

Vision Australia submission

Capability and Culture of the NDIA

Submitted to: National Disability Insurance Scheme Joint Standing committee

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# Capability and Culture of the NDIA: Submission to the NDIS Parliamentary Joint Standing Committee

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## Introduction

Vision Australia is pleased to have the opportunity to provide this submission to the NDIS Joint Standing Committee, as part of its review into the capability and culture of the NDIA. This submission will outline some of the key challenges that people who are blind or have low vision face in working with the NDIA and accessing information and support.

## Recommendations

* The NDIA should develop clear guidelines around evidence of disability, to support NDIS access for children under 7. This would significantly reduce financial burden and stress for families, whilst enabling Early Childhood Partners to offer more effective support, ultimately ensuring more efficient and timely access to essential services. The entry pathway for early intervention could also be simplified, to facilitate easier access to time critical supports.
* It may be valuable to consider training of specialised planners within the NDIA, particularly for low incidence cohorts such as blindness and low vision that staff may not encounter often. Anecdotal evidence suggests that improved planning outcomes are achieved where participants have access to a planner with either lived experience, or specialised knowledge of their disability type.
* The option of specialist review panels could be considered, such that if an unsatisfactory funding outcome occurs at first instance, a participant seeking a review can be guaranteed that their case will be considered by someone with specialised knowledge or lived experience of their disability.
* Participant involvement in the planning process could be improved through higher levels of direct contact between the participant and the NDIA delegate, as well as implementation of draft plans that are viewable by the participant and discussed with the planner prior to finalisation.
* Lack of accountability within the Agency erodes trust of participants and fails to promote fairness or transparency of process. There must be greater responsibility placed upon the NDIA to act within its own guidelines and processes, and to explain any failures to do so.
* Clearer processes around requests for supporting evidence must be developed within the Agency. Due weight and consideration should be given to evidence submitted by allied health professionals, who often have specialised knowledge and expertise as well as an established relationship with the participant.
* The NDIA should commit to consulting with the sector around operational challenges within the Scheme, and adopt a less adversarial approach when working with service providers.
* Misplaced assumptions around duplicated supports indicate an ongoing need for education within the Agency to support decision-makers in understanding the interface between different service types for people who are blind or have low vision.
* Greater clarity is needed around the role of plan managers and the ways in which participants and providers can reasonably expect them to administer funding. Mismanagement of funds leads service providers to take on an unacceptable level of financial risk that is not sustainable.
* The Information Linkages and Capacity building program is vital in fostering innovation within the scheme, and must continue.
* The NDIA should implement a streamlined process to ensure that those who experience difficulty in accessing information and support due to inadequate assistive technology skills are identified in the early stages of planning. Plans for these participants could include a base level of funding for assistive technology support and training. For participants with higher skill levels, the NDIA could provide resources such as video and audio demonstrations, to support participants in understanding how to perform basic functions within the portal.

## Early Intervention Supports for children who are blind or have Low Vision

Vision Australia finds that many families with children who are blind or have low vision experience a number of barriers when engaging with the NDIA. Despite recent reviews of the Agency’s early childhood approach, the access pathway to the Scheme through early childhood partners continues to be difficult for families to navigate. The NDIA has a list of impairments or conditions (referred to as List D), which will automatically qualify children for early intervention supports. Many children with vision impairment will not satisfy the requirements set out in this list because their exact diagnosis and the developmental impact of their condition is not fully realised. To date, no clear guidelines have been established by the Agency as to the specific evidence that must be provided to demonstrate that children not automatically qualified under List D have a need for ongoing supports. In the case of adults or older children, the agency will generally seek information about the impacts that vision impairment has on the person’s day-to-day life and level of functioning. It can be challenging to provide this information in an early childhood context, as it is common that children in this age group will not yet have a stable vision condition, and may not yet have evidenced developmental delay against the assessment markers that the NDIA uses to determine eligibility for the Scheme. A child’s vision will generally continue to develop until around 8 years of age, and the way in which they use it changes as they become more mobile and need to access visual information at greater distances. It is vital during this life stage that they can access services from specialised vision professionals, to ensure that their level of vision and its use in daily routines is monitored and is continuing to develop as expected. The lack of clear evidential requirements from the Agency means that many families incur the cost of obtaining reports from several medical professionals, in order to demonstrate their need for support to the NDIA. This is financially burdensome for families, and may prevent children from accessing essential services. We recognise that vision impaired participants represent a relatively small NDIS cohort with specific needs, and because of this, we often find that early childhood partners similarly struggle to support families through the NDIS access process and lack clarity on the information required to lodge an effective application. While most NDIS applications for vision impaired children are ultimately successful, there are many cases where families are making multiple attempts to access the Scheme, thus increasing the financial cost of engaging medical professionals and causing emotional distress. Delays in accessing funding can also increase the burden on service providers who are trying to support the family to meet outcomes and ensure that subsequent developmental delay does not arise. There is a need for clearer guidance from the Agency as to the evidence of disability requirements that families must meet in order to access early intervention supports through the scheme. Greater capacity building is also required to ensure that early childhood partners have base level knowledge, or access to resources concerning vision impairment, so that they can adequately support families to access relevant and meaningful early intervention services. Consideration should also be given to whether Scheme entry requirements could be simplified for early childhood participants. A simplified entry pathway would ensure that time critical early intervention supports can be delivered more effectively to these participants.

