



Submission to the Joint Standing Committee on the NDIS

Participant Experience in Rural, Regional
and Remote Communities

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Introduction

As of June 2023, 10,158 NDIS participants (around 2 % of the total) had “visual impairment” as their primary disability.

Among these:

- ☐ 29 % lived outside major cities
- ☐ 2 % lived in areas defined by the NDIA as remote or very remote
- ☐ 4 % identified as Aboriginal or Torres Strait Islander, compared to 8 % of all participants
- ☐ 16 % identified as culturally and linguistically diverse, compared to 9 % of all participants.

In the absence of other disabilities, people who are blind or have low vision can live very independently. However, they rely on specialist training to build their capacity to perform daily tasks, and on assistive technology to enable mobility and access to information.

The low prevalence and wide geographic dispersal of our cohort is one of the key challenges for the specialist providers offering these vision services. Further, the inconsistent understanding of vision impairment among Agency staff and local area coordinators adds complexity to the access and planning process, compounding the cost and difficulty of evidence gathering for people seeking support.

Building on recommendations by the Independent Review of the NDIS (the Review), as well as previous reports from this Committee, this brief submission offers some ideas to enhance the NDIS experience for people who are blind or have low vision living in rural, regional, or remote communities.

Recommendations

1. The NDIA should urgently create an easy-to-read document, in multiple formats, which explains to applicants and families how to request access to the NDIS based on vision impairment.
2. The NDIA and Department of Health should collaboratively develop a “Medical Evidence of Disability” policy which:
 - ☐ Introduces new MBS items for specialist assessment;
 - ☐ Improves integration between the NDIA and My Health Record, and the way vision impairment diagnoses are recorded by My Health Record;
 - ☐ Accounts for participants in rural, regional, and remote locations; and
 - ☐ Introduces improved evidence-gathering processes for low prevalence disabilities including, but not limited to vision impairment.
3. The NDIA should work with the vision sector to update the disability snapshot for blindness and vision impairment, to include more information about the availability of specialist vision supports.
4. In developing reforms to NDIS planning, the NDIA should prioritise choice for participants about the format of their planning meetings – teleconference, in person, at home, or in another location.
5. The NDIA, in collaboration with service providers and participants, should develop new

guidance for planners about how to account for provider travel when designing budgets.

6. The NDIA should introduce new line items to facilitate travel and service delivery for providers delivering to “thin markets”, where the prevalence of target disability is low and/or distances between participants is great. Providers should be able to access these line items in order to provide evidence for NDIS assessments.
7. As part of a new NDIS Rural, Regional and Remote Strategy, the Agency should co-design new approaches to serving participants in thin markets.
8. In developing its new First Nations Strategy, the NDIA should prioritise:
 - ☐ Creating resources and training modules for Aboriginal Community Controlled Health Organisations (ACCHOs) in fundamentals of vision rehabilitation and referral to specialist providers;
 - ☐ Building a workforce of First Nations NDIS planners; and
 - ☐ Reaching people with vision impairment who need disability supports but are currently unable to access them.

Access

Currently, to access the NDIS with vision impairment as a primary disability, an applicant must provide evidence of diagnosis from an ophthalmologist. This has proven to be a significant barrier to entry for people in rural and remote communities, where ophthalmologists may not be easy to reach.

Ophthalmology services are rare outside of metro areas. NDIS applicants therefore might need to travel long distances to meet a clinician who can complete an access request.

In some cases, multiple appointments, and therefore multiple long trips, are required, when a planner rejects an initial request. Sometimes, these rejections are due to small administrative errors or to an assessor failing to understand clinical terminology used in a report.

There are also many applicants who saw an ophthalmologist to address initial vision concerns but weren't aware that a report would be needed for NDIS access, and thus missed a valuable opportunity.

We support the Review's proposal (see Action 3.2) for a new, improved access request form that offers more guidance about what information and evidence an applicant and their supporters need to provide. However, the development process for such a form will take time, and meanwhile there are many people and families who are finding the NDIS application difficult and confusing. People living in rural, regional, and remote areas are especially impacted by this complexity because of extra travel costs and less access to specialists.

