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Blind Citizens Australia

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# Royal Commission into Aged Care Quality and Safety (2019) Submission

**To:**

Aged Care Royal Commission

Submitted via email to: ACRCenquiries@royalcommission.gov.au

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## About Blind Citizens Australia

Blind Citizens Australia (BCA) is a peak national representative organization which comprises of, and represents people who are blind or vision impaired. BCA was founded in 1975 with a mission to achieve equity and equality through the empowerment of people who are blind or vision impaired, created by promoting positive community attitudes and by striving for high quality and accessible services which meet our needs.

We provide peer support and individual advocacy to people who are blind or vision impaired across Australia. Through our campaign work, we address systemic barriers limiting the full and equal participation of people who are blind or vision impaired. Through our policy work, we provide advice to community and government on issues of importance to people who are blind or vision impaired.

As a consumer-based organisation, our work is directly informed by lived experience of blindness and vision impairment. Our members, our Directors and the majority of our staff are blind or vision impaired.

## About Australians who are Blind or Vision Impaired

There are currently more than 453,000 people who are blind or vision impaired in Australia[[1]](#footnote-1) with estimates that this will rise to 564,000 by 2030.[[2]](#footnote-2) According to Vision Initiative, around 80% of vision loss in Australia is caused by conditions that become more common as people age.[[3]](#footnote-3) This raises a number of implications for Australia’s aging population, with one in every four Australians projected to be 65 years of age or older by the year 2056.[[4]](#footnote-4)

In 2015, 3.5 million Australians were regarded to be older adults (65 years or older). Out of these older adults, 1.7 million reported living with disability and 654,000 had a profound or severe disability[[5]](#footnote-5). It is estimated that by the time people reach the age of 75 and over, at least 96% will have a vision impairment. This means that vision impairment will become the most prominent health issue within the population of older people.[[6]](#footnote-6)

Eye conditions that cause vision impairment for Australians include: age-related macular degeneration, cataract, diabetic retinopathy, glaucoma and uncorrected refractive error.3

Australians who are blind or vision impaired can live rich and active lives and make meaningful contributions to their communities: working, volunteering, raising families and engaging in sports and other recreational activities. The extent to which people are able to actively and independently participate in community life does, however, rely on facilities, services and systems that are available to the public being designed in a way that makes them inclusive of the needs of all citizens – including those who are blind or vision impaired.

# 1. Introduction

Blind Citizens Australia is grateful for the opportunity to present a submission to the Aged Care Royal Commission based on the feedback from our members on their experience of the Aged Care system. We want to contribute to the creation of improved outcomes for people who are blind or vision impaired in accessing aged care.

Blind Citizens Australia has been consistently involved in Aged Care–related matters with a longstanding history of work in the area. Our organisation currently seeks input from an Aged Care Reference Group, a group comprised of people who are blind or vision impaired.

Blind Citizens Australia received feedback between mid-June, and early August 2019 from members for this submission, relating to their experiences of Aged Care. A total of 29 submissions were received. This submission represents the aggregate experiences of our membership, supported by the feedback from our Aged Care Reference Group, ongoing work including previous submissions relating to Aged Care, and additional empirical evidence.

# 2. Terms of reference

Under the terms of reference of the Royal Commission, we have framed our submission in response to terms a, b (i) and c (i):

1. the **quality** of aged care services provided to Australians, the **extent to which those services meet the needs** of the people accessing them, the **extent of substandard care** being provided, including mistreatment and all forms of abuse, the causes of any systemic failures, and any actions that should be taken in response;
2. how best to deliver aged care services to:
	1. **people with disabilities residing in aged care facilities**, including younger people; and
	2. the increasing number of Australians living with dementia, having regard to the importance of dementia care for the future of aged care services;
3. the **future challenges and opportunities** for delivering accessible, affordable and high quality aged care services in Australia, including:
	1. in the context of **changing demographics and preferences**, in particular people's desire to **remain living at home** as they age; and
	2. in remote, rural and regional Australia[[7]](#footnote-7)

Our submission particularly response to b (part i) pertaining to the delivery of aged care to people with disability, namely blindness or vision impairment, “residing within aged care facilities” and broadening our scope to include people living outside of facilities. In response to terms of reference a, we examine the extent to which current age care services are meeting the needs of people who are blind or vision impaired and the “extent of substandard care being provided.” In response to c, bearing in mind the demographic shift with increased prevalence of low vision and blindness amongst older adults, we will provide recommendations.

