

Ph 1800 033 660 | E [bca@bca.org.au](mailto:bca@bca.org.au) | W [bca.org.au](http://www.bca.org.au/) | ABN 90 006 985 226

# Response to Joint Standing Committee on the NDIS Inquiry on Scheme Forecasting and Implementation

Joint Standing Committee on the National Disability Insurance Scheme  
PO Box 6100  
Parliament House

Canberra ACT 2600

Email: [ndis.sen@aph.gov.au](mailto:ndis.sen@aph.gov.au)

Author: Jackson Reynolds-Ryan, National Policy Officer

[jackson.reynolds-ryan@bca.org.au](mailto:jackson.reynolds-ryan@bca.org.au)

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## 1. Introduction

### 1.1 About Blind Citizens Australia (BCA)

Blind Citizens Australia (BCA) is the national representative organisation of Australians who are blind or vision impaired. Our mission is to inform, connect and empower Australians who are blind, or vision impaired and the broader community. 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 government and the community 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 most staff are blind or vision impaired.

### 1.2 About people who are blind or vision impaired

There are currently more than 453,000 people who are blind or vision impaired in Australia[[1]](#endnote-1) with estimates that this will rise to 564,000 by 2030.[[2]](#endnote-2) According to Vision Initiative, around 80% of vision loss in Australia is caused by conditions that become more common as people age.[[3]](#endnote-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 can 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.

## 2. Blind Citizens Australia's submission

Blind Citizens Australia (BCA) would like to make a submission to the Joint Standing Committee’s Inquiry into Scheme Forecasting and Implementation. Our response is based on consultations with our members, previous and current submissions, and advocacy work in the sector.

## 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:

1. The Disability Discrimination Act 1992 (Cth) (Austl.)
2. National Disability Insurance Scheme 2013 (Cth) (Austl.)
3. United Nations Convention on the Rights of Persons with Disabilities (CRPD) 2006
4. The National Disability Strategy 2010-2020 (this strategy coordinates the implementation of the UNCRPD)
5. The National Disability Agreement 2008
6. Exposure Drafts of the National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Amendments) Bill 2021.
7. Consultation Papers by the National Disability Insurance Agency (NDIA) on reforms to Home and Living, and Supported Decision Making.

## 4. Submission

Blind Citizens Australia (BCA) welcomes the opportunity to provide a response to the General Issues Inquiry by the Joint Standing Committee for the NDIS (the Committee). The last 2 years have been a time of change for both our society, and for the NDIS. In this time a range of legislative changes have been proposed as well as a range of policy adjustments by the Agency, clearly encapsulated in the twin ‘Home and Living’ and ‘Supported Decision Making’ consultations.

As we have noted in our submission to the ‘General Issues’ Inquiry conducted by this Committee, we are encouraged by the fact that the latest round of proposed legislative changes have seen the plan for independent assessments (or ‘robo-planning’) taken off the table, and the amendment to Section 34 relating to the language of ‘reasonable and necessary’ in terms of supports and services dropped. We have also welcomed the proposed changes outlined in the recent NDIA consultations in relation to putting home at the centre of planning discussions, and to increase the knowledge and skills of planners and LAC partners.

Whilst BCA has made submissions directly relating to these changes and consultations, we note that these are all likely to have a strong impact on the general implementation of the Scheme and should be subject to oversight from the Committee; therefore, in this submission we address the impact of some of the proposed legislative and policy changes, as well as identifying areas where we believe the opportunity for change has not been taken.

We would also like to note that it is important to always remember that people with disability are not a collective bloc, and diversity and cultural differences exist even within different disabilities. BCA would like to remind the Committee that co-design processes with stakeholders representing the full diversity of disability, as well as people with disability who identify as LGBTIQA+, First Nations people, or culturally and linguistically diverse (CALD), must be used during all consultation for future changes to the Scheme. Similarly, the NDIA should embrace user testing throughout any change to processes – before, during, after – to help understand what might need to be adjusted over time.

### The Impact of boundaries of NDIS and non-NDIS service provision on the demand for NDIS funding

While the transition to the NDIS, and the person-centred care it provides, has in many cases been a vast improvement in the quality of services and supports, BCA is aware that many people with disability, particularly those who also have mental health or other cognitive impairments, view it with suspicion and in some cases fear.

As an example, BCA is currently advocating for a member who in addition to being totally blind, experiences significant (though unspecified) mental health challenges. Up until recently this member has received some in-home care and community access supports through her Local Council; however the council is now saying that they believe she is eligible for the NDIS and as a result they can no longer provide supports, as to continue would risk illegality. This member has a visceral reaction to even the mention of the NDIS and refuses to engage in any way. We have been working with her service provider (Vision Australia) to prevent the Local Council from withdrawing those supports, as we genuinely believe that to do so would cause a significant deterioration of her mental health, to the extent she may need to be hospitalised. We therefore encourage the government to look at ways that people with disability can be provided appropriate supports in the rare circumstances that they do not wish to join the Scheme.

#### Recommendation

1. Ensure non-NDIS disability supports can continue to be provided for individuals who cannot engage with the Scheme, in cases where their mental and physical health is at risk.