As an immediate step, the NDIA should publish an easy-to-read document that outlines the process for an NDIS application based on vision impairment. This pathway should be outlined in text, diagram, and audio formats.

In the longer term, alongside regional, rural and remote participants generally, consultation around access reform should highly prioritise improving processes and guidance around applicants with low prevalence disabilities like vision impairment.

Regardless of access criteria, if diagnosis and medical evidence remain part of the NDIS application process in the future, the reform process should also consider how to minimise the difficulty of obtaining evidence for applicants outside of metro areas. This could take the form of a medical

evidence of disability policy, developed collaboratively between health and disability Ministers and Departments, and in consultation with relevant stakeholders, including the vision sector. The policy would consider options such as:

- ☐ MBS items for ophthalmology, optometry, and teleophthalmology reporting for NDIS and other disability-related applications, which can take longer than a traditional consultation;
- ☐ MBS items for orthoptists and occupational therapists to provide evidence and reporting around vision loss;
- ☐ Systems to ensure permanent vision diagnoses are registered through My Health Record, in order to avoid the need for repetitive and/or duplicative processes;
- ☐ Integration of My Health Record with NDIA systems, so a recorded diagnosis can be captured where available; and
- ☐ Facility for optometrists to provide evidence for access requests in some circumstances.

The Review's recommended Action 3.1 stipulates that evidence required to inform NDIS access decisions should be funded by Government. One of the goals of this policy should be ensuring that applicants don't have to pay to obtain evidence of their disability.

Equipping Planners with Knowledge

The planning process is generally inconsistent for participants who are blind or have low vision. This is often due to lack of knowledge among assessors about specialist services and their benefits. This remains true for participants in rural, regional, and remote areas, but for them, the experience can be even more complex, costly, and isolating.

Sometimes, participants and their supporters aren't themselves aware of the available support options. If assessor, participant and family all believe a person won't be able to perform tasks without help, the result will be a plan mostly consisting of core funding. If, for example, the participant or their supporters join a peer support group after their plan has become active, they'll only then realise how much independence is possible, and quickly seek a reassessment for more capacity-building funding. All of this is complicated by distance, requiring either interactions via phone (see below) or extensive, expensive travel.

The NDIA has acknowledged this problem and is taking some steps to address it. We appreciate, in particular, the commitment to developing a "guide to understanding supports" for children who are blind or have low vision, which will be a valuable resource for families with little understanding of what their child's future might look like.

The Review acknowledged the importance of ensuring planners have the right knowledge to make judgments about a participant's functional capacity, recommending a significant investment into "experience, training and qualifications of the Needs Assessor".

In 2019, the NDIA, in collaboration with V2020A Member Blind Citizens Australia, developed a "disability snapshot" to help Agency staff work with participants who are blind or have low vision. The snapshot is widely used, and has had a positive impact on planning conversations. This shows that planners are willing to access resources and guidance where necessary. However, the snapshot focuses on ensuring comfortable social interactions, and only includes limited information about the specialist support types participants typically benefit from.

The NDIA should work with the vision sector to update the disability snapshot for blindness and vision impairment, to include more information about the availability of specialist vision supports such

as orientation and mobility instruction. Planners should be encouraged to access this information when developing plans for a participant with “visual impairment” as a primary or secondary disability.

Planners Aren’t Accounting for Travel Costs

Many of the issues discussed in Chapter 9 of this Committee’s 2020 report on NDIS planning remain relevant today. For example, Occupational therapy Australia told that inquiry about planners failing to account for travel costs when calculating support hours. This problem has been exacerbated by well-meaning changes to the way providers can charge for their travel, which were designed to help them cover the costs of meeting participants outside of metro areas.

Most supports required by people who are blind or have low vision usually can’t be delivered in a clinical setting. Planners usually assume, especially regarding therapy supports, that participants will travel to service providers.

The result of this is a participant being told, for example, that they can access 20 hours of therapy supports in a year, then finding to their dismay that thanks to travel costs, they only receive 15 hours of service in real terms. Meanwhile, a participant who lives close to their provider will receive a higher proportion of the service discussed in the planning meeting.