# 3. Submission context

This submission is based on existing legislation and frameworks, noting gaps in the

fulfilment of requirements laid out in existing documentation. The pertinent acts and legislation are:

* *The Disability Discrimination Act 1992* (Cth) (Austl.)
* *National Disability Insurance Scheme 2013* (Cth) (Austl.)
* *Aged Care (Living Longer Living Better) Act 2013* (Cth) (Austl.) and associated standards
* United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006 (particularly Article 19, Living independently and being included in the community and Article 20, Personal mobility).
* The National Disability Strategy 2010-2020 (this strategy coordinates the implementation of the UNCRPD)
* Aged Care Diversity Framework, December 2017
* Web Content Accessibility Guidelines 2.1 (WCAG 2.1)
* National Aged Care Alliance, Position Paper for Assistive Technology for Older Australians, June 2018
* National Aged Care Alliance, Improving The Interface Between the Aged Care and Disability Sectors, June 2016
* Charter of Aged Care Rights (Charter of Rights), July 2019

# 4. Identified ongoing issues regarding Aged Care

## 4.1 Assessment process

Blind Citizens Australia has been aware of ongoing issues in regards to the assessment processes conducted to assess eligibility and subsequent access to My Aged Care. A consistent theme in feedback we have received is that assessment processes are inaccessible for people who are blind or vision impaired. In fact, the top issue identified was lack of provision of information in an accessible, alternate format.

Generally, information is accessed through the use of adaptive and assistive technology by people who are blind or vision impaired. The use of screen readers for magnification of text and images or voice navigation software are two common methods for accessing electronic information such as websites.

Under the *Disability Discrimination Act 1992*, it is stipulated that Australian Government agencies are required to provide information and services in a non-discriminatory, accessible manner. Additionally, the Web Content Accessibility Guidelines (WCAG 2.1) stipulate the Australian guidelines for website accessibility, whereby websites need to be compatible for use with screenreaders and voice navigation software.

In addition to issues with document accessibility, the feedback we have received to date reveals that there has been a lack of adequate, easy-to-understand information prior to assessments in order to prepare for them. In one case, the individual had to make six separate calls to obtain the necessary information regarding the assessment process. A different member reported that they have had three separate people contact them in relation to their assessment, making the process confusing with different information being dispensed. One member said she never heard back after an assessment.

For another member, after waiting 3 months of waiting for follow-up contact regarding a request for an assessment appointment, they were forced to make a follow-up call to enquire about when it would take place. This led to an assessment process occurring too rapidly for adequate preparation by the member, due to the timeframes imposed for the assessment process, timeframes which weren’t communicated to the applicant.

*“I received a call about a week later from someone about arranging an appointment for an assessment for CHSP assessment (this is what it turned out to be – I don’t think my options were explained to me at any stage). They said this would be done within a couple of days because, after that date, my original request for an assessment would expire and I would need to begin the process again… So there was no opportunity to prepare for my assessment meeting as I would have expected.”* (BCA member)

The lengthy time delays between prospective Aged Care participants and / or supporters making an initial inquiry and the subsequent follow-up contact by Regional Assessment Service (RAS) or Aged Care Assessment Team (ACAT) personnel was identified to be a persistent concern for respondents.

Additionally, there has been inconsistency in the referral process for disability-specific needs, coupled with a lack of support within Aged Care for permanent disability (i.e., acquired prior to the age of 65). Under section 22 of the *National Disability Insurance Scheme Act 2013*, the age eligibility requirements are that the: “person was aged under 65 when the access request in relation to the person was made” otherwise, the individual has to go through the Aged Care scheme for disability-specific support, which may not be appropriate when they have no other frail-ageing needs. Additionally, there is a misalignment for people who acquire disability between the ages of 65 and 67 because they may be left without support without being able to access the NDIS yet having only limited support from the Aged Care system, due to the age cut-off for the Aged Pension being raised to 67 (by 1 July 2023).[[8]](#footnote-8) This starkly contrasts with an individual who turns 65 whilst accessing the National Disability Insurance Scheme (NDIS); they are able to continue accessing disability-specific support under the NDIS.