### The interfaces of NDIS service provision with other non-NDIS services provided by the States, Territories and the Commonwealth

BCA remains concerned about the ongoing disparity between the services that can be accessed via the NDIS, compared with those available through the aged care system. According to Vision Initiative, around 80% of vision loss in Australia is caused by conditions that become more common as people age. This includes conditions such as: age-related macular degeneration, cataract, diabetic retinopathy, glaucoma and uncorrected refractive error[[4]](#endnote-4).

It is further estimated that at 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[[5]](#endnote-5).

Yet despite the significant overlap between disability – and in particular vision loss – and aging, access to appropriate assistive technology can be particularly problematic for people with disability who are excluded from the NDIS on the basis of their age. 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. 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[[6]](#endnote-6).

The provision of appropriate aids, equipment and services will ultimately promote independence for older Australians and allow them to live safely in their homes for longer. BCA believes all people with disability, regardless of age, should have equitable access to assistive technology supports, irrespective of whether that support is provided through the NDIS or the aged care system.

We note that these concerns have been reflected in the recommendations of the Aged Care royal Commission, which stated that people with disability should receive, through the aged care program, daily living supports and outcomes (including aids and equipment), equivalent to those that would be available under the NDIS to those aged under 65 with substantially similar conditions.

We urgently encourage the Federal Government work to implement this recommendation by committing to a national assistive technology program to support people with disability who cannot access the NDIS.

#### Recommendation

2. Establish 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.

### Variations in plan funding between NDIS participants with similar need

In the course of our advocacy work, BCA regularly supports members who have experienced problems in accessing the Scheme, including cases where individuals have been denied access to the Scheme initially due to not having a ‘diagnosis’ of legal blindness; as well as issues with accessing appropriate supports once in the Scheme, such as when participants are given approval for Assistive Technology (AT) that are not preferred by the participant, and which are more costly. We have also dealt with advocacy cases where we have noticed substantial differences in the quantum of supports and hours funded, even where two participants may have very similar needs. These outcomes seem to be at the mercy of individual planners at the Agency or LAC partners having a clear understanding of the functional impact of blindness and vision impairment.

In our response to the NDIA Consultation Paper on Home and Living, we supported the proposal to establish professional development and ongoing education and training around home and living supports for all planners, LACs and other Partners. We made the argument that this training is absolutely necessary, but that it must include specific education about the support needs of blind and vision impaired participants, including training on the diversity of vision loss. Such specialist training on the causes, varieties, and impacts of vision loss will help ensure planners and LAC partners have a greater understanding on the needs and supports for people who are blind or vision impaired.

We have also heard feedback from members who have had planners who, despite receiving recommendations from an assistive technology specialist, approved other equipment due for cost reasons, and did not adequately listen to or understand the specific benefits of the recommended product. We encourage the NDIA to establish an online base training module for planners, and we would encourage planners to be required to attend an NDIA approved assistive technology event every two years to maintain their knowledge of new assistive technologies to improve participant outcomes.

We are also concerned by the way planners and other decision makers in the Scheme misunderstand the important role that orientation and mobility (O&M) supports play for people who are blind or vision impaired. In many cases the people making these decisions have been trained in administration, not in the allied health fields, and may miss some nuances that would be picked up if they understood more about vision loss. In recent months BCA has provided advocacy support for several NDIS participants who have been negatively impacted by this lack of awareness and training. In one example an individual was denied funding for support worker hours because she had funding for a dog guide in her plan – which fundamentally misses the point that people who are blind or vision impaired use a mixture of mobility aids including dog guides, white canes and sighted guides depending on the environment they are in. A dog guide can provide important assistance, for example during the process of crossing a busy road. They do this by identifying pram ramps for safe crossing instead of gutters, locating audio visual indicator buttons to press to cross, and finally, by crossing a road when it is clear. They are trained in a manner of avoiding obstacles that a sighted guide who has not had formal training will not. However, at times dog guides can become overwhelmed with crowded and hectic new environments reducing their confidence resulting in them freezing due to the shift in guide conditions. In these situations a sighted guide is needed to assist the person who is blind or vision impaired to navigate the unfamiliar environment safely and confidently.

The Terms of Reference for this Consultation refers to possible measures that could be used to address any inequitable variation in plan funding. We note that despite NDIA’s policy and guidelines on providing communications and plans in a person’s preferred formats[[7]](#endnote-7), based on feedback we receive from our members, there are still significant inconsistencies and shortcomings in the process and outcomes. Part of ensuring participants can make decisions for themselves is the importance of being able to independently access information – especially sensitive content relating to a person’s NDIS plan and related supports – without requiring someone else to read it.

