communication impairment (aphasia) after suffering a stroke at the age of 67... I felt very frustrated and depressed and lonely when I wasn't able to have a 'voice', express my opinions and maintain my relationships with friends and families... Having access to a communication device has helped change my life so much for the better. Having a voice again is everything – I feel I can be included more in social interactions. I have started going out again and even been back down to my local social group. I feel like I have more control and choice because I tell people what I want. I am so much happier, and I can see that has made my wife and children feel the same way." (Male, 67)*

A similar impact can be seen for the following individual, who suffers from paralysis to one side of his body. Access to AT allows him to participate in everyday social settings:

*"[The AT] enables social interaction. We can sit at a bar, look over heads at a concert or sports game when there are people in front, stand up to dance or cheer and can reach counters or services which are at standing level." (Male, 73)*

### **3.2. Evidence of the significant unmet need for AT**

To explore the impacts of gaining access to AT, it is important to consider the experiences of both those individuals who have already acquired AT, and those who are yet to acquire AT. This section of results presents tables showing the impact on everyday life, and economic and social wellbeing separately for these two groups.

The below results indicate that, in general, AT has the ability to make just as great, if not a greater, impact on the lives of individuals who require AT, compared to those who have already acquired AT. This demonstrates that while some members of the community have been able to access much needed AT, there are still many individuals who have not been able to access AT that have a serious need for it.

**Table 5 – AT benefits everyday life (Already acquired AT)**

<i>What impact has gaining AT had on your opportunity to access the following?</i>	Little to no impact	A slight impact	A moderate impact	A great impact	An extreme impact
<b>Independent living</b>	2.7%	5.4%	13.5%	24.3%	54.1%
<b>Transport services</b>	19.4%	0.0%	19.4%	12.9%	48.4%
<b>Education</b>	38.1%	0.0%	14.3%	19.0%	28.6%
<b>Employment</b>	43.5%	4.3%	4.3%	13.0%	34.8%
<b>Recreation</b>	8.6%	8.6%	22.9%	20.0%	40.0%
<b>Everyday services</b>	11.8%	5.9%	8.8%	26.5%	47.1%

Results in Table 5 indicate that AT has a positive impact across the facets of everyday life for those who have already acquired AT. A particularly substantial impact can be seen across categories such as independent living, transport services, and everyday services, where close to, if not more than half of all respondents indicated an extreme impact on everyday life from accessing AT.

**Table 6 – AT is expected to benefit everyday life (Not yet acquired AT)**

<i>What impact would access to AT have on your opportunity to access the following?</i>	Little to no impact	A slight impact	A moderate impact	A great impact	An extreme impact
<b>Independent living</b>	4.1%	8.2%	14.3%	32.7%	40.8%
<b>Transport services</b>	8.5%	25.5%	14.9%	17.0%	34.0%
<b>Education</b>	29.4%	35.3%	8.8%	14.7%	11.8%
<b>Employment</b>	40.6%	18.8%	6.3%	15.6%	18.8%
<b>Recreation</b>	4.1%	8.2%	10.2%	34.7%	42.9%
<b>Everyday services</b>	8.5%	12.8%	10.6%	21.3%	46.8%

Findings from Table 6 demonstrate that those individuals who are yet to gain access to AT also expect to see a considerable improvement in accessing everyday facets of life. There is a particularly substantial impact expected to be seen across independent living, recreation, and everyday services. The difference in employment impacts between Table 5 and Table 6 suggest that many of those who have not yet acquired AT are in the retirement stage of life (and possibly that those who have acquired AT may have received some assistance from employers).

**Table 7 – AT Economic Impacts: The need for carers and formal supports (Already acquired AT)**

<i>What improvement has the AT you have acquired had on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>My need for carers and support workers</b>	29.2%	20.8%	16.7%	20.8%	12.5%
<b>The amount of money I spend on carers and support workers</b>	41.2%	17.6%	11.8%	23.5%	5.9%
<b>The likelihood of self-purchasing AT in the future</b>	33.3%	3.3%	26.7%	16.7%	20.0%
<b>My need for professional medical assistance</b>	46.2%	11.5%	26.9%	15.4%	0.0%
<b>My overall financial situation</b>	60.7%	0.0%	14.3%	17.9%	7.1%

Table 7 shows that gaining access to AT can create meaningful economic impacts. Over 70% and 66% of respondents indicated some level of improvement in their need for carers and support workers, and the likelihood of self-purchasing AT in the future, respectively. The level of economic impact can particularly be seen around the amount of money spent on carers and support workers, and the likelihood of self-purchasing AT in the future, where 29.4% and 36.7% of respondents indicated a great or extreme improvement, respectively.