*“[When I had my assessment, the assessor] was not able to tell me about any particular arrangements for meeting my disability-related needs, and seemed to be of the view that much of the assessment tool was quite inappropriate.”* (BCA Member)

There is a disconnect between the current use of the medical model of disability in assessment processes and the social model of disability which underpins the majority of the policy work in the disability sector. The social model stipulates that disability emerges in the relationship between a person who has a disability and the social and physical barriers created outside of themselves.[[9]](#footnote-9) The current assessment process focusses on providing care within the home environment compared to enabling independence in the community. Many members expressed frustration at this problem. Compounding this issue is the lack of “vision-specific supports.” (BCA member)

 *“[The] assessment was focussing on ageing factors, not the vision impairment which [I] have had all my life.”* (BCA member)

It is very important that the assessment process identifies disability-related supports for people, especially those with long-term disability, to ensure that appropriate and timely support is delivered to them.

**Recommendation 1:**

The identification of disability-related supports in the initial aged care assessment should trigger a referral process to a disability service provider chosen by the consumer after being provided different service provider options.

**Recommendation 2:**

All information is made available in a participant’s preferred format on request. This can include electronic, large print hardcopy, Braille or audio options.

**Recommendation 3:**

An amendment to the *National Disability Insurance Scheme 2013 Act* would enable people who acquired a disability prior to the age of 65 years of age to be eligible for access to the NDIS to meet their disability-specific needs.

## 4.2 Access to assistive technology or equipment

Many people who are blind or vision impaired access aged care have a specific need for obtaining assistive technology to enable them to meet their own living needs. These needs exist for all people with vision loss however for an individual with acquired vision loss, these assistive technology needs may be amplified whilst they adapt to their new living circumstances through needing assessment, training and purchase of new equipment. The type of assistive technology or equipment needed may include screen reading software, magnifiers, barcode scanners, talking microwaves or scales, navigation equipment, white canes, dog guides and many other types of technology. For individuals who are aged 65 or over though, the support is currently spread across departments at both state and federal level.8 Funding for technology within Aged Care will only be supported if the technology relates to ageing instead of disability. Complicating matters, state-based support may not be accessed if a person is applying for or accessing a Commonwealth Aged Care funding package.8

*“I… discovered that the state-based funding for equipment was not available to people either receiving [or applying for] Commonwealth funding packages, so [the] ACAT’s assessor’s report and recommendations would be put on hold until I had either applied for the state-based equipment funding or [I have] decided not to apply for it and restarted my application for a Commonwealth funding package”* (BCA member).

Consistently, we have received feedback that the inability to obtain assistive technology has been detrimental to obtaining independence in living. For example, we received feedback that it has been a real battle to have assistive technology requests fulfilled.

Further, we have received feedback that cost is prohibitive to obtaining the necessary technology where the funding has not been available: *“[I have] been using assistive technology since [the] 70s… [but I] find it quite difficult to [use the computer] independently. [I] can’t access JAWS due to cost.”* (BCA member). JAWS is voice navigation software for use with computers to read out information on the screen including audio-description embedded in images on webpages or other documents.

Members are finding that the inability to replace ageing and outdated assistive technology is a major frustration because they have been dependent upon it in living independently. In fact, according to the Assistive Technology for All Alliance (formerly Assistive Technology for Older People Alliance), “it is a powerful tool that facilitates social inclusion, economic participation and autonomy while creating cost benefits to health and social services.” Frustratingly, though, the current Aged Care system for older people does not provide equitable access comparative to the NDIS for younger peers, to have funded access to assistive technology.[[10]](#footnote-10)

*As time goes by, my technology (on which I depend so much) is ageing and I am find that I need to replace it and then I need assistive technology training.”* (BCA member)

**Recommendation 4:**

A National Assistive Technology Program which would alleviate the current situation of funding being distributed across multiple state and federal programs. This would provide better cost-benefit data for the provision of Assistive Technology to older Australians.9