Participants in rural, regional, and remote areas are already at a disadvantage because of where they live. This disadvantage shouldn’t be compounded by the planning process. We believe these miscalculations are almost always unintended errors. Guidance for planners about how to account for provider travel when building a budget could go a long way towards addressing this problem. This will be especially important if, as the Review recommends, there is a move toward whole-of-person budgets that aren’t based on support hours. If provider travel isn’t accounted for when considering a participant’s needs, then it could take up an even higher proportion of budgets in future.

Travel Costs are Hurting Providers

People who are blind or have low vision receive the most benefit from therapy conducted in their natural environment. The Agency has rightly acknowledged the value of this kind of support in relation to children in recent times, however this is equally important for adults who are blind or have low vision.

For example, if an adult has recently lost or is losing vision, they are likely most comfortable in their own home, which allows for introduction of new skills and challenges without the added stress of navigating an unfamiliar place. Further, it is by attending participants’ homes that therapists typically recognise opportunities for adaptation, such as application of Braille or large print labels, or specially designed household appliances.

Similarly, orientation and mobility specialists, who help clients learn to travel independently in their local area, clearly can’t deliver that training in a clinical setting.

Vision service providers and consumer organisations were experimenting with teleconferencing technology long before the COVID-19 pandemic, and there are some kinds of support where this option has proven successful. However, in the vast majority of cases, in-person training is the only solution.

The comparative paucity and geographic dispersal of participants, the specialist skills required to serve them, the need to travel to clients in most cases, and ongoing workforce challenges similar to those faced by the entire disability sector, create incredibly difficult business conditions for the few providers delivering specialist vision supports.

Even when planners account for provider travel, reimbursement is rarely sufficient to cover the extra cost, for example, of travelling five hours to meet a single client, as one provider recently reported. Though we welcomed the introduction of additional pricing levels based on the Modified Monash Model in 2020, there are many regional locations where the cost of travel for vision service providers remains high because of the small number of clients.

Rural, regional, and remote participants themselves tell us they feel frustrated and powerless. Assuming they have a plan that includes the supports they need, they'll find these supports very difficult to access. These participants feel that the very scheme that was meant to help them live similarly to someone without a disability is not even giving them an experience comparable to their peers in the blind and low vision community.

We are eager to collaborate with the NDIA to secure the sustainability of blindness and low vision services through a more nuanced approach to thin market pricing, which considers the problems faced by participants from rural, regional, and remote areas who are blind or have low vision.

This could be part of a new Regional, Rural and Remote Strategy for NDIS services, as recommended by this Committee in 2020, founded on new approaches proposed by the Review.

This should involve further line items for provider travel which more accurately reflect the costs of providing service in or around the homes of clients living in regional areas.

Planning via Teleconference isn't Right for Everyone

We welcome the Review's recommendation that assessments should be conducted directly by NDIA staff or contractors. As we understand the proposal, this would mean most of the organisations now acting as local area coordinators, which would transition to become navigators, would no longer perform planning functions. However, we worry that one of the unintended outcomes of this reform could be an overreliance on delivering assessments via teleconference in areas where planners aren't readily available.

This Committee's report on planning, written during the transitional period where COVID-19 was improving the general understanding of teleconferencing technology, recommended that participants be given a choice about how and where their planning meeting should be conducted, and we agree this should remain the case whatever reforms are put in place.

We've found that most participants prefer planning meetings to be held face-to-face. This preference is particularly common amongst adults who are entering the scheme after recent vision loss, who often don't have training in alternative ways of using smartphones or computers.

Most trials of the independent assessments pilot were conducted remotely. Participants were asked to perform a task by themselves under the assessor's observation, with the most common example being making a cup of tea. Attempting this while remaining in the frame of a video call very clearly demonstrated the impact of vision loss, but was also stressful, demeaning, and potentially dangerous.

Our members also tell us that remotely delivered assessments wouldn't be culturally safe for Aboriginal and Torres Strait Islander Peoples.

There are some situations, like plan reviews for experienced participants, where a remote assessment might be viable.

For a moment that will, in some cases, change the direction of a person's life, participants who are blind or have low vision should feel as comfortable as possible. In developing new approaches to

assessment and planning, the NDIA should seek to prioritise choice for the participants about how their planning meeting should be conducted, regardless of where they live. A participant should be able to meet their planner via teleconference, in their home, or in another setting, according to their preference.