**Table 8 – AT Economic Impacts: The need for carers and formal supports (Not yet acquired AT)**

<i>What improvement will the AT you expect to acquire have on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>My need for carers and support workers</b>	32.6%	13.0%	10.9%	28.3%	15.2%
<b>The amount of money I spend on carers and support workers</b>	32.5%	17.5%	15.0%	20.0%	15.0%
<b>The likelihood of self-purchasing AT in the future</b>	20.0%	13.3%	17.8%	24.4%	24.4%

<b>My need for professional medical assistance</b>	15.6%	20.0%	24.4%	17.8%	22.2%
<b>My overall financial situation</b>	13.0%	8.7%	15.2%	21.7%	41.3%

Table 8 provides evidence that there can be substantial positive economic impacts by providing AT to those who have not yet been able to access it. 48.7% of respondents predicted a great or extreme improvement in the likelihood of needing to self-fund a future purchase of AT, while 63% of respondents predicted a great or extreme improvement in their overall financial situation. This demonstrates a real economic need for AT amongst those who are yet to acquire AT.

Those yet to acquire AT predicted they will experience a greater economic benefit from gaining access to AT than those who have already acquired AT have experienced. Importantly, the average reported cost of AT for those who have already acquired and those yet to acquire was virtually identical<sup>3</sup>. This indicates that those who are unable to access AT may face more difficult economic conditions in their daily life, which could restrict them from being able to make a self-funded purchase of AT.

**Table 9 - AT improves social and mental wellbeing (Already acquired AT)**

<i>What improvement has the AT you have acquired had on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>My relationships with family</b>	21.2%	6.1%	18.2%	27.3%	27.3%
<b>My relationships with friends</b>	18.2%	12.1%	27.3%	21.2%	21.2%
<b>My general mental health &amp; wellbeing</b>	5.3%	10.5%	26.3%	21.1%	36.8%
<b>My ability to engage in community activities</b>	12.8%	28.2%	12.8%	15.4%	30.8%
<b>My ability to engage in social gatherings with others</b>	17.1%	22.9%	14.3%	14.3%	31.4%

Table 9 demonstrates the various social impacts of gaining access to AT. At least 42.4% of respondents rated a great or extreme improvement across their relationships with family and friends, general mental health and wellbeing, and ability to engage in the community and in social gatherings with others. Mental health and wellbeing particularly is associated with a sizable impact, as 57.9% of respondents indicated a great or extreme improvement. This demonstrates that gaining access to AT has the potential to reduce the strain on other areas of the healthcare system such as mental health, meaning the benefits of accessing AT are not isolated just to the individual receiving the AT, but extend to broader Australian society.

<sup>3</sup> The average cost of AT for those who have already acquired is \$5,209, while the average cost for those yet to acquire is \$5,176, resulting in a minor average difference in cost of 0.6%.

**Table 10 – AT is expected to improve social and mental wellbeing (Not yet acquired AT)**

<i>What improvement will the AT you expect to acquire have on the following?</i>	Little to no improvement	A slight improvement	A moderate improvement	A great improvement	An extreme improvement
<b>My relationships with family</b>	10.6%	6.4%	17.0%	31.9%	34.0%
<b>My relationships with friends</b>	8.2%	6.1%	18.4%	26.5%	40.8%
<b>My general mental health &amp; wellbeing</b>	5.9%	3.9%	11.8%	19.6%	58.8%
<b>My ability to engage in community activities</b>	3.9%	3.9%	9.8%	25.5%	56.9%
<b>My ability to engage in social gatherings with others</b>	3.9%	2.0%	11.8%	21.6%	60.8%

Table 10 provides further evidence that those yet to acquire AT have a serious need for it, through the vast social and wellbeing impacts it may have. Particularly in the areas of general mental health and wellbeing (78.4%), ability to engage in community activities (82.4%), and ability to engage in social settings with others (82.4%), those who are yet to acquire AT were highly likely to predict a great or extreme improvement from gaining access to AT. These numbers demonstrate that the need for AT in those who are unable to access it is real and important in the lives of those that live with a disability.