**Recommendation 5:**

An interim measure of a budget allocation of a $1,000 minimum can be introduced to be a component of all Aged Care packages, including Commonwealth Home Support Programme and Home Care Packages with a pathway for applications and a timely process for approvals of funding exceeding that amount for higher level Assistive Technology. This is parallel to the current Assistive Technology funding pathway for NDIS participants.[[11]](#footnote-11)

## 4.3 Available packages and waiting lists

The Aged Care system uses a model of two types of support: Home Care Packages (HCP) with four levels of packages (basic care needs at level 1 up to high care needs at level 4) and Commonwealth Home Support Programme (CHSP). We have received consistent feedback that two issues are occurring when people apply for packages: lack of availability for the appropriate package level for a person meaning they are subsequently approved at a lower level (HCP) and long wait times including up to 2.5 years, to either get onto an initial package or the preferred level package.

*“I had to wait 2.5 years to get onto a level 4 [HCP] package. I was put on a level 2 initially and [it took] a lot of back and forth to get this.”* (BCA member)

Compounding the long wait time is the issue that the scheme does not offer a broad scope for support to people who are blind or vision impaired.

*“I’ve been on a level 2 [package] and have been approved for level 3. It will take about 6 to 12 months to move up to level 3. The scheme doesn’t cater for disabilities [and it] is extremely limited and the waiting time for packages is far too long. This in itself is exhausting.”* (BCA member)

The need to step up to a higher level package generally is a result of the need for assistive technology, yet as previously mentioned, there are still issues with accessing technology even when a person who is blind or vision impaired makes requests to acquire equipment.

**Recommendation 6**

There needs to be an increase in available Home Care Packages and support under My Aged Care leading to reduced wait times for packages.

An assistive technology fund / program that sits alongside My Aged Care would also alleviate the waiting time or the need to access the higher level of support for some.

## 4.4 Costs relating to Aged Care

In a previous submission to the Aged Care Legislative Review, we addressed the issues relating to costs in Aged Care:

*“The aged care system is designed primarily to accommodate the generalist needs of older people who are experiencing deteriorating health due to the process of aging. It does not, however, recognize that the specialist supports that are uniquely required by people with permanent and severe disability can be far more cost prohibitive than those of the average older person. These specialist supports, such as orientation and mobility services and adaptive technology, are often required by people who are blind or vision impaired in addition to more generalist services. This means the rate of co-payment that is applied to people who are blind or vision impaired who exceed the income and assets test free threshold* ***has the potential to be significantly higher than that of the average older person****, simply because they may have additional support needs that cannot be met by generalist services alone. These arrangements appear to be largely inequitable, and even more so when considering that those younger people who are blind or vision impaired who are eligible for the NDIS are not required to make any financial contribution towards their care and support arrangements.*

*Further, we note that the income and asset-free threshold outline in the Schedule of Fees and Charges for Residential and Home Care is significantly lower for people who are living with a partner. People who are reliant on the pension as their sole source of income already receive a lower rate of pay if living with a partner. These circumstances currently* ***place a significant financial burden*** *on couples in instances where both people in the relationship are blind or vision impaired, or have another form of disability. These couples are often subjected to higher costs of daily living, with both partners sometimes having experienced long-term unemployment. As an example, people who are blind or vision impaired typically need to live in areas with better access to public transport and infrastructure where rental rates are exponentially higher. Living in an under-resourced, but more affordable area would result in dependence on others and greater social isolation.”*

The issues related to cost were repeatedly reflected in the submissions we received from members about their experiences of Aged Care.

*“[I pay] $60 per month for services and $180 per month in fees.”* (BCA member)

*“[I am] paying 38% of my package to [my] plan manager. [My] case manager is working on the issues for [me), but in the meantime [I am] paying $411 per fortnight from [my] pocket to be on… My Aged Care [which] means [I] am getting about $25 per fortnight for service paid by the government under the level 2 plan. [I] have received emergency funding for [my services] to continue for another 3 weeks.”* (BCA member)

*“I am concerned by… entry and exit fees and co-payment.”* (BCA member)

Several members raised particular concerns about the co-payment arrangements. This starkly contrasts with the NDIS system, in which co-payments are not required by participants and it reveals the financial inequity between the two systems.

