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# Response to Joint Standing Committee on the NDIS Inquiry on General Issues Around the Implementation and Performance of the NDIS

Joint Standing Committee on the National Disability Insurance Scheme
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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 annual Inquiry into General Issues Around the Implementation and Performance of the NDIS (the General Issues Inquiry). 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 12 months have been a time of change for the NDIS, with legislative changes being proposed as well as a range of policy changes by the Agency, encapsulated in the twin ‘Home and Living’ and ‘Supported Decision Making’ consultations.

We are encouraged by the fact that in the latest round of proposed legislative changes the plan for independent assessments (or robo-planning) has been taken off the table, and the amendment to Section 34 relating to the language of ‘reasonable and necessary’ in terms of supports and services has been 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 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. 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, and 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.

### 4.1 Proposed Legislative Changes

#### Access to Scheme

We largely welcomed the proposed legislative changes in relation to Becoming a Participant, with clarity being offered around the criteria of permanent impairment, or substantially reduced functional capacity (section 8 covers psychosocial disability), and clarity around Early Intervention Requirements. However, BCA would like to see further clarification around the following phrase in the changes to legislation:

“The impairment may be considered permanent, or likely to be permanent, only if there are no known, available and appropriate evidence-based clinical, medical or other treatments that would be likely to remedy the impairment.”

The boundaries of “available and appropriate” require demarcation, to determine the point that options are deemed to be exhausted for treatment and the length of measures a Participant would be required to execute to meet this criterion. We also question whether this takes into the economic cost, or physical access to the treatment, in terms of availability. Further, how is management of a treatment measured to be appropriate or inappropriate – would a clinical trial be considered appropriate, even if it carried significant risks to a person with disability seeking to enter the NDIS?

We would also like to bring to the Committee’s attention that BCA has received feedback from members about seemingly endless requests for re-evaluation of a disability meeting access criterion, despite the condition already being deemed permanent, with no treatment available or appropriate for their blindness – which is often functionally linked to a neurological condition. This is both demeaning for the individual, as they feel as though they are not being listened to about the facts of their own disability; and creates unnecessary delays and roadblocks to them accessing the support they need.

We would also like to bring to the Committee’s attention that while the disability sector is united in welcoming the proposed changes acknowledging the fluctuating nature of psychosocial disability; this fluctuation in functional ability is often the case more broadly. We note that a person who is blind or vision impaired who has residual vision may be able to use their remaining vision in low light but struggle in bright light or vice versa; fatigue may cloud their vision further restricting the visual field, or pain from straining the eye may substantially reduce capacity to see at any given time. Consequently, we would urge the Committee to recommend broadening the current legislative change to take into account disabilities other than psychosocial.

#### Plan Management and Payment of Supports

BCA welcomes the move to create a risk management strategy for the provision of supports to Participants. This safeguarding mechanism for Participants is a critical feature of any changes; a systemic failure in safeguards for Participants was revealed in the highly publicised circumstances surrounding the death of Ann Marie Smith in April 2020. However, we believe these changes could go further. We encourage the Committee to recommend the new clause which provides that the CEO must be satisfied that self-management of a plan does not create an ‘unreasonable risk’ to the participant be extended so that ‘unreasonable risk’ is also mitigated for plans that are not self-managed (‘unreasonable risk’ being defined in Section 10).

While BCA also welcomes the proposed changes around Payment of Supports – which would create a system whereby a Participant can tap a card to pay for the provision of services or supports – it is essential that any move to create a ‘tap-and-go’ system is electronically accessible for people who are blind and vision impaired, including the provision of accessible format information about how to operate this system. If this system is run via a smartphone app, it is essential that this app is compatible with screenreading technology e.g., Voiceover on the iOS platform.

This process requires codesign with people with disabilities, and user testing by people with disabilities, at every stage in the tap-and-go system development. Further, Participants of the scheme more broadly need to have the ability to opt out of any tap system, if they wish to pay via another method, or using a combination of methods.

#### Plan Variation and Reasons for Decisions

BCA welcomes the proposed legislative changes that will provide clarification around the language of Plan Reviews, as we believe these changes will help participants to understand the processes that are undertaken as part of a review. We particularly welcome the move to allow for plans to be varied without a complete reassessment, enabling minor changes or corrections to a plan, along with the changes that will legislate for the inclusion of timeframes for Plan Reviews, with a variation decision being capped to 21 days or less.