## Lack of Understanding Around Specialised Supports

It appears that there is a pervasive culture within the Agency that devalues specialised allied health and therapy services. These supports are often viewed by planners as being costly, when in actual fact, they generally increase a participant’s capacity, thus resulting in decreased reliance on other supports over time. Vision Australia service providers, as well as the NDIS participants they work with, frequently report a lack of capability of NDIS planners to understand the specific supports that people who are blind or have low vision rely upon. This inevitably results in adverse planning outcomes such as inadequate funding, or the inclusion of funding within the incorrect plan budget. Vision impaired participants often utilise a series of highly specialised supports that do not fit neatly into the plan budgets and support categories that the NDIA utilises. One example of this is orientation and mobility services, which generally involve the teaching of a number of complementary strategies that can support a vision impaired person to access the community safely and independently. These strategies may include navigation with a dog guide or white cane, in addition to other sensory awareness techniques such as echolocation and recognition of tactile cues. O&M is a long-established and evidence-based discipline and providers of these supports will undergo extensive practical training alongside university level qualifications. These services are not, however, well understood by NDIS planners. This is problematic, because where Agency staff do not comprehend the purpose or benefit of a particular support, they are reluctant to include it in participant plans. It is a common occurrence for planners to assume that orientation and mobility services can simply be delivered by a support worker, rather than a qualified professional. This generally results in inadequate funding being included in the plan, because the hourly rates for support workers are considerably lower than those paid to allied health professionals. This error also results in funding being included under the wrong support budget, which means that participants cannot spend it on orientation and mobility services or other vision related therapies. When this occurs, the only remedy available involves the participant applying for a plan variation to have the funding moved to the correct support budget. Requests for a plan variation are not always granted and may be declined by the NDIA. Similar challenges have arisen in relation to other specialised vision services, such as dog guide follow-up. These services are delivered by a qualified guide dog mobility instructor, particularly in situations where the dog and handler are learning new travel routes. They are also essential in ensuring that the dog and handler are continuing to work safely together as a team. It is similarly common for planners to assume that these services can be delivered by support workers, or in a group situation. Both assumptions are incorrect; dog guide mobility instructors possess extensive specialised training and the services they provide are individualised to each dog and handler team.

These are just some of the examples of the unique challenges that people who are blind or have low vision face in accessing specialised services through the NDIS. In order to address this, it may be valuable to consider training of specialised planners within the NDIA, particularly for low incidence cohorts such as blindness and low vision that staff may not encounter often. Anecdotally, we are aware of some participants who have had the opportunity to work with planners that have lived experience of blindness and low vision. Without exception, these participants report more consistent planning outcomes with appropriately funded supports, as well as a much more positive planning experience, resulting from the fact that they are working with someone who understand their needs. Even participants who are skilled in self-advocacy and familiar with the NDIS environment tend to find the planning process difficult and stressful. The option to work with a planner that has either lived experience or specialised knowledge around the participant’s disability would reduce the cognitive load that often results from having to justify the purpose and value of every support that is requested. If current staffing within the Agency does not allow for specialised planning, it would be worthwhile to consider the option of specialist review panels, such that if an unsatisfactory funding outcome occurs at first instance, a participant seeking a review can be guaranteed that their case will be considered by someone with specialised knowledge or lived experience of their disability. This could drastically improve the participant experience of the plan review process, whilst also minimising the volume of cases that require intervention from the Administrative Appeals Tribunal.

