

Vision Australia submission

NDIS Independent Assessments

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# Vision Australia submission – NDIS Independent Assessments

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## Introduction

Vision Australia is pleased to have the opportunity to provide this submission to the National Disability Insurance Agency regarding the introduction of independent assessments for NDIS participants. We understand that the implementation of independent functional capacity assessments is intended to deliver a simpler, faster and fairer approach to access and planning decisions. While we acknowledge that independent assessments may allow for greater equity of access to the scheme, Vision Australia has significant concerns that people with disability, as well as organisations with specialist knowledge of particular cohorts, have not been adequately consulted in the design of the assessment process, or in the selection of standardised assessment tools that are utilised. There has, to date, been no data to indicate the efficacy of the independent assessment process for low incidence disability cohorts such as people with blindness or low vision, who make up approximately 2% of scheme participants overall. While we believe the independent assessment process has the potential to lead to positive reform, this is only likely to be realised if there is extensive and ongoing consultation with participants, families and providers across the disability sector. It is vital that detailed information be provided by the Agency in order to clarify how assessments will work, how standardised tools will account for individual circumstances, and how information gathered as part of the process will be used to determine access and planning outcomes.

## Recommendations

* Both prospective and existing participants must have access to clear and sequential information about the steps involved in an independent assessment, so that they are informed and comfortable about what will happen at each stage of the process, who will be present, and the level of preparation they may be required to undertake prior. It is also essential that participants understand what level of choice, if any, they have around the organisations and individuals who conduct their assessments.
* It is crucial that all information provided both prior to and during the independent assessment be made available in as many formats as possible. Suitable options for people who are blind or have low vision must, at a minimum, include Braille, large print and audio.
* If access lists are removed, Vision Australia would be supportive of integration between Government systems, such that if legal blindness has already been proven for access to other services, this would also be sufficient to satisfy NDIS requirements concerning evidence of disability.
* Expertise and knowledge around the impacts of vision impairment is a key trait that we would want to see in an assessor. Even though the assessment tools themselves are standardised across disability types, it is necessary that assessors should understand the intersection between those tools and the common impacts on functioning which they are being asked to consider.
* Participants must also be able to include evidence from assessment reports from therapists who specialise in the persons disability, in our case blindness and low vision, as part of the assessment process. Specialist therapy staff not only have high levels of expertise but commonly have in-depth knowledge about a participants functional capacity formed over multiple years.
* It is crucial that all aspects of the independent assessment process are accessible. This includes access to information in the participant’s preferred format, accessibility of the venue and environment, and a clear understanding about the level of control that participants have over the assessment process.
* Transparency of process and an approach that supports ongoing participant engagement and feedback will be key in ensuring that both quality indicators and participant expectations are met. Independent assessments must be reviewable, in order to build trust and confidence in the framework. If a review process related to the independent assessment itself is unachievable, there must at least be independent and transparent monitoring of both independent assessors and the organisations that employ them, to ensure that quality standards are met.
* It is imperative that participants have access to the same information that their planning delegate receives about them through the assessment process. This should be provided to the participant and the planner at the same time, so that both parties can participate in planning discussions on an equal footing.

## Learning about the NDIS

### Question 1: what will people who apply for the NDIS need to know about the independent assessments process? How is this information best provided?

Both prospective and existing participants must have access to clear and sequential information about the steps involved in an independent assessment, so that they are informed and comfortable about what will happen at each stage of the process, who will be present, and the level of preparation they may be required to undertake prior. The information provided should include details about:

* How, when and by whom the assessment will be arranged;
* Who the assessor will be (including information about their professional qualifications, their employing organisation, and any choice the participant has to choose an alternative provider if they wish);
* Any preparation the participant may be required to do prior to the assessment, including details about how the process will work, the time taken to complete it and the types of questions the participant is likely to be asked;
* Any third parties who are required to participate in the assessment, along with details of the types of questions likely to be asked, so that the participant can make an informed choice about their nominee;
* Any support people that the participant may elect to attend the assessment with them;
* The impact the assessment has on the participant’s planning budget and options to review this if it is unsuitable;
* The level of access that participants have to the information recorded about them, including the ability to challenge it or seek an alternative assessment; and
* Additional documentation that may be appropriate to provide, along with information about how this is likely to be taken into account when determining a funding outcome.

