



Inquiry into NDIS Planning

Joint Standing Committee on the National Disability Insurance Scheme

6 September 2019

National body working in partnership to prevent avoidable blindness and improve vision care.

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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 change 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.

By working in partnership across government, non-government, private and community sectors, avoidable blindness and vision loss in Australia and our region can be prevented and treated and ensure that people who are blind or vision impaired of all ages, have equal access to services to support their independence and community participation.

For further information about this submission, please contact Vision 2020 Australia on policy@vision2020australia.org.au or 03 9656 2020.

Executive Summary

The introduction of the National Disability Insurance Scheme (NDIS) under the National Disability Strategy (NDS) has helped many Australians living with disability and improved their lives. Greater choice and control for people living with disabilities is strongly supported by Vision 2020 Australia's members, and for some people who are blind or have low vision, the NDIS has delivered substantial improvements in their lives. Our sector remains strongly committed to the aspirations of the NDIS and the potential it holds to transform the lives of people living with blindness, low vision or other disabilities.

There are, however, a range of fundamental system design and process issues that could be enhanced to better meet the needs of people who are blind or have low vision. People living with blindness and low vision represent a very small proportion of the overall number of Australians living with disabilities, and very specific assessments and services are required to best support their needs.

It can be challenging for staff charged with assessing the needs of all people with disabilities to understand their needs or what options might be available to support them. This has led to people with vision loss being refused supports and services that have been recommended by blindness and low vision specialists, without a clear rationale.

This is potentially further complicated by the ongoing developments in technology and supports for this group which, while offering them greater independence than ever before, can be challenging to keep abreast of. The progressive nature of some vision conditions also sets them apart from many of the disabilities commonly experienced in Australia.

Our members advise that some participants have met significant challenges in establishing plans, and subsequent supports, that appropriately meet their needs. In some instances, this has resulted in people who are blind or have low vision experiencing poorer outcomes or reduced quality of life than those experienced prior to the NDIS' introduction. For people experiencing progressive vision loss, the delays in plans have sometimes meant that by the time they receive supports they are no longer suitable: a dilemma that currently requires them to immediately commence the cycle again but does not allow their supports to ever 'catch up' to their needs.

The funding reforms that have underpinned the NDIS have also created practical challenges by exposing gaps between the disability, education and health systems. Our members report many examples of both children and adults who are blind or have low vision being unable to access the supports they might need because of ambiguities around which system should meet the associated costs.

Many people living with blindness or low vision can fully participate in school, the community and the workforce if they receive the optimum supports and services at the required times. This submission identifies some of the key challenges to be addressed to achieve this goal:

- Enhance the knowledge, experience and expertise planners and assessors about blindness and low vision and the supports and services they require
- Make more transparent the rationale regarding planning decisions
- Implement an integrated system wide planning for participants whose needs also span the education and health systems, to improve their outcomes and enhance system effectiveness
- Introduce greater flexibility in the planning and review processes to better accommodate the progressive and/or episodic nature of blindness and low vision.

This submission draws upon the collective expertise of the Vision 2020 Australia members, in particular its Independence and Participation Committee members (Committee membership is provided at Attachment A). It addresses nine of the terms of reference for the inquiry, and identifies eight possible solutions to address some of the challenges identified.

While there is a separate response to most terms of reference, many of the issues and potential solutions span multiple terms of reference. This means that a number of the possible solutions could potentially address the issues raised under several of the terms of reference, as summarised in Table One, overleaf.

It seeks not just to highlight the challenges, but to identify areas where Vision 2020 Australia believes it can bring its members together to work towards practical improvements that enhance the lives of Australians living with blindness or low vision, now and into the future.