The extensive social benefits that individuals expect to enjoy from gaining access to AT can be further seen from the below comments from respondents.

*“[I] need to purchase a voice amplifier to make my voice louder so it can be heard by others when I’m out and about in the community... It would give me the independence to talk to people, order a coffee or talk to the taxi driver on my own. Otherwise my voice due to Parkinson’s Disease is too quiet and difficult for people that don’t know me to hear.” (Male, 78)*

The results in this section indicate that individuals who have gained access to AT see a considerable positive impact across their ability to live their everyday life, their economic situation, their social interactions in the community, and their personal wellbeing and mental health.

Responses also indicate that individuals who have not yet acquired AT still have a serious need for it, and would see material benefits to their lives if they are able to access AT. It does not appear to be the case that these individuals have merely avoided acquiring AT because they do not have a real need for it. Instead, a series of factors, including wait times, cost, lack of available funding, and the complexity of AT limit these individuals from gaining timely access to AT. The following section provides additional data and analysis on these factors.

### 3.3. Why do individuals struggle to gain access to AT?

This section of the report focuses on the second research question, exploring what factors may limit individuals from gaining timely access to AT.

#### 3.3.1. The Cost of AT

One factor which may have a large impact on an individual’s opportunity to access AT is the cost of that AT. Some respondents detailed fairly low cost AT needs, such as crutches, a shower chair, or intercom system for their front door, which all have estimated costs below \$1,000. Other respondents described much more complex AT needs that come at a significant cost. For example, one individual requires a *“microprocessor knee [to] allow me to be more independent and decrease the risk of falls,”* (Female, 70) at an estimated cost of at least \$10,000. Another individual requires a highly specialised wheelchair with an estimated cost of at least \$30,000.

**Table 11 – Funding for respondents by cost of AT**

Estimated AT cost	Received partial funding %	Received full funding %	Received any funding %
\$1 - \$2,499	8.3%	16.7%	25.0%
\$2,500 - \$4,999	13.6%	9.1%	22.7%
\$5,000 - \$9,999	16.7%	8.3%	25.0%
\$10,000+	21.1%	10.5%	31.6%
<b>Full Sample</b>	14.6%	13.4%	28.0%

Table 11 shows the percentage of respondents that have been able to access funding for their needed AT, sorted by the AT’s estimated cost. Across the full sample of respondents, only 28% have received any funding towards their AT, with only 13.4% receiving funding equal to the full cost of their AT. 72% of the sample have either been denied funding, or have not applied for funding.

Across the cost bands, the percentage of respondents that have received any funding is fairly consistent, fluctuating between 22.7% and 31.6%. While the highest cost band of \$10,000+ shows the highest percentage of respondents that have received any funding at 31.6%, these individuals have the greatest need for funding assistance. The majority of respondents in this band that received funding only received partial funding, with only 10.5% of those in this band receiving funding covering the full cost of their AT. Receiving only partial funding towards an AT need can create significant issues for individuals, as one claimed, *“the funding I receive doesn’t cover the full cost of my AT. I am out \$100s each year paying for things myself and I still don’t have access to everything I need.”* (age and gender not supplied)

Some pieces of AT may need to be highly modified and specialised for the individual, creating large costs. Individuals who have large AT costs also report that a higher AT cost creates a barrier to accessing funding. One respondent commented, *“who pays for a \$30k wheelchair?”* (Female, 69)

### 3.3.2. Funding Sources

**Table 12 – Respondents receiving funding by funding source**

	Already received funding	Expecting to receive funding
<b>State Government</b>	10.8%	6.5%
<b>Federal Government</b>	5.4%	14.1%
<b>Non-Government</b>	6.5%	7.6%
<b>Total</b>	22.8%	28.3%

Another key factor that may limit an individual’s access to AT is available sources of funding. As indicated in Table 12 only just over half (51.1%) of respondents indicate they have either already received funding, or expected to receive funding towards their AT needs. Even those that do receive some amount of funding often face issues and difficulties in appropriately meeting their AT needs.