However, we do have concerns about some these changes, particularly that Section 48 allows a reassessment of a plan at the “CEO’s own initiative”, given this means the CEO could potentially vary or alter plans without the consultation or consent of a participant. The NDIS should operate with a Participant-centred approach, where people with disabilities are able to advocate themselves for funding for supports to live the life that they choose. We would also argue that any variation or reassessment needs to be supported by multidisciplinary or other professional recommendations. For example, and Orientation and Mobility (O&M) specialist has unique insights into the supports needed by people who are blind or vision impaired.

#### Governance and Board Structure

Despite the many positive changes that have been proposed by government and the NDIA, we would like to address an area of missed opportunity in relation to the governance and leadership of the NDIA. BCA members have raised significant concerns about the lack of mandated leadership requirements for board members of the NDIA.

The recent proposed changes to the Act sets out a requirement that, for the first time, people with lived experience of disability be considered for board appointments. While the appointment of people with disability to the NDIS board is a welcome addition to legislation, this wording implies that a person with disability may have a skill of ‘use of disability services’ and would not have other requisite board skills or knowledge. There are leaders with disability who serve on boards, are CEOs and participate in leadership development courses, who have governance and financial management skills. These people and their governance skills should be recognised in the appointment of people with disability to the NDIS board

We also highlight the difference in definition of “people with disability”, who may be NDIS participants, and “people with lived experience of disability” who may include family of people with disability; and we encourage the Committee to promote the appointment of both people with disability, and people with lived experience of disability, to the NDIA board. As one member noted, “unless the board has some representatives of the disabled community, the NDIS sad to say will never do what it [set] out to do”.

#### Recommendations

1. Provide Clarification and clear delineation of the boundaries around ‘reasonable and appropriate’ treatment that would be considered prior to access being granted to the NDIS.

2. The rules for Becoming a Participant are extended to acknowledge the fluctuating functional impact of some disabilities beyond psychosocial disabilities.

3. Extend the criterion for risk assessment in plan management beyond self-managed to plans that are not self-managed.

4. Ensure the introduction of a tap-and-go system for payment of supports has an opt-out option for Participants who wish to use an alternative method of payment, or a mixture of payment type.

5. Ensure introduction of a tap-and-go system for payment of supports is provided with accessible format information e.g., braille, large copy hard print, audio, or electronic format, and that the method for payment is accessible itself i.e., the Participant does not require third party assistance to complete a transaction. If this system is run via an app, it needs to be compatible with screenreaders like Voiceover on the iOS platform.

6. Require co-design processes in the design, creation, and implementation of a new payment system for NDIS Participants. People with disabilities must be able to provide input at every stage in the design process, and people with disabilities must be engaged in user testing prior to rollout of the system to ensure that it meets accessibility requirements.

7. Section 47A is amended to allow for a participant to be consulted and provide consent for any plan variation or reassessment. Further, it is strongly recommended that constraints are placed upon the CEO’s power; the boundaries of these constraints must be transparently stipulated with the rules.

8. The provision of reasons for decisions to all Participants is a legislated requirement for all decision making about NDIS plans, without the Participant necessarily needing to request the provision of reasons. This is equally applicable to scheduled or unscheduled review of plans.

9. Section 58 of the proposed changes is amended to include a legislated requirement for board members of the NDIA who have disabilities themselves, and therefore, direct experience of disability.

### 4.2 Increasing Skills and Knowledge of NDIA & Partners

It is clear from our feedback from members, that far too often the planning process is a ‘luck of the draw’ as to whether they have a planner who listens to their needs and includes appropriates support in a plan. Given the influence and long-term impact planners can have on the outcomes for participants, we welcomed the commitment by the Agency in the consultation paper ‘Home and Living – An Ordinary Life at Home’ to provide additional training and coaching to all LAC and NDIA Planners. However, BCA would like to see action from government to provide more transparency and accountability on the training that is being provided to staff and partners.

We note that a planner who has not had any in-depth training or education about blindness or vision impairment will not be able to provide an appropriate level of insight for an NDIA participant who is blind or vision impaired. Specialist training on blindness and the impact of vision loss, as well as on the full diversity of blindness and vision loss, is also important will help ensure planners and LAC partners have a greater understanding on the needs and supports for people who are blind or vision impaired. Importantly, planners should be made aware that any assessment of functional capacity should take place in unfamiliar environments, in addition to 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”.

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 would like to see a requirement for 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.

#### Recommendations

10. 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.

11. 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.

### 4.3 Improved Participant Experience

BCA is concerned by feedback from members that unpaid support persons (such as a family member) are often treated as the primary person to which to direct all communication, with an assumption that they will also be the person making decisions, not the person with disability. We ask the Committee reaffirm the importance of participants being at the centre of the process, are given room to exercise their own choice and agency as much as is possible, and that a support person (whether paid or unpaid) does not unreasonably take over decision-making in a person’s life.