The NDIA must ensure all communication and information to participants is in an accessible format, and in the preferred format of a participant e.g., large print hard copy, braille, electronic or audio. This includes all information provided ahead of meeting regarding reports and evidence that might be needed, as well as the post-meeting communication and draft plan. The Agency (and its partners) must also provide clear information on when specialist advice will help ensure participants get the technical supports most suited to their needs, with adequate time to do so. This in direct accordance with the United Nations Convention on the Rights of People with Disabilities (UNCRPD), Article 21 – ‘Freedom of expression and opinion, and access to information’, which outlines the importance of providing information in “accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost”, as well as “facilitating the use of sign languages, braille, augmentative and alterative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions”[[8]](#endnote-8). Further, providing consistently accessible formats for information will support the outcomes from the NDIS Participant Service Charter, which states that the NDIA, “will make it easy to access information and be supported by the NDIS to lead your life”[[9]](#endnote-9).

#### Recommendations

3. Ensure the new training and ongoing education for NDIS staff and partners includes content specifically relating to the needs of people who are blind or vision impaired. This should be developed using co-design processes.

4. Establish an online base training module for planners, and we would encourage planners to be required to attend an NDIA approved assistive technology event every two years to maintain their knowledge of new assistive technologies to improve participant outcomes

5. Commit to ensuring that if training for an item of AT is recommended by a specialist, this should be included as a fixed item in the participant’s budget alongside the item itself.

6. Ensure all communication and information to participants is in an accessible format, and in the preferred format of a participant e.g., large print hard copy, braille, electronic or audio. This includes all information provided ahead of meeting regarding reports and evidence that might be needed, as well as the post-meeting communication and draft plan.

### Ongoing measures to reform the scheme

We have welcomed a renewed focus on ensuring participants have flexibility in the way they use their plans, and to change them when necessary. Full plan utilisation will only occur when participants have the confidence that their plans adequately reflect their life, circumstances, and needs. In order for this to occur, we believe assessments of functional capacity should take place in unfamiliar environments, as well as in familiar ones. This is especially important for people who are blind or vision impaired, due to the different techniques or skills that may be applied in unfamiliar settings.

In feedback from members, we have been told “[there are] days where my vision is good in the morning, [but] bad at night”; it is therefore important that planners have the knowledge and skills to understand the need for flexibility in plans.

We also believe support coordination should be routinely offered as a fixed item in the first plan of all participants who are blind or vision impaired. This will help build plan utilisation by helping to ensure participants are able to make appropriate decisions early on about their support needs. It would also help reduce thin markets and the risk of market failure, which is not insignificant for smaller, more specialised areas such as blindness and vision impairment, often leading to low levels of full plan utilisation. It has been recognised by both the NDIA and other stakeholders in the sector that Support coordination could help address these challenges to ensure the scheme is equitable and usable for people who are blind or vision impaired[[10]](#endnote-10).

Similarly, we would also welcome an annual assessment by a specialist in assistive technology, as well as in O&M as a fixed item in plans for people who are blind or vision impaired, regardless of plan length.

Finally, BCA would like to highlight the importance of appropriately funded disability advocacy services. Access to advocacy, self-advocacy and self-determination supports, including mechanisms to self-represent to government, are enshrined in the United Nations Convention on the Rights of Persons with Disabilities. Advocacy services support people with disability to exercise their rights and freedoms by the provision of individual advocacy support; enabling people to advocate for themselves; and influencing long-term, systemic change. Yet despite the widely accepted importance of disability advocacy in protecting and promoting the rights and safety of people with disability, it remains chronically under-funded.

The introduction of the NDIS has only increased demand for advocacy support, while people attempt to navigate this new complex and confusing system; but many disability advocacy organisations have been relying on short term funding increases and extensions. Supporting people with disability to self-advocate is a crucial way to build independence and confidence, and ensuring a provision of funding to enable a participant to build the necessary skills to be able to advocate for themselves across all decision-making spaces will help develop their sense of empowerment over their own lives.

#### Recommendations

7. Include support coordination as a fixed item in the first plan of all participants who are blind or vision impaired.

8. Provide the option for an annual assessment by a specialist in assistive technology, as well as in orientation and mobility as a fixed item in plans for people who are blind or vision impaired.

## 5. Summary of Recommendations

BCA strongly recommends the following actions:

1. Ensure non-NDIS disability supports can continue to be provided for individuals who cannot engage with the Scheme, in cases where their mental and physical health is at risk.

2. Establish 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.

3. Ensure the new training and ongoing education for NDIS staff and partners includes content specifically relating to the needs of people who are blind or vision impaired. This should be developed using co-design processes.

4. Establish an online base training module for planners, and we would encourage planners to be required to attend an NDIA approved assistive technology event every two years to maintain their knowledge of new assistive technologies to improve participant outcomes

5. Commit to ensuring that if training for an item of AT is recommended by a specialist, this should be included as a fixed item in the participant’s budget alongside the item itself.

6. Ensure all communication and information to participants is in an accessible format, and in the preferred format of a participant e.g., large print hard copy, braille, electronic or audio. This includes all information provided ahead of meeting regarding reports and evidence that might be needed, as well as the post-meeting communication and draft plan.

7. Include support coordination as a fixed item in the first plan of all participants who are blind or vision impaired.

8. Provide the option for an annual assessment by a specialist in assistive technology, as well as in orientation and mobility as a fixed item in plans for people who are blind or vision impaired.

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