As the NDIS has been gradually introduced over the past decade, some individuals with an AT need indicate it has been more difficult to gain funding through state and non-government funding programs. As one individual states, *“since the NDIS came providers will not assist anymore unless you have NDIS”*. (Female, 68)

This has created particular issues for individuals over 65, and those who fall outside the eligibility criteria for the NDIS due to not meeting other criteria. These individuals may struggle to gain appropriate funding through other programs. Several respondents faced such issues, stating they could not access any funding as *“I was rejected for access to NDIS,”* (age and gender not supplied) or *“I wasn’t eligible for any external funding”* (Female, 57).

Those that believe they may be eligible for the NDIS and try to navigate the system often face issues doing so. One respondent described a difficult experience trying to navigate the system – *“NDIS [funding is] not attainable – [I] put in five separate applications each with a review and they were all knocked back and needed more evidence when I had already given them everything I had. I couldn’t afford to go to more specialists so they could write me support letters because I am spending all my money on wheelchair hire, physical therapy and essential medications.”* (Female, 22)

Another respondent described their similar experience – *“I received a convoluted trail of information regarding the process of joining the NDIS in order to receive a plan and funding afterwards. Their system is not set up for participants to succeed.”* (Female, 25)

The majority of those who have gained funding, or expect to gain funding, from the federal government receive funding through aged care packages. These packages often are unable to adequately meet an individual’s AT needs and allow them access to the AT they require. For example, one respondent suffers from Motor Neurone Disease and is no longer able to move through the community independently, creating considerable AT needs. The cost of his AT is estimated at somewhere over \$10,000. While this individual has access to an aged care package, this package is intended to fund not only AT, but also carers. The package is *“woefully small”* to pay for both AT and carers, forcing the individual to choose to *“keep my aged care package for carers”* (Male, 68). As a result, he has only been able to put \$1,000 of external funding towards acquiring AT, creating a shortfall of at least \$9,000, even though he has access to an aged care funding package.

Some respondents that were ineligible for funding under the NDIS were able to receive some funding through a state government program. Respondents received funding through programs such as the State-Wide Equipment Program (SWEP) in Victoria, the Queensland Medical Aids Subsidy Scheme, Queensland Artificial Limb Service, Western Australian Limb Service for Amputees (WALSA), and EnableNSW.

Some individuals who fall outside the eligibility criteria of the NDIS saw state government funding programs as their only real opportunity to be able to access funding, but still struggled to do so. One individual suffers from *“voice and speech loss, loss of balance, slow walking, pain and fatigue with mobility”*. He has identified a need for a *“digital voice as close to mine with my sound, accent and language [to] help me keep some of my identity and culture. I think people would treat me better and have an improved connection as a person, and not just a person who uses a standard text to speech voice”* (Male, 68). This AT has an approximate cost of \$3,000, yet the individual, who is ineligible for the NDIS, is struggling to gain funding through a state government program. While they hope that *“SWEP may be [able] to contribute,”* they are not hopeful of being successful in receiving funding as there are *“too many requirements to fund through SWEP.”*

Multiple respondents who received funding from a state government program also indicated that their funding was tied towards a specific piece of AT, and they did not have the level of choice they desired in choosing the piece of AT they felt was most appropriate for their needs.

Individuals that find themselves ineligible for any government funding are sometimes able to have their AT needs funded by a not-for-profit organisation. Respondents received funding from organisations such as the Robert Rose Foundation, the Motor Neurone Disease Association of South Australia, and the Motor Neurone Disease Association of Queensland. In some cases those who weren't able to access funding from a not-for-profit organisation have been forced to turn to family and friends to fund their AT needs, as one respondent reports their AT needs were *“funded in full by my parents”* (Female, 34).

The experiences of respondents show that there are issues associated with accessing AT funding from any source that limit an individual's ability to gain timely access to necessary AT. However, nearly half of all respondents indicate that they are not eligible for any funding program at all, and must self-fund any AT purchases. Self-funded purchases of AT are explored further later in this report.