Participants will need to have a clear understanding of how the standardised assessment tools are used to measure their level of functioning, as well as how the information gathered using those tools will influence access and planning outcomes. The term “functional capacity” and its application in a practical context will also require explanation, in order that participants are able to understand how the questions asked of them throughout the assessment process reflect the ways in which they manage daily tasks or implement support strategies across the various life domains. Additionally, if the observational component of independent assessments is to continue beyond trial phase, participants must be given clear information about how this will impact assessment results and consequent funding outcomes. Some Vision Australia clients who have participated in the independent assessment pilot have advised that the intended purpose of the observational task was not explained to them by the assessor. They were, therefore, unsure as to whether they should choose an activity with which they felt competent, or a task with which they would ordinarily require some level of support.

It is also essential that participants understand what level of choice, if any, they have around the organisations and individuals who conduct their assessments. It would be beneficial, for example, to profile individual assessors on the basis of their qualifications and experience, so that participants can make an informed choice about the providers they work with.

It is crucial that all information provided both prior to and during the independent assessment be made available in as many formats as possible. Suitable options for people who are blind or have low vision must, at a minimum, include Braille, large print and audio. However, for participants who have low levels of literacy, or have difficulty in reading and absorbing information independently, a conversation about the process with their LAC or chosen assessment provider may be more appropriate and should be offered. It is likewise important that assumptions about a person’s preferred information format are not made based on disability category, and should be confirmed with each individual prior to commencement of the assessment process. One participant who took part in the pilot found that it was presumed their vision impairment meant they would require materials such as prompt cards in large print. The participant in question was, in fact, a Braille reader, and failure to capture this data beforehand meant she did not have full and equal access to all of the information required during the assessment. Another participant was sent information by email prior to the assessment, which he was unable to access. No other effort was made to confirm key details with the participant, who therefore felt ill prepared on the day and was stressed by the assessment process before it had even commenced.

### Question 2: What should we consider in removing the access lists?

Vision Australia remains unconvinced that the removal of the access lists will result in a fairer and more streamlined NDIS access process for people who are blind or have low vision. People who are legally blind and have been for some time, often do not regularly visit a specialist in relation to their eye condition, because there are no mitigating treatments available or periodic checks to be conducted. If removal of the access lists results in these participants being required to seek specialist advice to provide evidence of disability, they will either have to wait for extended periods of time to be seen through the public health system, or incur costs of obtaining relevant reports. This seems counterintuitive, given that the onus and expense of providing evidence is cited by the NDIA as one of the complexities that the introduction of independent assessments was designed to avoid. If access lists are to be removed, Vision Australia would be supportive of integration between Government systems, such that if legal blindness has already been proven for access to services through Centrelink, or a state-based transport scheme, this would also be sufficient to satisfy NDIS requirements concerning evidence of disability. At the very least, it is essential that General Practitioners should still be able to certify legal blindness, in order to guard against unreasonable cost and delay for participants. Similarly, given the challenges often associated with accessing an ophthalmologist through the public health system, evidence from only one specialist should be required for vision impaired participants who are not legally blind.

### Question 3: 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?

Vision Australia’s primary area of expertise is in working with people who are blind or have low vision and as such, our comments are confined to this disability cohort. It seems reasonable that if a prospective NDIS participant has already qualified for the Disability Support Pension Blind, their disability is expected to be lifelong. There are also several eye conditions for which there is no cure that could reasonably be regarded as being permanent. Similar principles would apply in relation to deafblind participants, for whom neither hearing nor vision impairment is likely to improve.

### Question 4: How should we make the distinction between disability and chronic, acute or palliative health conditions clearer?