Additionally, concerns have been raised about the inconsistency between access requirements to the Disability Support Pension (blind) and Aged Care, whereby the latter is means tested. In Aged Care, there is an additional means-tested care fee incurred on top of the basic daily fee.

*“The fact that My Aged Care is means-tested does not sit well with people on a blind pension.”* (BCA member)

*“[There is a] means-tested care fee [of] $8.62 per day, approximately $300 per month. [I was] initially charged the maximum rate due to [a] Centrelink calculation error. [Further], due to [my] partner having some superannuation, [we have] to pay the care fee.”* (BCA member)

The discrepancy in means-testing for Aged Care comparative to no means-testing for NDIS creates a financial inequity for participants of Aged Care. Plus, the other additional fees imposed on Aged Care participants, comparative to NDIS participants, deepens the financial inequity for Aged Care participants. The entry and exit fees charged by providers are particularly concerning with members noting that there is a lack of transparency around different levels of fees charged by providers and service users being unaware that they can negotiate or challenge fee charges.

**Recommendation 7:**

Costs relating to Aged Care need to be reviewed and revised. Rules for co-payments should be revised with an exemption applied for specialist services and supports for disability-specific needs.

**Recommendation 8:**

Equity between the Aged Care and NDIS system should be achieved through reviewing the current means-tested fees for Aged Care. Prior to a review, the income and assets-test free threshold for two people with disability living in a de facto or married relationship should be the same as for single people for the purposes of calculating co-payment for Aged Care.

**Recommendation 9:**

Greater transparency is required for fees charged to Aged Care participants by Aged Care and Disability Service Providers. The establishment of a website and other electronic and printed resources for the purpose of dissemination of fee information in a concise manner with the ability for comparison should be undertaken by the government section overseeing Aged Care or by independent consumer organisations like Choice. Investment and long-term infrastructure to create a resource for the use of participants across the Aged Care system will enable greater control and choice by participants in accessing appropriate Aged Care and disability support. In addition, a price list whereby prices are set by the government for services like the NDIS currently uses would help to regulate pricing in the Aged Care system.

## 4.5 Availability of information in accessible formats

Information availability in accessible formats is a major issue, with people who are blind or vision impaired requiring documentation or other information in hard copy in large font, electronic format, Braille or audio. Unfortunately, information is frequently only availability in digital or electronic format which causes extra issues due to the low rates of digital literacy amongst older adults. This has led to members seeking solutions to gain access information in their preferred format. For example, the frustration at the lack of accessible information even led to contacting a local MP to achieve a satisfactory outcome.

*“The biggest barrier has and continues to be a lack of access to information in alternate formats. I cannot read websites so [I] have to rely on others I trust to read any contractual agreements and documents to me. When I was with another service provider for the first 2 years, I had to go the health minister just to get information I needed.”* (BCA member)

It seems that staff working across the sector are unaware of their obligations to provide alternate format production for information that they are providing to consumers. This is particularly pertinent for provision of service agreements and any guidelines for service. Notably, the issues around format production extend to: confusion around who is responsible for alternate format production leading to either a) stating upfront that it cannot be done or b) shifting the enquiry to multiple people across multiple departments in an effort to find someone who can help, leading to long time delays in producing the alternate format. In the NDIS, the NDIA is responsible for the process of provision of information and therefore, the Aged Care system needs to adopt a similar approach.

**Recommendation 10:**

Develop process within the Aged Care system for the production and distribution of information by government and service providers, in a person’s preferred format. An Action Plan for disability in the diversity framework would also prompt this process.

**Recommendation 11:**

Aged Care service providers to provide all Aged Care participants with an accessible format version of the Charter of Rights[[12]](#footnote-12). This Charter can help with informed decision making and understanding rights when accessing Aged Care services.

## 4.6 Access to disability-related support in the Aged Care system

The Aged Care system is primarily based on the provision of services relating to ageing rather than any specific disability-related support services. Not only does this mean that assessment processes are inappropriate for people who are blind or vision impaired (see section 4.1), it also means service delivery does not assist in enabling independence or improved daily living for people who are blind or vision impaired. The Aged Care system needs to be able to tailor support at a level which meets the specific needs of people who are blind or vision impairment, in addition to the support which meets frail-aging needs.