## Participant Involvement in the Planning Process

One of the key challenges of the current NDIS model is that it lacks the facility for collaboration within the planning process. This occurs because participants are effectively quarantined from the decisions that are made about their funding. In most cases, the participant has their planning conversation with a local area coordinator, who then provides information and recommendations to the Agency planning delegate, who then decides on and approves the quantum of funding. A finalised plan is sent to the participant, with no opportunity for them to view the document prior, or comment on whether their needs and goals have been accurately captured. This multilevel planning process has a high margin for human error and arguably leads to inconsistency in funding decisions, because the planner has no direct access to the participant and vice versa. It is Vision Australia’s view that many of the adverse funding outcomes that occur could be avoided through greater interactivity in the planning process. It is generally the case that participants never have a discussion with the person who is responsible for building their plan, and the supports discussed with the LAC during their planning meeting are often vastly different from those that they ultimately receive. Moreover, as there is currently no capacity for the participant to view the plan before it is finalised, there is consequently no opportunity to resolve simple errors or issues. The only option available to the participant is the instigation of a plan review, which is time and resource intensive for all parties involved. In 2021, the NDIA did consult on the notion of providing draft plans to the participant prior to finalisation, and facilitating direct meetings between planning delegates and participants. Many participants and providers such as Vision Australia were supportive of this proposed approach, yet somewhat disappointingly, it has not come to fruition. We recommend that the NDIA pursue this work, in the interests of fostering collaboration and improved relationships with participants.

## Lack of Adherence to NDIA Funding guidelines

It has been positive to observe in recent times the increased commitment by the Agency to publish operational guidelines on its website that provide concise information about the supports that the Scheme generally will and will not fund. This has helped to provide additional clarity for participants and set reasonable expectations about what the NDIS can fund. Regrettably, however, there are numerous instances where the Agency fails to follow its own guidance principles, leading to frustration for participants and poor planning outcomes. This occurs with particular frequency in relation to participant transport funding. Vision Australia is aware of numerous instances where participants who are blind or have low vision and are employed, have been denied transport funding in their NDIS plan. This occurs despite the Agency having operational guidelines in place that clearly specify that participants working for more than 30 hours a week are eligible for level 3 transport funding. Requests from the NDIA for written reasons as to why it has made these decisions in contravention of its own stated policies are routinely ignored, both at plan review stage and in cases that reach the AAT.

Similarly, recent changes have been made to Federal legislation which require the NDIA to provide participants with reasons when making a reviewable decision. In our experience, this rarely occurs in practice. Many of our clients report never receiving information from the NDIA to explain why supports or funding have been declined. Even where the participant specifically requests written reasons, it is not uncommon for the planner to provide a one-line response. This could hardly be considered adequate, given the time and funding which participants invest in providing supporting evidence to justify the supports they have requested. This also impacts providers, who rely on this formal feedback from the NDIA to support participants with additional evidence when reviewing the decision.

This lack of accountability within the Agency’s culture is unfortunate, as it erodes trust of participants and fails to promote fairness or transparency of process. There must be greater responsibility placed upon the NDIA to act within its own guidelines and process, and to explain any failures to do so.

## Unreasonable Requests for Supporting Evidence

Vision Australia has worked with many participants who express concern and frustration about the quantum of their funding that must be spent on report writing. There appears to be a particularly worrying trend for the NDIA to request participants to provide functional capacity assessments, regardless of whether these are required or relevant. A functional capacity assessment (FCA) is generally carried out by an allied health professional (most commonly an occupational therapist), and is intended to analyse the participant’s functional performance in areas of self-care and day-to-day activities around the home. These assessments involve a comprehensive evaluation of all aspects of the participant’s daily life and are therefore time consuming to complete, often taking up to ten hours. There is a justifiable need for these reports in some circumstances, particularly where the participant’s situation has changed significantly, or where they are requesting substantial additional supports as part of their next plan. It is common, however, for the NDIA to request an FCA to support the purchase of equipment, home modifications or to maintain current levels of therapy funding in a future plan. An FCA should not be required in these instances; the Agency has assessment processes for equipment and home modifications in place, and adequate evidence of future therapy needs can generally be provided as part of a standard plan progress report. We have seen situations where the participant has already had a relatively recent FCA, yet the Agency will request another, before agreeing to review the participant’s support needs. This process is unnecessarily prohibitive for participants, who often don’t have sufficient therapy funding remaining in their plan to cover the FCA. Alternatively, they are directed to spend significant amounts of funding on evidence, which could have been used for therapy intervention and which, in many circumstances, may not add value to the decision-making process. There are also indications in some cases that the evidence provided is never read or considered at first instance. We have encountered several situations where participants have been asked to provide information at their review which has already been given as part of the initial planning decision. It is suggested that clearer processes around requests for supporting evidence must be developed within the Agency, and consideration given to the funding impacts that these requests have on participants.