We would note that despite NDIA’s policy and guidelines on providing communications and plans in a person’s preferred formats[[4]](#endnote-4), the reality is that based on feedback we receive from our members, there are significant inconsistencies 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. We urge the government to require the NDIA to 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.

We also urge a change in law to require the NDIA (and its partners) toprovide 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”[[5]](#endnote-5).

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, in order to ensure they are able to make appropriate decisions early on about their support needs. Thin markets and market failure is a real risk for smaller, more specialised disability 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[[6]](#endnote-6). Similarly, we would welcome a recommendation by the Committee for an annual assessment by a specialist in assistive technology, as well as in orientation and mobility (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

12. Ensure participants are at the centre of all communication, and correspondence is not sent to support person unless specifically requested.

13. Ensure all information, communication and materials are available in as many accessible formats as possible (e.g., large print hard copy, braille, electronic or audio), and in the preferred format of a participant. 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

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

15. 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

16. 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.

17. Consider ways to appropriately fund disability advocacy to support people with disability navigate different service systems.

## 5. Summary of Recommendations

BCA strongly recommends the following actions:

1. Provide Clarification and clear delineation of the boundaries around ‘reasonable and appropriate’ treatment that would be considered prior to access being granted to the NDIS.

2. The rules for Becoming a Participant are extended to acknowledge the fluctuating functional impact of some disabilities beyond psychosocial disabilities.

3. Extend the criterion for risk assessment in plan management beyond self-managed to plans that are not self-managed.

4. Ensure the introduction of a tap-and-go system for payment of supports has an opt-out option for Participants who wish to use an alternative method of payment, or a mixture of payment type.

5. Ensure introduction of a tap-and-go system for payment of supports is provided with accessible format information e.g., braille, large copy hard print, audio, or electronic format, and that the method for payment is accessible itself i.e., the Participant does not require third party assistance to complete a transaction. If this system is run via an app, it needs to be compatible with screenreaders like Voiceover on the iOS platform.

6. Require co-design processes in the design, creation, and implementation of a new payment system for NDIS Participants. People with disabilities must be able to provide input at every stage in the design process, and people with disabilities must be engaged in user testing prior to rollout of the system to ensure that it meets accessibility requirements.

7. Section 47A is amended to allow for a participant to be consulted and provide consent for any plan variation or reassessment. Further, it is strongly recommended that constraints are placed upon the CEO’s power; the boundaries of these constraints must be transparently stipulated with the rules.

8. The provision of reasons for decisions to all Participants is a legislated requirement for all decision making about NDIS plans, without the Participant necessarily needing to request the provision of reasons. This is equally applicable to scheduled or unscheduled review of plans.

9. Section 58 of the proposed changes is amended to include a legislated requirement for board members of the NDIA who have disabilities themselves, and therefore, direct experience of disability,

10. 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.

11. 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.

12. Ensure participants are at the centre of all communication, and correspondence is not sent to support person unless specifically requested.

13. Ensure all information, communication and materials are available in as many accessible formats as possible (e.g., large print hard copy, braille, electronic or audio), and in the preferred format of a participant. 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.

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

15. 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.

16. 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.

17. Consider ways to appropriately fund disability advocacy to support people with disability navigate different service systems.

1. Vision 2020. *State of eye health in Australia*. <http://www.vision2020australia.org.au/our-work/avoidable-blindness-and-vision-loss> [↑](#endnote-ref-1)
2. Australian Network on Disability. *Disability statistics*. <https://www.and.org.au/pages/disability-statistics.html> [↑](#endnote-ref-2)
3. Vision2020. *Eye health in Australia*. <http://www.visioninitiative.org.au/common-eye-conditions/eye-health-in-australia> [↑](#endnote-ref-3)
4. NDIS. Creating Your Plan. <https://www.ndis.gov.au/participants/creating-your-plan/receiving-your-approved-plan/your-plan-other-formats> [↑](#endnote-ref-4)
5. United Nations. Convention on the Rights of Persons with Disabilities – Article 21. <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-21-freedom-of-expression-and-opinion-and-access-to-information.html> [↑](#endnote-ref-5)
6. Vision2020. *Submission on Planning Policy for Personalised Budgets and Plan Flexibility*. <https://www.vision2020australia.org.au/resources/submission-to-the-ndia-planning-policy-for-personalised-budgets-and-plan-flexibility/> . [↑](#endnote-ref-6)