At the heart of the suggested solutions is a genuine desire of the blindness and low vision sector to work collaboratively with the NDIA and government to see the NDIS reach its full potential for people who are blind or have low vision. The sector stands willing and able to work collectively to help design, implement and support changes that will make a real difference to those participants

Table One: A number of solutions can address challenges identified in multiple terms of reference for the Inquiry

Potential Solutions	ToR A	ToR B	ToR C	ToR G	ToR H
Enhance operational guidelines	X		X		
Enhance training and development	X		X		
Trial blindness and low vision hotline	X		X		
Increase flexibility of process		X			
Engage planners with specialist assessment		X			
Embed consultation before making funding				X	
Funded providers generate information that assists in review processes					X
Introduce “standard therapist hours”					X

Response and Recommendations to the Terms of Reference for the Inquiry

Vision 2020 Australia, the national peak body for the blindness and low vision sector, welcomes the opportunity to make a submission to this Parliamentary Inquiry.

Over 20 organisations involved in blindness and low vision services are members of Vision 2020 Australia, and many other member organisations also have a strong interest.

Vision 2020 Australia's works with its many members to advocate for changes that can achieve the full participation of people who are blind or vision impaired in the community.

The National Disability Insurance Scheme has a critical role to play in achievement of this goal and Vision 2020 Australia and its members are strongly committed to the principles of choice and control that underpin the scheme.

ToR A: The experience, expertise and qualifications of planners

ToR C: The ongoing training and professional development of planners

Vision 2020 Australia members have cited many examples of NDIS plans demonstrating a lack of understanding of blindness and low vision by planners or partners. This includes content that indicates little understanding of:

- the functional impact of vision loss and its variability
- the availability of low vision aids and equipment to help reduce functional loss
- which supports and services will have the greatest impact in improving quality of life
- the episodic nature of vision impairment.

Applying this knowledge to the planning process is critical to ensuring people who are blind or low vision receive the appropriate supports for their condition.

However, Vision 2020 Australia members report different NDIS planning outcomes for participants with same/similar conditions and circumstances, despite a comparable standard of specialist assessment and accompanying evidence being provided to demonstrate the need for the recommended supports. This variation suggests there are opportunities to enhance operational guidelines and/or the knowledge and expertise of planners.

Enhancing guidelines and training

The sector is keen to work with the NDIA to develop opportunities to enhance planners' understanding of the varied functional impact that vision impairment can have on daily living of people with blindness or low vision. The sector already has wide-ranging

resources and online training options which provide information on the range of supports and services that are available, and the roles of different specialists that work within the blindness and low vision space.

There would also be merit in equipping planners with additional information about the roles that a range of expert practitioners play in relation to blindness and low vision services.

Trialling an expert hotline for planners

It is recognised that planners have a broad and complex task in seeking to support the planning of services and supports for a large and diverse group of participants.

It is thus timely to think about whether there could be external supports established that enable planners to access advice and information from technical experts to ensure they are well equipped to both understand the needs of people who are blind or have low vision and appropriately work with them in developing meaningful, appropriate plans. This would allow planners to be better supported in their roles by giving them access to information they can utilise in their work, rather than expecting them to know and maintain current knowledge pertinent to the diverse mix of participant disabilities.

As there are a relatively small number of participants who are blind or have low vision in the NDIA and there is scope through Vision 2020 Australia to support development of such a cross sector approach, an initial trial in the blindness and low vision sector would allow the NDIA and government to test such an approach on a modest scale and assess to what degree such supplementary supports could enhance planners in meeting diverse participant needs.

Potential solutions

1. NDIA work with Vision 2020 Australia members to identify areas where evidence based, operational guidelines could be developed to assist planners in effectively assessing and responding to the needs of people who are blind or have low vision
2. NDIA to enhance training and development opportunities for planners, collaborating with Vision 2020 Australia members to ensure that this training is informed by and draws on the expertise of existing sector specialists
3. Trial a blindness and low vision 'hotline' that planners could utilise to access specialist information that allows them to effectively engage with people who are blind or have low vision and source information about currently available services and supports that may require consideration.

ToR B: The ability of planners to understand and address complex needs

Within a broad system of disability supports, the needs of people who are blind or have low vision can be considered to be complex as:

- There is significant variation in what constitutes appropriate and necessary supports for participants, because both their visual conditions and their activities and environments differ
- Some of the conditions, the needs, and the 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, but current funding and planning models don't really accommodate these
- A range of visual conditions are progressive and so delays in access supports and/or required training for participants can result in those supports no longer being suitable, or in some instances, the opportunities for people to complete training that would help them better manage their further vision loss are lost.