### 3.3.3. Current wait times for AT

A further obstacle in gaining access to AT is wait times for funding applications to be approved, and for AT to be customised and delivered.

13 respondents indicated that they have applied for AT funding and are currently waiting to receive a funding outcome. While on average they believe a reasonable wait time between funding and receiving an outcome would be 3 months, the average current wait time is 16.5 months. These individuals typically have highly complex and costly AT needs, such as highly modified wheelchairs, or prosthetic limbs.

In some cases, wait times become quite extreme. One respondent indicated their current wait time since submitting an application for funding is 68 months. This individual appeared to have become quite disillusioned with the funding process, commenting that they don't expect to receive funding *“for the next 1,000 years”* (Male, 64).

The COVID-19 pandemic appears to have had a mixed effect on wait times for AT. 54% of respondents currently waiting for AT indicated that the pandemic has had a moderate or greater delay on their acquisition of AT, while 46% reported that the pandemic has had no impact.

Respondents generally indicated that the “myriad of delays and bureaucracies” (Male, 65) made the application process for AT funding difficult, and prompted many to consider self-funding their own purchases of AT.

### 3.4. Those who cannot gain access to AT are driven towards self-purchases

A combination of factors, including cost, lack of access to funding, and wait times, contribute to difficulties in accessing AT. This causes individuals to have needs that remain unmet, unless they are able to find an alternative method to gain access to AT, such as a self-funded purchase.

AT needs are often complex, and individuals often require more than one item of AT. Table 13 indicates what percentage of respondents have made a self-funded purchase of AT.

**Table 13 – Self-funded purchases of AT**

	Partly self-funded	Fully self-funded	Partly or fully self-funded
<b>All current AT needs met</b>	13.0%	32.6%	45.7%
<b>Still have outstanding AT needs</b>	15.2%	28.3%	43.5%
<b>Total</b>	28.3%	60.9%	89.1%

Table 13 provides evidence that 89.1% of respondents have made some kind of self-funded purchase of AT. Responses from individuals indicate that in general, they are driven to self-fund their AT when they have no other funding options available, and have an unavoidable need for AT. As one respondent indicated, “whether I received funding or not, I NEEDED [AT] to walk, there was no other option” (Male, 77). This is a sentiment shared by a number of respondents, who felt they have no alternatives but to find a way to purchase AT using their own funds. Another individual shared their circumstances of suffering from “Huntington’s Disease and need[ing] a wheelchair to access the community.” They indicated they felt left out of the AT funding system, posing the question, “When in aged care, who funds [this]? (Female, 69)”

Other individuals have not yet made a self-funded AT purchase, but may well be forced to make one in the future, having “no funding mechanism to support an AT purchase – I am not eligible for [any] schemes” (Female, 29).

Nearly half of those who have self-funded a purchase still have outstanding AT needs and require further funding. One respondent, who suffers from a range of disabilities and ailments, detailed a myriad of AT they require, including “a powered wheelchair with tilt and raise, a hoist for transfers, a toilet commode, continence aids, and a neck lanyard attached to a mobile phone” (Male, 73). As is the case with other individuals, some of the required AT are far more complex and costly than others. Comments from respondents generally indicate that while they may be able to self-fund the purchase of a relatively simple AT, it is not feasible to self-fund a purchase of more costly AT.

The comments provided by respondents make it clear that individuals are not making self-funded purchases of AT simply for convenience, or because they have adequate savings to fund all their needs. Rather, they are making self-funded purchases out of necessity, facing a choice of finding a way to self-fund, or going without the AT they need to improve their quality of life.

## 4. Conclusion

The results of this study indicate that gaining timely access to AT can have a substantial impact on the daily lives of individuals living with a disability, particularly through the ability of AT to enable individuals to achieve desirable social and economic outcomes. Particularly in areas such as mental health and wellbeing, community engagement, and access to recreation and everyday services, respondents indicate that AT has a real and meaningful impact in their lives. Those that have been unable to access AT indicate they experience hardship in these areas, and can see that gaining access to AT would considerably improve their lives.

While funding schemes, such as the NDIS and various state government based programs, do help connect individuals in the community with the AT they need, there is a large portion of the community that fall through the cracks and are unable to have their AT needs met.

