

Submission to the National Disability Insurance Scheme

**Access and Eligibility Policy with Independent Assessments**

February 2021**About Vision 2020 Australia**

**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 are involved 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.

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# Executive Summary

Vision 2020 Australia appreciates the opportunity to provide feedback to the NDIA during this period of transition and reform, and its members are keen to see further enhancements to the experiences of applicants and participants in the NDIS.

The National Disability Insurance Scheme has had positive impacts on the lives of people who are blind or have low vision.

Like all major reforms, there are however opportunities to enhance the scheme’s operations, and the government and agency’s willingness to adapt the scheme in response to feedback from participants, providers and others is welcome.

The introduction of independent assessments (IAs) arguably represents the most significant reform since its inception. Vision 2020 Australia’s members are eager to work closely with government and the NDIA to ensure changes to assessment arrangements improve outcomes for people living with blindness or low vision.

It can be challenging for staff charged with assessing people with a vast array of disabilities to understand everyone’s individual needs, or what options might be available to support them. This is especially true in the case of people who are blind or have low vision, who represent only around 2 per cent of NDIS participants.

While it is clear that a number of our cohort have been enrolled in the second pilot of the IA process, in progress at time of submission, as yet the sector does not have certainty about:

* Who will be performing IAs, and what understanding these assessors will have of blindness and low vision
* How the assessment tools will capture the unique needs of people with vision loss
* What recourse people will have when they are dissatisfied with their IA.

In addressing questions raised by the NDIA in its consultation paper, this submission explores issues related to the proposed assessment process and identifies some strategies to ensure that the NDIS remains an empowering and capacity building support for our cohort. Potential options explored include:

1. Automatic eligibility for the scheme based on qualification for the Disability Support Pension Blind.
2. Performance of IAs by specialists in blindness and low vision, or an alternative approach whereby sector partners conduct the IAs.
3. Asking applicants about their accessibility requirements at the beginning of their application process, and before an IA is conducted.
4. Exemption from IAs for people who have progressive conditions (E.G brain tumours, in order to ensure supports are introduced at point of need.
5. Avoiding remote independent assessments for people who are blind or have low vision.
6. Considering alternatives to the performance component of independent assessments.

Vision 2020 Australia and its members look forward to working with the agency and government to ensure that reforms to assessment deliver improvements for all, including those applicants/participants with blindness and low vision.

# Learning About the NDIS

Vision 2020 Australia appreciates the NDIA’s questions about how to provide applicants with the information they will need to travel through the application process.

IAs are an unfamiliar process, with few equivalents in other areas of life. Applicants with vision loss may apply to the NDIS at various stages of life depending on the reasons for their vision loss. Some applicants may be children who were born with blindness or low vision. Others will be adults who have acquired vision loss through a progressive medical condition, stroke, or injury.

Many of these applicants are applying to the NDIS at transitional points in their lives: they are not just learning how to navigate a system to secure supports and assistance that is new to them. They and their families are also learning how to live with the functional impacts of vision loss.

1. Consultation question: What will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

The first step to ensuring an inclusive process for people with vision loss is to ask applicants about their preferred format for receiving information at the beginning of their journey.

The NDIS provides supports such as assistive technology (AT) and training which allow people with vision loss to access information in a variety of ways, but at the point of application, many people with vision loss will not yet have developed those capacities and skills.

*It is essential that the NDIA commit to providing information to applicants in as many formats as possible…and support the associated infrastructure*

It is therefore essential that the NDIA commit to providing information to applicants in as many formats as for participants, and ensure the infrastructure is available to facilitate this.

In order to help applicants understand what an IA will entail, the NDIA must tell them:

* What the assessment is designed to measure (explaining terms like functional impact and capacity)
* What choice of assessor is available, and how they can make that selection
* What will happen during their IA (including which assessment tools will be used)
* That they can choose where to have the IA done, and who can accompany them
* Whether the IA will contain a performance component, and if so, that they can choose what task the assessor will observe
* What will happen following the IA (e.g. eligibility confirmation, draft plan, planning meeting)
* What recourse they will have if they are dissatisfied with the process or results of an IA.