People who are blind or vision impaired have varied needs for key supports, which will differ according to how they spend their time and the things they want to do, as well as the characteristics of their visual condition.

Some of those supports may be ongoing, but alongside these, episodic or ad hoc supports may also be needed. For example, if a person moves house, starts a new job or starts using a new piece of assistive technology, assistance from occupational therapists, orthoptists or orientation and mobility instructors, for example, may be required.

In some instances, a participant's vision loss may be progressive, and their needs change over time, providing a system that enables that variation to be effectively identified and responded to is essential as is the ability to understand that in some instances because conditions are progressive, an increase in functional capacity over time may not be readily achievable and the goal is to keep participants as independent as possible despite potential decline in their vision.

Securing timely access to appropriate and necessary supports for participants with progressive conditions is important as delays in planning and approval can mean that by the time participants receive the supports and services originally identified, they are no longer appropriate for their level of functional capacity. There is also the potential for training opportunities for participants with progressive visual to be lost if there are significant delays, as in some instances they need a certain level of vision to be able to readily complete the training.

Increased flexibility in the use of available funding and potentially providing some funds for early intervention while the full planning process is completed could make a significant difference in these circumstances, for example, the ability to reallocate funding from different support categories without a formal plan review would be one way of providing increased flexibility for participants to respond to their changing needs or training requirements.

Due to the factors outlined above, people living with blindness or low vision can thus significantly benefit from assessment by specialist staff prior to establishing or revising

their plans. Review and acceptance of a specialist assessment will greatly assist planners to better understand and address the complex needs of clients, and to consider their future.

Potential solutions

1. Increase flexibility throughout the planning process to make it easier for participants to respond to changes in their functional capacity by reviewing the supports and services they require.
2. Engage planners in the specialist assessment process prior to plan establishment or review so that they understand the basis for recommended reasonable and necessary supports.

ToR E: Participant involvement in planning processes and the efficacy of introducing draft plans

Vision 2020 Australia members strong support a central role for participants in the planning process, but note that participants who are blind or have low vision sometimes feel that they are not adequately consulted or supported throughout the planning process.

Member organisations report that a practical consequence of this in some instances is that participants have found that supports and services, particularly pieces of assistive technology, have been removed or substituted in plans against specialist eye health professional advice and without their consultation.

Empowering participants with vision loss to effectively self-advocate for the supports and services they need is critically important, particularly given they will often have a deeper understanding of the specific supports that are available.

The rationale for developing draft plans as a starting point for the planning process is recognised, however the breadth of presentations, underlying conditions and individual preferences and priorities may make these difficult to apply in the area of blindness and low vision.

The sector would be keen to assist in the development of any such guidance or materials if this were to be pursued, to ensure they are fit for purpose.

ToR G: Reassessment process, including the incidence and impact of funding changes

Sudden and unexpected changes to funding levels can have a severe impact on participants who are blind or have low vision. It can lead to people being no longer able to support themselves independently throughout their activities of daily living.

The sector has advised that changes in funding levels for people who are blind or have low vision commonly occur due to a number of misconceptions:

- Lack of recognition of the deteriorating nature of progressive eye diseases can lead to supports or services being altered unnecessarily or at the wrong time
- Children with vision loss accessing early childhood early intervention have had their plans reduced on the basis that they have already received a year of interventions and would not require further funding, which demonstrates a lack of understanding of changing developmental needs and milestones.

These unilateral changes to funding levels has a negative impact on participants as they are forced to continually seek plan reviews and contest these changes, rather than receiving the benefits of accessing the supports and services they require.

Potential solution

1. Amend processes to embed consultation with participants and specialists before a decision is made to amend funding levels.

ToR H: The review process and means to streamline it

Vision 2020 Australia members report that the review process can be onerous and would welcome changes that streamline the process but also ensure participants have continued access to the support they need.

One suggestion made was that all providers paid to deliver a service provide a standardised report that notes the outcomes and identifies recommendations for the future, which might reduce the need for participants themselves to re-tell their stories and could also allow for greater preparation in advance of a review. This may also reduce the need for Planning review reports.