There also appears to be a culture within the Agency whereby allied health professionals are asked to provide evidence to justify supports, yet their opinions are not valued or taken into account as part of the funding decision. Their opinions are questioned by NDIA staff who have limited knowledge of disability, and who, in many cases, have not even met the participant. Therapists often have both extensive knowledge of the participant, and a comprehensive understanding of the specialised supports they receive. Currently, planners are making decisions about how much therapy support is needed to achieve the participant’s goals, but without reference to advice from allied health professionals. The lack of willingness to consult with the sector has been a pervasive issue within the NDIA for quite some time. It is an unfortunate attitudinal barrier, because the Agency and service providers should generally be working toward the same goal of improving outcomes for the participant. There is a need for cultural change within the Agency to facilitate open dialogue with the disability sector and reduce the adversarial approach that often exists between the NDIA and service providers. Clear commitments from the Agency to consult with the sector around operational issues within the Scheme would be a positive first step in achieving this.

## Perceived Duplication of supports

Vision Australia acknowledges that the NDIS is an insurance model, that focuses on building a person’s capacity with the aim of reducing their need for supports over time. Unfortunately, however, there appears to be a tendency within the Agency to make inaccurate assumptions about duplicated supports. It is unclear as to whether this stems from a lack of understanding, or whether there are staff KPIs around sustainability that may also contribute to the decisions being made. As an example, Vision Australia is aware of several cases where people who are blind or have low vision that choose to use a dog guide as their mobility aid, have been denied access to personal transport funding as part of their NDIS plan. The reason generally given by the Agency is that access to a dog guide and transport funding are viewed as equivalent supports. At least one of these recent cases has proceeded to the AAT. This indicates a fundamental lack of understanding of the role and purpose of a dog guide. The assumption that a dog guide entirely removes the need to access point-to-point transport, such as taxis, due to the increased independence that it provides, fails to take account of factors such as:

* The inability of public transport services to reach all areas of the community;
* The fact that transport for people with disability is time crucial, as it is for everyone. People who are blind or have low vision need to be able to care for their families, attend their jobs and educational institutions, and the frequency or availability of public transport is not always conducive to this; and
* The fact that there are, and likely always will be, areas and circumstances where it is unsafe or impractical for a person who is blind or has low vision to travel as a pedestrian, even with the assistance of their preferred mobility aid.

There has also been at least one case where a participant’s core supports have been substantially reduced following receipt of a dog guide. The argument provided by the NDIA in this instance was that a dog guide would reduce the need for core supports to access community groups etc., due to the increased independence that it provides. Once again, this represents a fundamental lack of understanding of a dog guide’s role in the life of its handler. While it may improve the person’s ability to navigate their community safely and independently, a dog guide does not replace the social interaction with other human beings that is afforded by participation in community activities. In other cases, access to workers to support with tasks such as shopping has been reduced following receipt of a dog guide. Again, these supports should be viewed as complementary, rather than equivalent. For example, a dog guide may enable a handler to navigate the supermarket environment more independently, but cannot assist them to choose the correct items from the shelf, or explain what is available, in the same way that a support worker would. The apparent tension between capital funding for a dog guide, against the ongoing provision of other supports, has the potential to place many people who are blind or have low vision in the untenable position of being forced to make a choice between independent mobility, and the capacity to engage fully in social and civic life. These issues indicate an ongoing need for education within the Agency to support decision-makers in understanding the interface between different support types for people who are blind or have low vision.

## Costs of doing Business with the NDIA

Vision Australia is a well-established provider that has worked within the NDIS framework since the Scheme’s inception. We continue to find, however, that the costs of conducting business with the NDIA are immense. The business model operates in such a way that service providers are required to take on an unacceptable level of financial risk around service delivery. Administration of funding for participants who are plan managed is particularly problematic, and we are experiencing increasingly concerning challenges with third party managers who are bad debtors. There are numerous circumstances where participants have agreed to receive services and their plan manager has indicated that funding is available, however, they fail to quarantine the relevant amount. By the time the service has been invoiced, the participant has insufficient funding remaining in their plan to pay for it. The NDIA offers plan managers the facility to set aside funding to be spent on services with particular providers, however, many plan managers ideologically refuse to do so. This places service providers at substantial revenue risk.

This is a fundamental misunderstanding of the role of plan managers, and is all too common. It appears to be a greater problem with smaller plan managers who have taken on more than they have capacity for; there are excellent examples of plan managers who handle participant funding with a high degree of competence. There is limited oversight or accountability by the Agency where participant funds are poorly managed, often leaving service providers with no option but to write off the debt. Greater clarity is needed around the role of plan managers and the ways in which participants and providers can reasonably expect them to administer funding. The NDIA updated its plan management guidelines in 2020, however, this was largely unhelpful and seems to have increased confusion, rather than eliminating it.