# Accessing the NDIS

## Additional opportunity to remove financial and administrative burden

1. Consultation question: What should we consider in removing the access lists?

Vision 2020 Australia’s members recognise the importance of decreasing the financial and administrative burden for participants.

This has been an important part of the rationale for introducing IAs, however removing the access lists has the potential to increase administrative and financial burdens for some applicants/participants who were previously exempt from some requirements under Access List A.

Vision 2020 Australia suggests an additional change to the proposed approach to IAs to avoid the new system imposing unnecessary financial and administrative burden for participants who were previously on Access List A, specifically those who are legally blind.

The removal of the access lists means that people on Access List A who were previously deemed automatically eligible for the scheme would now require an assessment process. For people who are legally blind, this is an unnecessary requirement as a) other government processes will likely have already established the degree of their disability, and b) at the point a person is legally blind they will absolutely require a level of support under the NDIS to address the functional impacts of their vision loss: the issue is mainly how much.

*To reduce the financial and administrative burden for participation, a person with vision impairment who has already established eligibility for the Disability Support Pension Blind should be exempted from the medical evidence requirements of an NDIS application.*

People who are blind or have low vision seeking to access the Disability Support Pension must often undergo a number of processes in order to establish their disability, which includes providing proof from an ophthalmologist of their vision loss. If proof is provided that the person is legally blind (i.e. visual acuity is <6/60), applicants are automatically eligible, and are paid a special version of the DSP, typically referred to as the DSP Blind.

The kinds of tests proposed for inclusion in the access components of the IA are the same as those used to establish eligibility for DSP Blind.

It is thus proposed that when an applicant to the NDIS can provide evidence they are in receipt of DSP Blind, the access component of the independent assessment should be expedited with no requirement to supply separate medical evidence.

There are a small number of cases where a person may be legally blind but not in receipt of DSP Blind (E.G. children aged under 16). In these instances, if the NDIS applicant is able to provide medical evidence that demonstrates they are legally blind, Vision 2020 Australia proposes that they too have an expedited IA process.

Such an approach would maintain the integrity and universality of the proposed system for IAs, ensuring that all participants go through the same process for assessment of functional capacity as part of the planning process but avoiding unnecessary administration and costs by:

* removing duplication of effort in instances where an applicant/participant has previously provided the relevant information to DSS for purposes of the Disability Support Pension, and
* not expending additional IA resources on the access component of an assessment in other cases where vision loss is so profound that a level of NDIS support will be required.

## Distinguishing between disability and health conditions

1. Consultation question: How can we clarify evidence requirements from health professionals about a person’s disability and whether or not it is, or is likely to be, permanent and life long?

This question is not so relevant in the blindness and low vision space, as most of the causes of permanent vision loss and the likely prognoses are well documented and can be readily communicated in medical advice.

*A range of vision conditions are progressive but the course of that progression and its function impacts can vary significantly, meaning the needs of people with vision loss can change suddenly*

Unfortunately, the conditions for which blindness and low vision services are sought are usually permanent with no prospect of significant improvement under currently available treatment regimens. That means that for people with blindness and vision loss, support through the NDIS aims to maximise function and independence but will be needed on an ongoing basis.

Arguably the most challenging element in relation to vision loss is that while a range of conditions are progressive, the timing of that progression (and hence the nature of functional changes) cannot readily be predicted and people living with permanent vision impairment can experience sudden changes.

1. Consultation question: How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

This is unlikely to be achieved as for a wide range of instances, the two will co-exist, with an underlying health condition causing or contributing to the disability.

For example, in the blindness and low vision area, a range of genetically inherited conditions can lead to progressive vision loss, rendering people legally blind, or diabetes can lead to permanent scarring at the back of the eye with permanent vision loss.

