



Submission to the National Disability
Insurance Scheme

Supporting Young Children and their Families Early, to Reach their Full Potential

February 2021



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

The NDIS is currently undergoing a significant program of reform in response to feedback from participants, the recommendations from the Tune Review and other identified opportunities for improvement.

Vision 2020 Australia appreciates the chance to comment on the consultation paper *Supporting young children and their families early, to reach their full potential*.

As that paper recognises, there are opportunities to enhance current arrangements and Vision 2020 Australia members have identified a range of actions that would help ensure that any reforms deliver improvements for children living with vision loss. These include:

1. Testing the tools intended for the tailored ECEI independent assessment process through a pilot process similar to the one in progress in the general scheme, ensuring children with vision loss are included.
2. Collaborating with the blindness and low vision sector to ensure planning and access decisions in the ECEI context are informed by the complex and variable nature of vision loss, and prioritise preventing developmental delay.
3. Creating clearer guidelines about what supports should be provided by the NDIA, and what supports should be delivered by state education systems.
4. Ensuring any new reporting obligations introduced following this consultation are appropriately funded for service providers.
5. Routinely including support coordination in plans for children with vision loss, in order to maximise plan utilisation, improve support for families and encourage accessing of mainstream supports where they are available.
6. Resourcing Aboriginal Community Controlled Health Organisations (ACCHOs) to provide supports and services, such as support coordination and independent assessments, for Aboriginal and Torres Strait Islander children with vision loss and their families.
7. Considering how large group peer support activities such as camps could be funded through plans of attending children.
8. Allowing telehealth training as an option for some supports, while retaining in person delivery of support for Aboriginal and Torres Strait Islander children and families as well as independent assessments for all children.
9. Supporting stable and reliable internet for children with vision loss and their families through NDIS plan funding when it is not easily accessible otherwise.
10. Including communication between service providers as one of the principles for best practice in the ECEI process, and ensuring appropriate funding is available to facilitate this.
11. Ensuring that any new obligations and rules designed to encourage best practice do not result in children with vision loss being unable to access necessary supports.

General Questions

Consultation Question: Do you have any specific feedback in relation to:

- **the increased focus on STEI outside of access to the Scheme**
- **the proposed increase in age range for the EC Approach from under 7 to under 9 years of age,**
- **the desire to see more successful transitions from the Scheme to the next state of life.**

Optimising STEI for Children with Vision Loss

Vision 2020 Australia member organisations who provide services to people who are blind or have low vision emphasise how important timely intervention is to equip people to effectively manage the impacts of their vision loss, and prevent adverse (but avoidable) consequences.

This is particularly so for children who are born with, or develop, vision loss, because without appropriate supports, that vision loss will interfere with their development. Vision 2020 Australia therefore strongly supports the NDIA's priority of improving access to Short Term Early Intervention (STEI) supports outside the scheme.

In implementing this new approach, however, the NDIA needs to ensure that there is clarity around the resources available and how these can be used. This is important, as there have been past experiences in which families accessing new and unfamiliar systems through STEI have not been clear about what can be provided and/or service providers have not been reimbursed for STEI services provided in good faith.

To deliver on the true potential of STEI, it is essential that there be capacity for:

- Children with obvious functional impairment to access such supports while a medical diagnosis is being sought (for example, where there is a significant reduction in vision for which common causes have been eliminated but a full diagnosis has not been confirmed) and
- They are assessed at being at significant risk of developmental delay because of that vision loss, although the delay itself may not yet have manifested.

Vision 2020 Australia's members believe the ECEI process is a great opportunity to reach children with permanent vision loss more quickly, and begin the adjustment process for a child and their family as soon as possible. Our members are eager to work with the NDIA to optimise system settings for this cohort, by:

- Educating decision-makers about the variety of vision conditions and their causes and symptoms.
- Establishing the appropriate trigger points for referral to the NDIS by medical practitioners, and promoting these.
- Ensuring that experts are accessed as early as possible in order to ensure a child's functional capacity is appropriately assessed.
- Creating alternative criteria to medical diagnosis for children who need STEI supports but whose cause of vision loss hasn't yet been established.

Increasing Age Limit for ECEI Access

Vision 2020 Australia's members broadly support the increase in age limit for the ECEI process. While it is not clear how it would play out in practice, benefits potentially include:

- More timely introduction of supports for children with vision loss without complex and burdensome entry processes for families during a period of transition.
- Better capturing of milestones in a child's development by clinicians in order to establish needs.