Those individuals who have not yet acquired the AT they need generally have just as great a need as those who have acquired AT. It is not the case that they are able to live their best possible daily life without AT, but instead face a series of obstacles in gaining access to AT, such as high cost, ineligibility for various funding programs, and excessive wait times.

Many individuals see no alternative but to fund their own AT purchase, at considerable personal expense, or rely on the generosity of their family and friends. Ultimately, many people in the Australian community continue to live without the AT they have a real need for.

## References

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## Appendix – Survey Materials

The following displays the survey instrument that was administered to survey respondents. Please note the questions shown here are those shown to participants that indicated they have already acquired AT at some stage in the last two years. Individuals who indicated they have not yet acquired AT answered questions that were substantively the same, but contained slightly different wording to appropriately reflect their circumstances.

Q1.1

**Thank you for your interest in this survey.**

The purpose of this survey is to understand the benefits and issues involved in the provision of Assistive Technology and any unmet need.

*For the purposes of this study we define Assistive Technology (AT) broadly as products, equipment, instruments, or software that help a person with disability function and participate in society. They are sometimes also referred to as 'aids and equipment', 'medical appliances', or 'medical devices'.*

We are seeking responses from individuals who have a need for AT, and are NOT financially supported through an NDIS plan, regardless of whether or not the AT has been acquired yet.

We expect this survey to take no longer than 10-15 minutes to complete. The survey may be completed by someone on behalf of the individual with the need for AT, in which case it should be completed from the perspective of the person with the need for AT.

Your responses are completely anonymous, confidential, and highly valued. This survey is being conducted by researchers from the University of Melbourne for the Assistive Technology for All Alliance. Only the researchers will have access to the raw data. This study has been approved by the University's Human Research Ethics Committee (HREC 20900). For further details of the risks and benefits of participation, the contact details for the researchers, or to lodge a complaint with the research ethics committee please refer to the plain language statement available [Here](#).

If participating in this project causes you distress or discomfort, there is help available: 1800RESPECT can provide you with support, information and referral to assist in supporting people with disability. You can contact them on 1800 727 732 or through online chat. <https://www.1800respect.org.au/> BeyondBlue provides information and support to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live. There is specific support available for people with disability. Call 1300 22 4636 or visit <https://www.beyondblue.org.au/> SANE Help Centre provides counselling, support, information and referrals to adults who identify as having a complex mental health issue, complex trauma or high levels of psychological distress. 1800 18 7263 or <https://www.sane.org/>

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Q1.2

Complete the following for yourself, or on behalf of the person you are representing, to confirm your eligibility for this study.

I/the person I represent (select all that apply)

- is actively seeking or have/has acquired AT or require AT (1)
- is not on an NDIS plan (2)
- consent to participate in this study (3)

Q1.3 Please indicate below whether you are responding to this survey based on your own experiences, or you are responding on behalf of another person with a need for AT.

If you are responding on behalf of another person with a need for AT, please answer the remainder of this survey from their perspective.

- I am responding to this survey based on your own experiences (1)
- I am responding on behalf of another person with a need for AT. (2)

Q1.4

For the purposes of this study we define Assistive Technology (AT) broadly as products, equipment, instruments, or software that help a person with disability function and participate in society. They are sometimes also referred to as 'aids and equipment', 'medical appliances', or 'medical devices'.

What is your current situation with respect to AT (select all that apply):

- I have acquired AT in the last 2 years (1)
- I have self-funded AT purchase(s) in the last 2 years (2)
- I have accessed external funding for AT purchase(s) in the last 2 years (3)
- I have been placed on an AT waitlist in the last 2 years (4)
- I have a current need for AT, but no access to fund an AT purchase(s) (5)

Q1.5 Please briefly describe the nature of your functional impairment that AT will assist.

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Q4.1 For the purposes of this survey, we would like you to focus on the AT that would have greatest impact in your daily life. This must be AT you have acquired, or sought to acquire in the last 2 years, or that you have a current need for.

Q4.2

Please briefly describe this AT, and how it would impact your daily life.

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Q4.3 At what stage in the process of acquiring this AT are you?