It is important to note that the presence of a palliative or acute health condition will not necessarily obviate the need for disability related supports. Vision Australia would suggest that the distinction between disability and a chronic health condition should be based on the functional purpose of the supports that are provided. Even for participants who need extensive medical support, the impact of vision impairment may nonetheless influence their functional independence and performance of daily tasks. It is important that those with chronic medical conditions are still able to access services through the NDIS to improve their skills and independence.

It would also be worthwhile for the NDIA to provide clearer information for both participants and health professionals as to what constitutes good evidence of disability. In our experience, participants with chronic health conditions often provide extensive reports about these, but overlook basic evidence around indicators of disability. There can be considerable overlap between disability and health related needs and the distinction between these is not always evident, either to participants or their treating medical professionals.

## Undertaking an Independent Assessment

### Question 5: what are the traits you most want in an assessor?

Blindness and low vision is a low incidence disability cohort, constituting approximately 2% of Scheme participants overall. Consequently, there is significant concern from both participants and organisations across the sector that independent assessors may not possess the requisite knowledge and experience to effectively engage with people who are blind or have low vision. Expertise and knowledge around the impacts of vision impairment is a key trait that we would want to see in an assessor. Even though the assessment tools themselves are standardised across disability types, it is necessary that assessors should understand the intersection between those tools and the common impacts on functioning which they are being asked to consider. If assessors do not have this level of knowledge and experience, there must be the facility to include evidence from other professionals with relevant expertise. The impact of this is likely to be compounded where the participant experiences dual sensory loss. For example, an assessor with expertise in blindness or low vision would not necessarily have extensive knowledge of hearing impairment, as it relates to deafblind participants. If assessors possess generalist disability knowledge only, there is also a risk that they may be biased towards the areas of interest associated with their allied health profession. For example, a deafblind participant who recently took part in the independent assessment pilot was assessed by a physiotherapist. The questions asked of her throughout the process related primarily to physical mobility, which while somewhat relevant, didn’t reflect the primary nature of her disability. The participant’s main area of support need was communication, and only one question relating to this was explored during the assessment. It is not unreasonable to suppose that, however unintentionally, the assessment may have been conducted in this way because it reflected the provider’s area of interest and professional expertise, rather than the participant’s situation and need.

### Question 6: What makes this process the most accessible that it can be? For example, is it by holding the assessment in your home?

It is crucial that all aspects of the independent assessment process are accessible. This includes information provided both prior to and during the assessment, such as prompt cards, questionnaires and other written materials. The participant’s communication preferences must be observed; a blind participant should not be forced to have materials read to them, for example, where their preference is to access the information in Braille independently.

Accessibility of the assessment venue is also a relevant consideration. Participants must have a choice about where an assessment is conducted. This does not appear to have occurred consistently during the pilot, with some of the Vision Australia clients we spoke with identifying that they were given no option as to where their assessment would take place. If participants choose somewhere other than their own home, alternative venues must be both physically accessible and able to be reached via the participant’s preferred mode of transport.

It is important that participants should be able to complete an independent assessment in an environment that is comfortable for them. While it may be the preference of many participants to have an independent assessment in their own home, it should be noted that this is also the environment that is likely to be best adapted to the participant’s needs, and where they will potentially exhibit their highest level of functioning. This would need to be reflected in results, and is demonstrative of the fact that it is necessary to ensure that participants are not unfairly disadvantaged by the environment in which their assessment is conducted. Similar considerations would apply for participants who are undertaking assessments remotely; it must be ensured that results and outcomes are not hampered because the assessor cannot observe the participant in a face-to-face setting.

Finally, it will be necessary for participants to understand how much control they have over the assessment process. This may include factors such as knowing whether the assessment can be postponed if the participant is unable to continue, understanding how the assessor will record information throughout and ensuring there is adequate time to clarify the process where needed. It is important to be aware that in many circumstances, participants may be inviting an unknown assessor into their own environment and this must be managed respectfully. One vision impaired participant who took part in the independent assessment pilot stated they were uncomfortable with how the provider managed the observational components of the assessment in their own home. The participant had chosen to take the bin out as her assigned task, but the provider, advising that he did not wish to accompany her outside to observe it due to his choice of attire for the day being unsuitable for the weather, requested that she choose something else. The participant felt uncomfortable completing the activity that was ultimately nominated, but given the nature of the assessment felt nonetheless compelled to comply.