*“The only services I have ever accessed as a result of [my Aged Care] assessment have been community transport on fewer than half a dozen occasions and an occupational therapist… I could not see anything else which would meet my disability-related needs at the time.”* (BCA member)

Several members additionally provided feedback that services relating to their disability that were previously being provided by local councils were no longer available. Councils across different regions were named by members. This gap in service delivery needs to be addressed.

*“The two things I wanted was help with gardening and help with sorting my possessions… Neither help was available to me through [my local] council. I think this is quite unfair, as both these needs are met by other councils, and advertised in My Aged Care booklets.”* (BCA member)

It is also problematic that the current Aged Care Diversity Framework does not have a specific Action Plan connected to it for the diverse group of disability. An Action Plan could help drive an approach to integrating disability-specific supports into the Aged Care system. Additionally, the Action Plan could clearly distinguish that Aged Care needs occur on a vast spectrum, with some individuals being highly independent with few care needs to individuals who are living in residential care under full-time care. The Aged Care system needs to accommodate people for the level of independence and need which is appropriate to their circumstances rather than the current model of a once-size-fits-all approach, i.e., individual variation for level of care needs to be accommodated.

**Recommendation 12:**

The inclusion of disability as a special needs group in the *Aged Care (Living Longer Living Better) Act 2013* would ensure disability-specific supports are identified in the assessment process and relevant referrals are made.

**Recommendation 13:**

The development of Disability Action Plan under the Aged Care Diversity Framework would help in development, planning and implementation of disability-specific support into the Aged Care system. Additionally, the Action Plan would clearly distinguish that there are individual variations in level of care and support needs and that appropriate accommodation for level of independence is accommodated.

## 4.7 Service Provider Concerns

Blind Citizens Australia has identified several concerns relating to the service provision by blindness service providers and the Aged Care system, particularly around dog guide (the generic term for Guide Dogs and Seeing Eye Dogs) support and financial concerns relating to service provision.

Blind Citizens Australia received feedback that the process in relation to support for dog guides and training within Aged Care is unclear, both to members and to service providers.

We received feedback that it took up to 8 months in one instance to get access to funding to support maintenance and care costs for a member’s dog guide.

Blind Citizens Australia also identified that high administration fees set by plan managers and service providers are problems in Aged Care access. In addition to the issues raised in section 4.4, other specific issues were identified.

Amongst the reported concerns, members provided feedback that:

* Invoices had not been paid.
* Services they previously accessed for free now have a fee, therefore they no longer access them.
* Services were terminated abruptly; entry and exit fees charged by providers before and after service provision.
* Accounting errors by providers assisting with plan management.
* Services (like orientation and mobility) not being covered by Aged Care funding leaving the service provider or service user to cover cost.
* Fees to access services are too high meaning that they cannot afford regular or ongoing support.

Several members reported that they are feeling pressured by service providers to sign up for My Aged Care to access blindness service providers including joining My Aged Care prior to trialling equipment.

The feedback received has been that not only have changes to service provision affected both cost and delivery, but also it has been detrimental for wellbeing:

*“So, while my disability needs have not really changed, with the removal of block funding to service providers and the advent of individual funding packages, for support, I think my situation as a person who is blind has become more precarious.”* (BCA member)

*“There are ways that I could go out into the community and even perform voluntary work if only I had the support and the technology I need to do so…. The issue preventing me from pursuing these activities is that my aged care package, even though it is at the highest level, only covers the cost of my accommodation and health care. There is no further capacity in my package to hire support workers. Volunteers to take me out and pursue the things that mean most to me are hard to find, so I am limited to what the facility has to offer most of the time, unless I can convince an acquaintance to take me out. The activities the nursing home provide are not suited to my needs, as they are often visual in nature and not fulfilling for me.”* (BCA Member who lives in an aged care facility)

**Recommendation 14:**

The process and funding pathway for dog guide support needs to be clarified, with the government departments responsible for Aged Care funding providing clear, accessible information about the funding available for dog guides and dog guide support.