The key issue is that regardless of the cause of vision loss, these people suffer diminished functional capacity. This exposes them to the same risks of adverse outcomes as other NDIS participants, the very risks that the NDIS exists to address.

For people with vision loss, the NDIS remains the best mechanism via which their functional capacity can be retained or rebuilt.

The functional impact of vision loss should be the key consideration in determining access to the scheme, as there are no other alternatives which meet the needs of those Australians, and ensure they have the same opportunities to participate as others.

*For people with vision loss, the underlying health condition and the disability it causes co-exist….the key issue is that people with vision loss are exposed to the same risk of adverse outcomes as other NDIS participants, and the NDIS remains the best mechanism for addressing these*

# Undertaking an Independent Assessment

## Skills and traits of assessors

1. Consultation question: What are the traits and skills that you most want in an assessor?

To be able to effectively assess the needs of a person with vision impairment, assessors need to have a strong knowledge of:

* How to work and interact with people with vision impairment
* The conditions that cause that vision loss, their impacts and their likely progression
* How those conditions and the associated vision impairment is likely to impact their activities of daily living, noting that this will differ according to how they spend their time and the things they want to do, as well as the characteristics of their vision condition, particularly for those whose vision will degenerate over time.
* What the most appropriate training, support and equipment is to address the current functional impairment but also its likely progression.

This can be particularly challenging for generalist assessors as the needs of people who are blind or have low vision are comparatively complex, because:

*Assessing the functional impacts of vision impairment and identifying the most appropriate supports can be particularly challenging given the variability in its causes, its impacts and its progression*

* Some of these conditions, associated needs, and available supports are highly technical and constantly evolving as technology and other factors change.
* Alongside ongoing support, there may be a need for episodic or ad hoc supports, particularly as a range of vision conditions are degenerative, resulting in a change in need over time.
* As a range of sight threatening eye conditions are progressive, there is sometimes a time limited opportunity for affected people to be trained in the use of equipment and supports while they still have a level of functional vision. Such training is much easier to complete early in the course of their condition, and better equips them to manage the impacts of further deterioration in their sight.

Vision 2020 Australia thus recommends that at a minimum, the workforce recruited to conduct IAs includes professionals with sufficient skills and knowledge of vision impairment and its functional impacts.

These specialist assessors are most likely to apply the assessment tools in a way that accounts for the complexities of this low prevalence disability, without the need to train a large number of workers in issues relevant to a small cohort of participants.

Specialist assessors for this cohort could include, for example, appropriately experienced orientation and mobility specialists, occupational therapists and orthoptists. This solution would ensure that the assessment tools were used in the way which is most likely to correctly identify both the capacity and the needs of these applicants.

It is understood that in the ECEI pathway, assessments will be conducted by Early Childhood partners, rather than a separate assessor workforce and this would be the ideal arrangement for applicants/participants with vision impairment.

*Vision 2020 Australia recommends that at a minimum, the workforce recruited to conduct IAs include professionals with sufficient skills and knowledge of vision impairment and its functional impacts, and that the option of utilising partners rather than a separate workforce (i.e. the Early Childhood model) be considered*

## Fit for purpose assessment tools are also essential

Alongside ensuring that assessors have the skills and understanding required to work effectively with people who are blind or have low vision, it is also essential that the tools they use can accommodate the particular needs of this group.

Vision 2020 Australia members provided early advice in relation to assessment tools and at that time, expressed concerns that the CHIEF assessment tool was not able to effectively record information about how vision impacted on functional capacity.

Vision 2020 Australia members appreciate the NDIA’s clear commitment to including people who are blind or have low vision in the second pilot of IAs, but remain concerned that the assessment tools may not be fit for purpose for vision impaired applicants/participants.