A further cost of business arises because service providers are required to conduct work as part of their service delivery for which they cannot recoup funding from participants. The majority of Vision Australia therapy services need to be delivered in the participant’s own environment, in order to be effective. For example, orientation and mobility services are used to support participants in navigating safely in the community, often involving teaching of specific travel routes and instruction with a long cane or Seeing Eye Dog. Similarly, occupational therapists will often need to work with participants on customised adaptations to their home environment, in order to ensure the best possible level of safety and functioning. The need for services to be delivered in this way means in turn that the costs of travelling to participants are also high. Even in metropolitan areas, we incur non-billable travel costs for most service events that are not recoverable. There appears to be an erroneous assumption within the Agency that providers can viably deliver services at the current price caps, however, this fails to take into account the volume of unpaid work that service providers do. This relates not only to travel costs, but also to advocacy and plan implementation support that providers often become involved in, due to the complexity and adversarial nature of the Scheme.

Thin cost margins also mean that there is currently little opportunity for innovative service design and delivery within the NDIS. The model focuses exclusively on hours of service, and is therefore a largely transactional arrangement between providers and participants. Any investment in innovation from not for profit organisations such as Vision Australia is therefore reliant on philanthropic funding. We cannot stress enough the importance of continuing initiatives such as the Information, Linkages and Capacity building (ILC) program. While we recognise that the ILC program does not currently sit within the NDIA’s sphere of operations, it is nonetheless a crucial part of the NDIS framework. ILC grants remain important not only for the provision of Tier 2 services, but also to pilot and trial service innovations that can benefit the sector more broadly.

## Participant Information and support

Many participants continue to struggle to access consistent and reliable support from Local Area Coordinators. Stated NDIS practice is that participants should receive up to ten hours of support from a LAC, however, this level of plan implementation guidance is commonly unavailable. We often find that participants who are blind or have low vision have difficulty in understanding plan budgets and how these can be used. They also struggle to access the NDIS participant portal, which is not an intuitive environment, particularly for those using screen readers or magnification software. It is also unlikely that most Local Area Coordinators will possess the specialised skills necessary to manage the needs of these participants. We suggest that the NDIA should implement a streamlined process to ensure that those who experience difficulty in accessing information and support due to inadequate assistive technology skills are identified in the early stages of planning. Plans for these participants could include a base level of funding for assistive technology support and training. For participants with higher skill levels, the NDIA could provide resources such as video and audio demonstrations, to support participants in understanding how to perform basic functions within the portal. In the long-term, the provision of appropriate and accessible information to these participants has the potential to build technological and financial capacity, and provide participants with a higher level of agency with respect to their funding and choice of supports.

## Conclusion

Vision Australia thanks the NDIS Joint standing Committee for its consideration of this submission. We wish you well in your deliberations, and would be happy to provide additional information about any of the matters detailed in this paper.

## About Vision Australia

Vision Australia is the largest national provider of services to people who are blind, deafblind, or have low vision. We are formed through the merger of several of Australia’s most respected and experienced blindness and low vision agencies, celebrating our 150th year of operation in 2017.

Our vision is that people who are blind, deafblind, or have low vision will increasingly be able to choose to participate fully in every facet of community life. To help realise this goal, we provide high-quality services to the community of people who are blind, have low vision, are deafblind or have a print disability, and their families.

Vision Australia service delivery areas include:

* Allied Health and Therapy services, and registered provider of specialist supports for the NDIS and My Aged Care
* Aids and Equipment, and Assistive/Adaptive Technology training and support
* Seeing Eye Dogs
* National Library Services
* Early childhood and education services, and Felix Library for 0-7 year olds
* Employment services, including National Disability Employment Services
* Accessible information, and Alternate Format Production
* Vision Australia Radio network, and national partnership with Radio for the Print Handicapped
* Spectacles Program for the NSW Government
* Advocacy and Engagement, working collaboratively with Government, business and the community to eliminate the barriers our clients face in making life choices and fully exercising rights as Australian citizens.

Vision Australia has gained unrivalled knowledge and experience through constant interaction with clients and their families. We provide services to more than 26,000 people each year, and also through the direct involvement of people who are blind or have low vision at all levels of the Organisation. Vision Australia is therefore well placed to provide advice to governments, business and the community on the challenges faced by people who are blind or have low vision fully participating in community life.

We have a vibrant Client Reference Group, with people who are blind or have low vision representing the voice and needs of clients of the Organisation to the Board and Management. Vision Australia is also a significant employer of people who are blind or have low vision, with 15% of total staff having vision impairment.

We also operate Memorandums of Understanding with Australian Hearing, and the Aboriginal & Torres Strait Islander Community Health Service.