**Recommendation 15:**

Corresponding with recommendation 9, blindness service providers need to produce clear and transparent, accessible information in relation to fees for service and service coverage by funding under Aged Care. Entry and exit fees should be reduced where possible.

**Recommendation 16:**

The Aged Care Pricing Commission should be granted both the ability to regulate fees associated with costly supports and to investigate service providers whereby financial misconduct may be taking place.

## 4.8 Lack of disability-awareness training for Aged Care service providers

Blind Citizens Australia has received feedback that disability-awareness training is lacking in Aged Care. This includes service providers, nursing or residential homes whereby support needs for disability-specific rather than age-related issues are needed to be understood.

This reported lack of training means staff in the Aged Care system lack the fundamental understanding to provide appropriate support to people who are blind or vision impaired and to meet their basic living needs. The lack of training also leads to lack of independence for individuals. There is also the threat of isolation of people who are blind or vision impaired by being disconnected from community- and centre-based activities.

Members have reported systemic lack of disability-specific needs being met, and this extends to the interactions they have had with staff from Aged Care providers.

*“Every staff member that I get I have to train them on how to guide and assist blind people. There is no awareness.”* (BCA member)

“*I moved into an aged care facility after suddenly losing my sight when I was in my early 50s. With no family support, this was the only option given to me…. I am now in my 70s and over the past 20 years, there has been no opportunity to develop orientation and mobility skills, and no access to assistive technologies…. Staff do not allow me to move around the facility independently as it is viewed as a health and safety risk. There is no other physical reason for me to be moved around the facility in a wheelchair, but that is the only option given to me.*” (BCA member)

Training needs to be achieved by Aged Care Providers approaching Blindness Service Provider to deliver appropriate evidence-based training by the allied health professionals and specialists, including:

* Orientation and mobility specialists who can train people to guide people around areas and also provide feedback about spatial layout of facilities for ease of access;
* Occupational therapists who can provide training in how to use techniques to help people who are blind or vision impaired undertake activities and also they can provide advice and recommendations to improve the accessibility of facilities or spaces;
* Assistive technology specialists who can provide training on accessible format production and other assistive technology use which may help people who are blind or vision impaired;
* Other professional staff or clients with lived experience, who can provide advice and training around effectively and respectfully communicating with people who are blind or vision impaired, and any other advice which is pertinent to a particular person’s situation or the space in which Aged Care services are being provided.

**Recommendation 17:**

Mandatory training needs to implemented around disability awareness in TAFE courses related to Aged Care. Blindness and vision impairment needs to be a major part of this training due to age-related vision loss being a major health factor for many older adults.

**Recommendation 18:**

Aged Care service providers need to work with blindness service providers to provide staff training in offering disability-specific, particularly blindness-related support to service users. This training can include: Orientation and Mobility; Occupational Therapy; Assistive Technology and other services.

# 5. Recommendations

Blind Citizens Australia has found across the board that there are systemic issues with the Aged Care system in meeting the needs for people who are blind or vision-impaired. As a result of these issues, we have recommendations for government and Aged Care service providers:

* **Recommendation 1:** The identification of disability-related supports in the initial aged care assessment should trigger a referral process to a disability service provider chosen by the consumer after being provided different service provider options.
* **Recommendation 2:** All information is made available in a participant’s preferred format on request. All information is made available in a participant’s preferred format on request. This can include electronic, large print hardcopy, Braille or audio options.
* **Recommendation 3:** An amendment to the *National Disability Insurance Scheme 2013 Act* would enable people who acquired a disability prior to the age of 65 years of age to be eligible for access to the NDIS to meet their disability-specific needs. **Recommendation 4:** A National Assistive Technology Program which would alleviate the current situation of funding being distributed across multiple state and federal programs. This would provide better cost-benefit data for the provision of Assistive Technology to older Australians.
* **Recommendation 5:** An interim measure of a budget allocation of a $1,000 minimum can be introduced to be a component of all Aged Care packages, including Commonwealth Home Support Programme and Home Care Packages with a pathway for applications and a timely process for approvals of funding exceeding that amount for higher level Assistive Technology. This is parallel to the current Assistive Technology funding pathway for NDIS participants.
* **Recommendation 6:** There needs to be an increase in available Home Care Packages and support under My Aged Care leading to reduced wait times for packages. An assistive technology fund / program that sits alongside My Aged Care would also alleviate the waiting time or the need to access the higher level of support for some.
* **Recommendation 7:** Costs relating to Aged Care need to be reviewed and revised. Rules for co-payments should be revised with an exemption applied for specialist services and supports for disability-specific needs.
* **Recommendation 8:** Equity between the Aged Care and NDIS system should be achieved through reviewing the current means-tested fees for Aged Care. Prior to a review, the income and assets-test free threshold for two people with disability living in a de facto or married relationship should be the same as for single people for the purposes of calculating co-payment for Aged Care.
* **Recommendation 9:** Greater transparency is required for fees charged to Aged Care participants by Aged Care and Disability Service Providers. The establishment of a website and other electronic and printed resources for the purpose of dissemination of fee information in a concise manner with the ability for comparison should be undertaken by the government section overseeing Aged Care or by independent consumer organisations like Choice. Investment and long-term infrastructure to create a resource for the use of participants across the Aged Care system will enable greater control and choice by participants in accessing appropriate Aged Care and disability support. In addition, a price list whereby prices are set by the government for services like the NDIS currently uses would help to regulate pricing in the Aged Care system.
* **Recommendation 10:** Develop process within the Aged Care system for the production and distribution of information by government and service providers, in a person’s preferred format. An Action Plan for disability in the diversity framework would also prompt this process.
* **Recommendation 11:** Aged Care service providers to provide all Aged Care participants with an accessible format version of the Charter of Rights. This Charter can help with informed decision making and understanding rights when accessing Aged Care services.
* **Recommendation 12:** The inclusion of disability as a special needs group in the *Aged Care Act 1997* would ensure disability-specific supports are identified in the assessment process and relevant referrals are made.
* **Recommendation 13:** The development of Disability Action Plan under the Aged Care Diversity Framework would help in development, planning and implementation of disability-specific support into the Aged Care system. Additionally, the Action Plan would clearly distinguish that there are individual variations in level of care and support needs and that appropriate accommodation for level of independence is accommodated.
* **Recommendation 14:** The process and funding pathway for dog guide support needs to be clarified, with the government departments responsible for Aged Care funding providing clear, accessible information about the funding available for dog guides and dog guide support.
* **Recommendation 15:** Corresponding with recommendation 9, blindness service providers need to produce clear and transparent, accessible information in relation to fees for service and service coverage by funding under Aged Care. Entry and exit fees should be reduced where possible.
* **Recommendation 16:** The Aged Care Pricing Commission should be granted both the ability to regulate fees associated with costly supports and to investigate service providers whereby financial misconduct may be taking place.
* **Recommendation 17:** Mandatory training needs to implemented around disability awareness in TAFE courses related to Aged Care. Blindness and vision impairment needs to be a major part of this training due to age-related vision loss being a major health factor for many older adults.
* **Recommendation 18:** Aged Care service providers need to work with blindness service providers to provide staff training in offering disability-specific, particularly blindness-related support to service users. This training can include: Orientation and Mobility; Occupational Therapy; Assistive Technology and other services.

# 6. Concluding remarks

Overall, the experience for members accessing the Aged Care system has been frustrating, with a number of barriers and accessibility issues plaguing the sector. These experiences are summarized by these members:

*“At a time when there is seemingly more disability support available, and technological advances of various kinds have offered the promise of enhanced independence and choices, the introduction of market forces into this picture, especially for those who happen to be aged over 65, has the cruel effect of dangling the promise of improvement just beyond reach. At least, that’s how it feels to me.”* (BCA member)

*“[I] feel discarded. [I] didn’t stop work until 6 years ago due to vision loss. [I] lost a lot of social connections and [I’m] finding it difficult to get out of the house. Social isolation and [being] less active… has led to health issues. [I have] lower confidence [because I’m] not able to go out independently. [I] was quite active before significant vision loss. [I] feel suicidal sometimes [and I] dread waking up in the morning. [It is] discrimination, [I] can’t access vision-specific support that those on the NDIS can, including equipment.”* (BCA member)

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