Another method of streamlining the review process would be to potentially introduce, “standard therapist hours,” that go into a plan on an annual basis, when the participant’s primary disability is low vision or blindness. This would help to reduce the anxiety of a plan review and needing to retell your story by providing reassurance the participants critical supports will be present.

Potential solutions

1. Explore options to have funded providers generate key information that could assist in review processes and reduce the time and documentation required at review.
2. Review the possibility of including a mechanism such as, “standard therapist hours,” to provide greater reassurance to participants.

ToR J: The circumstances in which plans could be automatically rolled-over

ToR K: The circumstances in which longer plans could be introduced

For adults whose vision impairment is non-progressive and whose lifestyle is not changing significantly, plans could be automatically rolled over or longer plans introduced, if the participant elects for this to occur.

Ensuring that the participant is empowered to exercise choice and control over whether their plan is automatically continued or extended must be central when considering this option.

There may also be circumstances when it is evident that a participant has not used all of their approved hours but is working towards a goal or outcome. If the participant decides that they wish to continue pursuing this goal and feel that they are adequately supported by their current plan, then they may wish for it be rolled over.

It is also recommended that increased flexibility to revise unexpected changes for participants on long-term plans be considered a priority so that wait times for any changes to supports and services would be minimised.

ToR L: The adequacy of the planning process for rural and regional participants

The lack of access to planners experienced in the needs of people living with blindness and low vision is exacerbated for those living in rural and some regional centres.

They may experience significant delays for required appointments which can negatively impact their overall outcomes, they may also have to travel long distances for appointments which can cause logistical challenges and increased costs.

Case studies

Case study/Example 1

RIDBC has had several clients who have transitioned from the early intervention NDIS funding packages that have had significant reductions in their packages. E.g. One participant had a \$22,000 package reduced to \$11,000 in their review plan when they transitioned to school.

The reason provided by planners for the reduction included, “the child was going to school and was no longer requiring support for early intervention.” Funding of wheelchairs and other positioning equipment that enables the child to participate in-home and community activities have also been common items that have not been included in these participants review plans once they have turned seven years of age.

Early intervention helps to provide the foundation skills required for a child’s ongoing development and learning. The support needs of a child with vision impairment may change when they transition to school, however these continue to be ongoing and significant. There are significant areas of development that vision impairment can impact on which require support outside of the school curriculum to enable the child to fully and meaningfully participate in home and community life.

As the child grows, their equipment needs will also need to be reviewed to ensure they are positioned for optimal visual function across all daily activities such as mealtimes, bath time, recreation and leisure.

Case study/Example 2

The Royal Institute of Deaf and Blind Children (RIDBC) has recently witnessed the impact of NDIA planners not fully understanding the key role of the orthoptist in conducting functional vision assessments. This includes both children who are seeking access to NDIS, and those with NDIS funding, who are having their plan reviewed to reflect their changing needs as they progress through early childhood.

Orthoptic assessments provide the NDIA planner with information relevant to building appropriate plans. These orthoptic assessments focus on reporting functional information related to daily activities that is age and activity appropriate.

Previously, orthoptic assessments have been included in the application for Capacity Building Supports, and these assessments have been approved. However, recently families have reported to RIDBC that Early Childhood Early Intervention partners and Local Area Coordinators have denied funding for the inclusion of orthoptic assessments in new and reviewed participant plans. When families have questioned this decision, clarification has been sought from senior team leaders within NDIA.

Families have been informed that such orthoptic assessments are the responsibility of the health system. It has also become apparent in several recent review planning meetings that the planners were not aware of orthoptists and queried whether this was a new profession.

Attachment A – Vision 2020 Australia Independence and Participation Committee Membership

- Australian College of Optometry
- Blind Citizens Australia
- Blind Welfare Association of South Australian Inc.
- Brien Holden Vision Institute
- Centre for Eye Research Australia
- Glaucoma Australia
- Guide Dogs Australia
- Guide Dogs Victoria
- Optometry Australia
- Retina Australia
- Royal Institute for Deaf and Blind Children
- Royal Australian New Zealand College of Ophthalmology
- VisAbility