*Vision 2020 Australia seeks further discussion with the NDIA as trial 2 results emerge so we can work together to ensure the final assessment tool is suitable for use with people with vision impairment*

Vision 2020 Australia seeks further discussion with the agency as results from the trial come in, so that we can pool our expertise to ensure the final tools are appropriate for the task.

Vision 2020 Australia members have expressed particular concerns about the performance component of IAs (sometimes referred to as participant interaction), and the suitability of this component for assessing the functional impacts of vision impairment because of its relatively narrow focus.

For example, if a person with vision loss chooses a task they can perform well, and the assessor fails to understand this performance in the larger context of their condition, this may lead to an unreasonably high measurement of capacity which fails to recognise that outside a familiar environment or a task they are comfortable with, an applicant is much less capable.

Vision 2020 Australia members note that in a range of instances, people with vision impairment may have developed strategies that enable them to function well in their home environment but have much less capacity to independently travel and access the community. It is difficult and risky to both the individual and the assessor to assess the latter unless the assessor has access to (or possesses) specific expertise in the field.

Conversely, an applicant may choose or be asked to perform a task which is difficult for them at the time of the assessment. This would be both a risky and a highly demeaning experience, at a point where some people, especially those who acquire vision loss, feel extremely vulnerable.

Given that people who are blind or have low vision are at greater risk of depression, and that during their application process they may lack knowledge about how independently they can live with their new vision level, this component risks negatively impacting on an applicant’s mental health without gathering reliable data.

The sector thus strongly encourages the NDIA to consider alternatives to the proposed performance component of IAs to determine functional performance and capacity for people with vision impairment.

*The proposed performance component of IAs poses risks to individuals who are blind or have low vision, and are unlikely to provide accurate measures of performance. The blindness and low vision sector is keen to work with the agency around alternatives that could be implemented within the IA framework.*

While one option might be to exempt this group from this component on the grounds identified in the consultation paper (that the process is likely to do more harm than benefit to the individual, and may pose a safety risk to the individual or the assessor”), the blindness and low vision sector would be happy to contribute its time and expertise to explore potential alternatives that could be implemented within the overarching IA framework.

1. Consultation question: What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

See response to questions 1 and 10.

1. Consultation question: How can we ensure independent assessments are delivered in a way that considers and promotes cultural safety and inclusion?

It is important that there be flexibility in how, when and by whom assessments are conducted as Vision 2020 Australia members advise that remote assessments and/or other approaches that do not allow a trusting and respectful relationship to be built between the assessor and individual will not be effective.

Ensuring Aboriginal Community Controlled Organisations are resourced and supported to perform IAs for Aboriginal and Torres Strait Islander Peoples with vision loss will be an important aspect of ensuring culturally safe assessments, with rural and remote communities prioritised.

# Exemptions

1. Consultation question: What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

Vision 2020 Australia members agree with the paper’s suggestions that people who have suffered from trauma should be exempted from IAs, as well as those who may suffer behavioural issues that would render the IA invalid.

*Exemptions from the IA process are essential where individuals have suffered trauma, have significant behavioural and/or extremely progressive conditions*

Additionally, it would be valuable for people whose vision loss was caused by extremely progressive medical conditions (e.g. brain tumours) to be exempted from IAs in instances where earlier possible provision of supports and services is needed.

In these cases, as mentioned in the consultation paper, an alternate process should allow treating medical professionals to quickly provide evidence of the functional impact of an applicant’s vision loss.

# Quality Assurance

1. Consultation question: How can we best monitor the quality of independent assessments being delivered and ensure the process is meeting participant expectations?

While the NDIA’s decisions are reviewable by the Administrative Appeals Tribunal (AAT), a body independent of the NDIA, IAs will not be. But with planning and access decisions so significantly informed by IAs, it is essential that they be accountable to a similar review process. The agency has said that:

* an independent assessment can be rendered invalid if it is considered to have been inconsistent with the independent assessment framework, or if there is a significant change in a person’s functional capacity or circumstances.