The Benefits and Limitations of Alternative Commissioning

Recommendation 14 from the Review's final report proposes the development of "alternative commissioning arrangements" to support community-controlled service provision in rural, regional, remote areas and First Nations communities.

We strongly believe that self-determination will prove integral to reaching current and potential participants who are currently either underserved or completely unconnected to the NDIS.

We know that Aboriginal and Torres Strait Islander Peoples are three times more likely to experience blindness or vision loss than other Australians. The fact that only 4 % of participants who are blind or have low vision identify as First Nations, compared to 8 % of participants generally, raises concerns that there are people who are eligible for support they can't access.

Through previous consultation, the Committee has likely become familiar with common causal factors for this disconnect, including lack of cultural safety, an over-reliance on technical terminology and distrust of Government. In Aboriginal and Torres Strait Islander communities particularly, we've sometimes heard that a lack of awareness of vision rehabilitation options is an additional barrier. Engaging with the complex application process, and all the travel and discomfort that entails, seems hard to justify without the promise of greater independence as a result.

A service provider delivering fly in, fly out support to children who were vision impaired in a Northern Territory community told us recently that families already felt overwhelmed by a series of urgent, intersecting challenges. Given the limited capacity among families, providers and local health workers, helping a child in the here and now was prioritised over engaging with bureaucracy.

All of this absolutely proves the necessity of alternative commissioning approaches, with early trials already showing promise. We were encouraged by some of the successes born out of NACCHO's NDIS Ready program, designed to equip ACCHOs to become registered providers.

Training modules and other resources to help local workers understand blindness and vision impairment would be valuable. These could look similar to resources developed for special needs groups in aged care and could be accessible on an as-needed basis. This would assist workers in informing people about the options available to them.

Unfortunately, it isn't possible to quickly upskill workers in specialist vision supports. Orientation and mobility instruction, for example, is a complex discipline learnt through years of education and training. There are situations where local support workers have reenforced training from visiting instructors, but the strategies that enable safe and independent travel must be taught by qualified specialists.

We look forward to the development of the Agency's new First Nations Strategy, which, with the support of the advisory council and First Peoples Disability Network, will likely develop culturally informed approaches to some of the problems we've described. However, a strategy that fails to consider the unique challenges of serving First Nations people with low prevalence disabilities would be incomplete.

We know that vision conditions are over-represented among Aboriginal and Torres Strait Islander

Peoples. We therefore suspect there are many people with vision loss who aren't even considering applying for the NDIS, and therefore are vulnerable to adverse and costly health outcomes such as falls, depression, and early entry to residential aged care. The Agency should also commit to explicitly mention vision loss in the new First Nations strategy, and work with the blindness and low vision sector to explore ways to connect with these unreached people.

Given that access and planning seem to be the biggest obstacles for First Nations peoples seeking support, the NDIA should also urgently prioritise building up a workforce of local, First Nations planners. These planners, who would ideally be respected and connected members of their communities, would have a unique understanding of the context in which people with disability are looking for help, and would be able to guide them through the process at a pace that's right for them, and with language that is relevant to their culture, and upholds their dignity.

About Vision 2020 Australia

Vision 2020 Australia is the national peak body for the eye health and vision care sector. Working with and representing almost 50 member organisations, we focus on supporting policy and funding changes to prevent avoidable blindness, enhance eye care delivery and better meet the needs of people who are blind or living with low vision.

Our members span a wide range of areas and engage in local and global eye health and vision care, health promotion, low vision support, vision rehabilitation, eye research, professional assistance, and community support. This means that the work we do in developing sector-supported policy and advice brings a diverse range of expertise and perspectives to bear, and that the perspectives and experiences of both service users and service providers are at the heart of our work.

Avoidable blindness and vision loss in Australia, and our region, can be prevented and treated by working in partnership across government, non-government, private and community sectors. People of all ages who are blind or vision impaired will benefit from these partnerships, with improved access to services that support their independence and community participation.

For further information about this submission, please contact Vision 2020 Australia via email, policy@vision2020australia.org.au