- I have already acquired the AT (1)
- I have already received funding for AT, but have not yet acquired it. (2)
- I am waiting for AT funding (3)
- I have not yet applied for AT funding (4)

Q4.4 Approximately when did you apply for AT funding?

	Month (MM) (1)	Year (YY) (2)
Please enter a numerical date in Month (MM), Year (YY) format (1)		

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Q4.5 Approximately when did you receive funding for AT?

	Month (MM) (1)	Year (YY) (2)
Please enter a numerical date in Month (MM), Year (YY) format (1)		

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Q4.6 Approximately when did you receive your AT?

	Month (MM) (1)	Year (YY) (2)
Please enter a numerical date in Month (MM), Year (YY) format (1)		

Q4.8 To what extent has COVID-19 delayed your acquisition of AT?

- Little to no delay (1)
- A slight delay (2)
- A moderate delay (3)
- A great delay (4)
- An extreme delay (5)
- N/A (6)

Q4.9

How many **months** do you believe would be a reasonable time to wait between applying for your AT, and having your AT delivered?

\_\_\_\_\_

Q4.10 How many **hours per week** of formal support (i.e., paid carer or support worker) and informal care (i.e., unpaid carer such as a relative, friend etc.) do you typically receive per week when not having access to AT?

- Formal Care (1) \_\_\_\_\_
- Informal Care (2) \_\_\_\_\_

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Q4.11 How many **hours per week** of formal support (i.e., paid carer or support worker) and informal care (i.e., unpaid carer such as a relative, friend etc.) do you estimate you will need per week, or currently need per week, when you have access to AT?

- Formal Care (1) \_\_\_\_\_
  - Informal Care (2) \_\_\_\_\_
-

Q4.14 When did you first identify a need for AT?

	Month (MM) (1)	Year (YY) (2)
Please enter a numerical date in Month (MM), Year (YY) format (1)		

Q4.15 When did you first take action about your need for AT?

	Month (MM) (1)	Year (YY) (2)
Please enter a numerical date in Month (MM), Year (YY) format (1)		

Q4.16 What information sources did you make use of to learn more information about AT? (Please select as many information sources as you made use of)

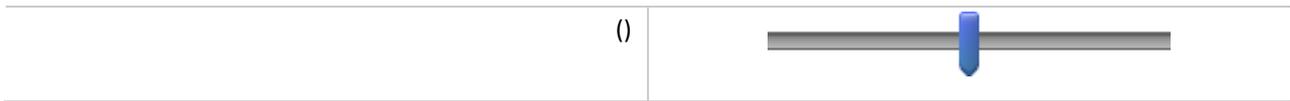
- Doctor (GP) (1)
  - Specialist Doctor (2)
  - Internet/Google search (3)
  - Friends or family (4)
  - Community organisation (e.g. COTA) (5)
  - Allied Health professional (6)
  - Disability Specific Organisation (7)
  - Assistive Technology Centre or Database (8)
  - Other (please specify) (9) \_\_\_\_\_
- 

Q4.17 How did you find the process of learning information about AT?

- Extremely easy (1)
  - Somewhat easy (2)
  - Neither easy nor difficult (3)
  - Somewhat difficult (4)
  - Extremely difficult (5)
- 

Q4.18 Approximately what is the typical cost of your AT (in Australian Dollars (AUD))?  
(sliding scale -- click on slide to move)

0      2000      4000      6000      8000      10000



Q4.19 Approximately how much external funding have you received towards your AT (in Australian Dollars (AUD))?  
(sliding scale -- click on slide to move)

0 2000 4000 6000 8000 10000



Q4.21 Where have you received external funding for AT from?

Federal Government (if possible specify government department) (1)

\_\_\_\_\_

State Government (if possible specify government department) (2)

\_\_\_\_\_

Non-Government Source (please specify) (3) \_\_\_\_\_

I don't know if my funding comes from Government or a Non-Government source (if possible please specify name of organisation) (4) \_\_\_\_\_

Q4.23

Have you purchased AT using some of your own personal funds or funds of immediate family members (i.e a self-funded purchase)?