There is however the need to ensure that such changes do not adversely impact on the support children should be eligible to access via state and territory education systems. There is already a lack of clarity in the roles and responsibilities between the disability and education systems when it comes to support for children with disabilities, and there is a risk that this could be exacerbated.

To address this and deliver on the promise of the reforms, it would be timely for the NDIA to take the opportunity to create more specific guidelines regarding which supports the NDIS will fund for children who also need support in school.

It should also be noted that there are variations in the level of resourcing provided through state and territory education systems for school aged children with disabilities. A national approach that ensures that every child experiencing disability receives the support they need, when they need it, regardless of where they live is essential to minimise the risk of developmental delays.

The NDIA is encouraged to consider how it could better support this outcome through its current reform process, recognising the complexity and interface issues.

Transition Process for People with Vision Loss

Consultation Question: How can we make the process of transitioning out of the NDIS something to celebrate?

Vision 2020 Australia understands the desire to facilitate more children building their capacity to the extent that they will no longer need supports, but this is largely not possible in relation to vision impairment, as the majority of vision conditions appearing in children are not correctable.

There is no current method to build the capacity of a child with vision loss to the extent that they will no longer need support and thus the NDIA should assume that children with vision loss will usually travel through the ECEI pathway toward long-term access to the scheme.

Terminology

Consultation Question: How can we help families and carers better understand some of the terms the NDIA, and Early Childhood partners use?

While it is necessary in the longer term for all participants to understand the principles that underpin the NDIS, the ECEI process is designed to capture a specific group of people at the beginning of their journey.

Overall awareness of how people live with vision loss remains low, so the families and carers of children with vision loss often seek to absorb a great deal of new information in order to see the shape of their child's future.

Vision 2020 Australia's members therefore suggest that in its communications with families and carers in the ECEI space, the NDIA should:

- Minimise the use of terms which are not generally well-understood outside the disability sector (e.g. capacity building)
- Focus on simple messages about support. "The NDIS/STEI is here to help your child achieve their goals and live the life they choose".
- Explain the term "natural settings" as any place where a child spends time. Many parents of children with vision loss will be eager to hear that the NDIS intends to minimise a child's segregation from their peers and communities and prioritise integration where possible.

Support with Achieving Goals

Improving Goal-setting Processes

Consultation Question: What is the best way for us to check in with families and carers on how their child is tracking to meet the goals for their child?

Vision 2020 Australia and its members support the NDIA's intention to improve processes for goal-setting and measurement of outcomes within the ECEI space. This could include a mandatory early childhood provider report, as referenced in the NDIA's consultation paper. However the introduction of any new systems should:

- Avoid duplication of other reporting obligations.
- Provide appropriate funding for service providers to complete their obligations.

Vision 2020 Australia's members strongly believe the goal-setting process should be family-centred, but informed by conversations with experts in blindness and low vision, because families will not always have a strong knowledge of what is possible and how long it should take.

Identified learning and development goals for this cohort should be achievable but appropriately ambitious in order to make best use of the ECEI process.

Accessing Mainstream Supports

Consultation Question: How can we better support families to connect with services that are either funded or available to everyone in the community?

Over many years, Vision 2020 Australia's members have found that the majority of parents of children with permanent vision loss are very eager to see children access mainstream supports and services wherever possible.

This appears to be due to the general perception that integration is both a priority and a sign of positive progress. When a child with vision loss is not being directed toward supports outside the NDIS, this can often be because these options have been found unsuitable and an NDIS support is the most suitable to the child's situation. It is essential that any messaging or advice is able to accommodate this nuance, particularly as those being referred to disability specific supports are usually those who most need them.

It is also true that some families aren't aware of mainstream options available to them. Some opportunities to improve awareness of mainstream alternatives to NDIS supports for ECEI participants with vision loss include:

- Better deployment of ILC funding toward this purpose

- Creation of peer support groups (see below)
- Routine inclusion of support coordination in plans for children with vision loss.

This is another area where the lack of clarity between the education and disability interface can pose significant challenges.

Vision 2020 Australia members have observed that families of children with vision loss will sometimes make the choice to learn and focus on one system rather than attempting to navigate two, along with the additional challenges of understanding impacts of vision loss, and learning to act as an advocate on a child's behalf.

Clarifying this interface would help ensure that children and their families who are experiencing significant disability that impacts their education and learning can be better supported to manage those impacts and achieve their learning aspirations.

Targeted Supports

Telehealth Support for Rural and Remote Participants

Consultation Question: If you live in a remote or very remote part of Australia, what are some ideas you have on how we can get early childhood supports to work in your community or communities like yours?