### Question 7: How can we ensure that independent assessments are delivered in a way that ensures and promotes cultural safety and inclusion?

It will be particularly important to ensure that appropriate supports are available throughout the assessment process for participants from culturally and linguistically diverse backgrounds. This includes access to relevant information prior to the assessment in an appropriate language and format, as well as relevant support throughout the assessment itself and equal access to reported results once the process is complete. It may be valuable for participants to have access to bicultural workers, or someone who knows their history and language. This would help to ensure not only that cultural needs are met, but also that information is conveyed accurately. While interpreters or translators could be utilised for this purpose, it is important to recognise that they may not have the requisite understanding of disability or the knowledge and linguistic skills to accurately represent what is being said. It is noted that at times in the past, migrant services have been utilised as a link between the participant and the local area coordinator, as they had pre-existing knowledge of the participant’s background and situation. While this is unlikely to be appropriate across the board, it may be worthwhile to explore these options on a case by case basis. It is important that independent assessments for CALD participants are appropriately resourced through the tender process, as they will likely suffer a disproportionate disadvantage if appropriate supports are not made available. It may also be beneficial to consider whether additional support coordination hours should be offered for participants who have recently relocated to Australia and may not be intimately familiar with its Government systems and the differing avenues of support available.

## Exemptions

### Question 8: What are the limited circumstances which may lead to a person not needing to complete an independent assessment?

It seems reasonable that if the assessment process is likely to be traumatising to the participant to the extent that an effective result cannot be achieved, or if there is a reasonable risk of harm to the participant or the assessor, an exemption should be granted. Greater clarity must be provided, however, to detail how planning outcomes and overall quantum of funding will be dictated where an assessment cannot be undertaken. Vision Australia would prefer to see an assessment process which, although standardised, can nonetheless be adapted sufficiently to cater to a variety of client needs and situations. Participants must not be disadvantaged by their lack of capacity to engage with certain aspects of the access and planning process. If it transpires that there are high numbers of participants for whom the standardised assessment tools cannot be appropriately adapted, we respectfully suggest that more work to refine the assessment framework may be required.

## Quality Assurance

### Question 9: How can we best monitor the quality of independent assessments and ensure the process is meeting participant expectations?

Transparency of process and an approach that supports ongoing participant engagement and feedback are likely to be key in ensuring that both quality indicators and participant expectations are met. It is essential that the NDIA and its contracted assessment organisations work together to develop a continuous improvement model that is not simply driven by complaints. Participants must have the opportunity to provide meaningful feedback about the assessment process, and must be confident that there is a framework in place for that feedback to be considered and acted upon. All of the assessment pilot participants that we sought input from as part of this submission said they had been given no opportunity to provide feedback. One participant had called the Agency in order to do so, but was left with the distinct impression that it was not considered important and wouldn’t be passed on. A rating system that allows participants to review the quality of their assessment provider may also serve as a transparent indicator as to whether participant expectations are being met.

Vision Australia also believes that a transparent and reviewable process is key to ensuring that independent assessments meet the expected level of quality and result in the outcomes they are intended to achieve. We have grave concerns that, based on the information in the consultation paper, it appears that there is no intention to provide a review process related to independent assessments, or to give participants an avenue to seek input from an alternative assessor if they feel their needs have not been accurately captured or represented. This gives participants a clear indication that the agency sees the work of independent assessors as being beyond reproach or review, and this is likely to erode confidence in the process as a whole. The argument that independent assessments are not reviewable because they do not constitute a “decision” for the purposes of the NDIS rules seems a semantically perverse interpretation of the legislation, given the significant flow on impact those assessments will have upon plan budgets and funding outcomes. If a review process related to the independent assessment itself is unachievable, there must at least be independent and transparent monitoring of both independent assessors and the organisations that employ them, to ensure that quality standards are met. Data should also be published by the Agency to provide statistics around the average levels of funding that various disability cohorts receive once independent assessments are introduced. If these levels of funding exceed or are equal to those participants receive currently, this would help to build trust in the process and demonstrate that access to the Scheme is becoming fairer and more equitable as intended.