No (1)

Yes, partly self-funded (2)

Yes, fully self-funded (3)

Q4.24 Why did you make a self-funded purchase of AT? (Please select all options that are relevant to you)

- A self-funded purchase provided me with a greater choice of AT (1)
  - I experienced too many delays in receiving external funding for AT (2)
  - I experienced too many delays in the delivery of externally-funded AT (3)
  - Other (Please briefly specify) (4) \_\_\_\_\_
- 

Q4.25 Do you feel making a self-funded purchase of AT was worthwhile?

- Yes (1)
- No (2)

Q4.26

Thinking about the AT you have acquired, what impact has gaining access to AT had on your opportunity to access the following?

	Little to no impact (1)	A slight impact (2)	A moderate impact (3)	A great impact (4)	An extreme impact (5)	N/A (6)
Independent Living (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transport services (e.g. driving, public transport) (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Employment (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recreational activities (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Everyday services (e.g. retail, bank, post office) (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.28

Thinking about the AT you have acquired, what improvement has your AT had on the following?

	Little to no improvement (1)	A slight improvement (2)	A moderate improvement (3)	A great improvement (4)	An extreme improvement (5)	N/A (6)
My need for carers/support workers (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The amount of money I spend on carers/support workers (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The likelihood of self-purchasing equipment in the future (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My need for professional medical assistance (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My overall financial situation (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.30 Thinking about the AT you have acquired, what improvement has your AT had on the following?

	Little to no improvement (1)	A slight improvement (2)	A moderate improvement (3)	A great improvement (4)	An extreme improvement (5)	N/A (6)
My relationships with family (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My relationships with friends (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My general mental wellbeing (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to engage in community activities (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to engage in social gatherings with others (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q4.32

Do you receive assistance from a paid support worker(s) (e.g., aged care worker, disability support worker etc.)?

Yes (1)

No (2)

Q4.33

The next two questions are about the support worker who works with you the most (your primary paid assistance worker)

List three words or phrases that describe how the support you receive from your primary worker impacts your life?

Impact 1 (4) \_\_\_\_\_

Impact 2 (5) \_\_\_\_\_

Impact 3 (6) \_\_\_\_\_

Q4.34 List three words or phrases that describe how the impact of the support you receive from your primary worker changed or is expected to change with AT?

Change in Impact 1 (1) \_\_\_\_\_

Change in impact 2 (2) \_\_\_\_\_

Change in impact 3 (3) \_\_\_\_\_

Q2.1 Please enter your age (as a whole number)

\_\_\_\_\_

Q2.2 What state/territory do you currently live in?

- ACT (1)
- New South Wales (2)
- Northern Territory (3)
- Queensland (4)
- South Australia (5)
- Tasmania (6)
- Victoria (7)
- Western Australia (8)

Q2.3 Which option best reflects your current employment status?

- Full-time employed (1)
- Part-time employed (2)
- Casual employed (3)
- Self-employed (4)
- Not employed, but seeking employment (5)
- Not employed, and not seeking employment (6)

Q2.4 Which option best reflects your current living status?

- Living independently (1)
- Living with family (2)
- Living in a residential facility (3)

Q2.5 What is your primary language?

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Q2.6 What cultural group or ethnicity do you most identify with?

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Q2.7 What gender or gender group do you most identify with?

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Q49 Thank you for completing this survey.

Please confirm below and click through to the next screen to confirm you would like your responses to be collected by the research team.

You are able to withdraw your participation, and any data you have already provided will not be used by the researchers. Please note to maintain your anonymity you will not be able to withdraw your participation after submitting your responses by confirming below and clicking through to the next screen.

- Yes, I confirm I would like my responses to be collected for this survey (1)
- No, I would like to withdraw my participation (2)

Q2.8 Thank you for your participation in this study. Your responses will help us to understand the benefits of gaining access to, and reducing wait times for AT.

If participating in this project has caused you distress or discomfort, there is help available: 1800RESPECT can provide you with support, information and referral to assist in supporting people with disability. You can contact them on 1800 727 732 or through online chat. <https://www.1800respect.org.au/> BeyondBlue provides information and support to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live. There is specific support available for people with disability. Call 1300 22 4636 or visit <https://www.beyondblue.org.au/> SANE Help Centre provides counselling, support, information and referrals

to adults who identify as having a complex mental health issue, complex trauma or high levels of psychological distress. 1800 18 7263 or <https://www.sane.org/>