*Consistent with the principles of choice and control, and the shared commitment to transparency, an independent review process that can where necessary trigger a funded full or partial re-assessment is essential*

* a complaints process will be established for those dissatisfied with assessments or assessors.
* it does not intend to fund new assessments for those who disagree with the results of an IA.

Clearly, if an assessment does not accurately reflect a participant’s functional capacity there are negative consequences for the applicant’s access decision.

It is thus important that there be a mechanism for a participant to seek an independent review of that assessment if they feel it does not reflect their functional status/need. This would likely, by nature of the issue at hand, require the system design to allow for either a full or partial, funded re-assessment to be undertaken.

Vision 2020 Australia members have indicated that the current appeals mechanism, which has involved both internal review processes and the capacity to seek an independent review (via the AAT) has been an effective way of achieving this to date.

## Innovative approaches to informing participants, enhancing quality

To ensure the IA process is meeting participant expectations and be true to the principles of choice and control, Vision 2020 Australia believes it is important that the system enables participants and applicants to

*Creating a platform where individuals can both report on their experiences and access information about the experiences of others would help drive continuous quality improvement and further empower individual applicants/participants*

1. Readily access information about the skills, qualifications and experience of assessors, to help ensure a good fit between the participant/applicant’s circumstances and the assessor,
2. Be supported to actively provide feedback about their IA experience, which will inform future applicants and participants in their choice of assessors.

Such a system would provide a valuable mechanism for providing both positive and negative feedback, to the benefit of all involved, and would be in keeping with the fundamental principles of choice and control underpinning the scheme. Consideration could be given to a web -based system, such as those currently being used to share stories of individual health and care services and provide service providers with opportunities to drive real-time quality improvement. A dedicated NDIS version could potentially deliver similar benefits.

# Communications and Accessibility of Information

1. Consultation question: How should we provide the assessment results to the person applying for the NDIS?

Vision 2020 Australia appreciates recent improvements made by the NDIA in regard to the provision of information in a participant’s preferred format. In order to ensure the inclusivity of the application process going forward, members believe the NDIA should:

* Ask participants about their preferred format for information delivery at the beginning of their application process.
* Provide an applicant with IA results, in their preferred format, at the same time as planners receive them.
* Explain the results of an IA in a narrative format, rather than or in addition to a table or diagram.

Accessibility isn’t only about provision of information. It also involves the overcoming of other barriers. Some people, at the point of their application to the NDIS, have lost vision suddenly due to an injury. This is a traumatic event, and in order to avoid negative impacts on mental health and ensure the fairest assessment process, that IA should be conducted by a trauma-informed assessor.

*Remotely performed IAs should be avoided for people with vision impairment, as a range of practical factors will limit their effectiveness and reliability*

The prospect of IAs performed remotely via teleconference is also of significant concern to Vision 2020 Australia’s members. While remote IAs may partially address concerns raised by members around workforce availability and thin markets, for people living with vision loss they are also likely to be more challenging to participate in effectively and may produce less reliable results.

This would be particularly challenging for applicants who are new to living with vision loss, as they are likely to struggle significantly to use screen reading or magnification software, therefore making the setup of a teleconference problematic.

Other factors that may limit the effectiveness of remote assessments include:

* The inability to incidentally observe applicants and recognise functional limitations, which the frame of a video call may not reveal.
* Poor internet connectivity, particularly in more rural or remote communities – the very communities where local assessors are least likely to be available.
* Issues of cultural safety, with Vision 2020 Australia members who work with Aboriginal and Torres Strait Islander Peoples indicating that remote IAs would not be culturally safe or appropriate for this cohort, since they offer less opportunity to build rapport with an applicant.

Vision 2020 Australia members recommend that remotely performed IAs be avoided for assessment of people with vision impairment, given a range of practical factors will likely limit their effectiveness and/or reliability.