## Communications and Accessibility of information

### Question 10: How should we provide the assessment results to the person applying for the NDIS?

The Agency must give a clear commitment to provide timely information about independent assessments in the participant’s preferred format. For participants who are blind or have low vision, particular thought must be given to the ways in which information is presented. For example, where results are provided in graphical or tabular form, they should also be explained in the narrative of the report to ensure that those participants who cannot effectively work with visual information have the same level of access to the data that is presented about them.

It is also imperative that participants have access to the same information that their planning delegate receives about them through the assessment process. This should be provided to the participant and the planner at the same time, so that both parties can participate in planning discussions on an equal footing. The NDIS is based on the admirable principles of choice and control and it is important to ensure that these are not undermined by providing other parties with information about a participant that the participant themselves does not have, or cannot easily access. We do not consider it acceptable, for example, that participants may receive only a summary of their independent assessment, whilst the planning delegate has access to a full report. There is currently a lack of clarity in the information presented by the Agency as to whether participants will automatically be able to access their independent assessment results, or whether specific requests for this information will have to be made. This must be clarified before assessments are introduced, but Vision Australia would be supportive of the former option, so as not to increase stress and administrative burden upon participants. It is concerning that, of all the participants we sought feedback from as part of this submission, none have received a copy of their independent assessment results, and most were specifically advised that these would not be provided to them at all.

## Additional comments and Observations

Having perused all material made available by the NDIS concerning independent assessments, as well as seeking input from blind and vision impaired participants who have taken part in the pilot to date, Vision Australia has major concerns about the implementation of this strategy by the Agency.

Firstly, every blind or vision impaired participant who has provided feedback stated that they did not believe the assessor obtained a full and accurate picture of their functional capacity, based on the observational task they were asked to complete. In one case, a third party who attended the assessment noted that there were several safety issues associated with performing the task that the assessor, observing via videoconference, appeared unaware of. Vision Australia would question whether the observational task adds any meaningful data to the assessment results, particularly where it is not observed in a face-to-face setting. Many adults will find it demeaning to be asked to “perform” in this way, and the completion of one trivial task is unlikely to give any real indication of the person’s level of functioning on an ongoing basis. We are of the firm view that this component of the assessment process should be dispensed with, and that assessors should instead have a meaningful discussion with participants about how they manage daily tasks. This could take place in conjunction with the use of the assessment tools, so as not to unduly influence the standardisation of the process

Regarding the questions contained in the standardised tools, All of the participants we spoke with said that they felt the need to provide additional comments to explain their situation in relation to many of the assessment questions. All felt that the standard rating scale did not give sufficient context to their situation and the various disability related supports and strategies they use in daily life. Most participants also said the questions were ambiguous and poorly worded. Although participants were permitted to provide additional comments, all said they received no feedback or acknowledgement to indicate whether the assessor included this information or took it on board.

Finally, vision Australia is vehemently opposed to the need for all participants to elect a nominee to complete part of their assessment. We acknowledge that there are circumstances where this is appropriate, such as when conducting assessments for children, or where the participant does not feel able to answer all questions in their own right. For adults with full capacity who are capable of articulating their own needs however, the requirement for a nominee seems entirely superfluous. In most circumstances, the participants who provided feedback for this submission said they did not feel their nominee was well equipped to respond to the questions asked, and that they would have been better placed to provide this information to the assessor themselves. The fact that participants in the pilot are, in most situations, being requested to leave the room while a third party discusses their needs and level of functioning is both concerning and deeply offensive. Given that participant involvement in goal setting, planning and choosing services is instrumental to the scheme, it is disappointing to see this level of exclusion and ableism in the Agency’s approach to independent assessments. Input from nominees should be viewed as an optional component of the assessment, either where the age, capacity or preference of the participant deems it is required.

## Conclusion

Vision Australia thanks the NDIA for its consideration of this paper. We would be happy to provide additional information about any of the matters discussed in this submission.

## 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.