Vision 2020 Australia's members understand the need for delivery of supports, services and training via telehealth to children who are blind or have low vision in rural and remote locations. In some cases this may be the best solution to problems specific to the sector, including:

- Extremely low prevalence, meaning training large numbers of workers is inefficient.
- Thin markets and risk of market failure
- The highly specific nature of supports required.

Often a high-quality video connection will be the most reliable method of tracking and measuring a child's progress. The rural and remote areas in which telehealth service provision is most necessary are also the areas in which internet connectivity is most costly and least consistent.

In [our submission to the Department of Social Services](#) in relation to the development of a new National Disability Strategy, Vision 2020 Australia advocated for the acknowledgement that all people with disabilities require reliable, affordable internet access. This echoes the more detailed proposal in [the submission by ACCAN](#) during the same process.

Both of these submissions provide more information about how this might be partially or completely achieved, but one suggestion was that the NDIS should fund the provision of internet to people with disabilities in specific circumstances. Vision 2020 Australia's members propose that, given the issues mentioned above, vision loss in children should be considered one of those specific circumstances. Ensuring internet connectivity would also facilitate better peer-to-peer connections within this community, as discussed further below.

There are some forms of training and support which are likely not deliverable via telehealth. In these instances, the NDIS should fund the facilitation of face-to-face support, by subsidising travel either for a specialist trainer or for a participant and their family.

Members also report that the provision of supports and assessment processes via telehealth should not be considered culturally safe for Aboriginal and Torres Strait Islander Children living with vision loss. In these situations, the building of rapport with a child and their family is crucial, and during this transitional period this is only achievable in person. Vision 2020 Australia thus encourages the NDIA to ensure that Aboriginal and Torres Strait Islander community controlled organisations are funded and resourced to provide assessment, supports and other services to Aboriginal and Torres Strait Islander children with vision loss.

While recognising the important role that remote service delivery can play, Vision 2020 Australia does not support its use for the provision of independent assessments remotely as that is unlikely to provide full or reliable results. Please see our separate submission relating to the NDIA's proposed access and eligibility policy and independent assessments for more detail regarding this.

Improving Peer to Peer Support for Families and Children

Consultation Questions: How can our Early Childhood partners and mainstream services best support peer-to-peer connections?

Are you interested in helping us co-design an approach that would make peer-to-peer networks easier to find and join for people?

Vision 2020 Australia's members are eager to work with the NDIA to better facilitate the provision of peer support for children with vision loss. This can be particularly vital for this cohort, because:

- Since their prevalence is so low, many will meet another child who is blind or has low vision for the first time through such a process.
- Peers of a similar age can inspire one another to learn and develop.
- Families can view positive examples in other children and find support in other families.

A variety of innovative programs exist or have operated in the past to connect young children with vision loss. These can include day activities, but some of the most effective examples have been camps which children can attend to learn valuable skills such as orientation and mobility or assistive technology. This is particularly important for children living in remote or rural areas, where speaking to children with blindness or low vision can be difficult or impossible.

The NDIS has not been an ideal setting for funding of these programs due to the focus on small groups and/or one-to-one supports. Many of these programs have relied significantly on philanthropy, and are now extremely fragile following the instability caused by the COVID-19 pandemic.

Given that this is a shared priority, Vision 2020 Australia and its members are eager to work with the NDIA to investigate how the plans of ECEI participants could be used to help them access these services, as well as whether the NDIA has an opportunity to help promote them.

While this is not a complete solution, in an era where travel presents unusual risks, Vision 2020 Australia believes that reliable internet connections are profoundly essential to children with vision loss and their families, some of whom are feeling isolated and cut off from people who can share their experiences. We therefore suggest that the NDIA should view quality, reliable internet as a necessity for this cohort, and fund it in plans in cases where it is not easily available.

Children and Families with Vulnerability

Consultation Question: How can we better reach and get support to young children and families who experience vulnerability and remove barriers so they can receive outcomes in line with other children and families?

Vision 2020 Australia's members appreciate the NDIA's clear priority of creating a scheme that is more equitable. If the independent assessment process works as intended, this could help improve outcomes for children and families by diminishing the financial and time burden of evidence gathering.

The best way to make the NDIS as inclusive as it can be for children with vision loss and their families is to remove access barriers, and minimise burdensome assessment processes. Our previous recommendations will all improve the scheme's accessibility to everyone.

Some options to consider that might further support vulnerable children with vision loss and their families include:

- A psychosocial assessment, performed by a qualified social worker, as part of the ECEI entry pathway
- Acknowledgement of the benefits of including social work in the plans of children who are vulnerable.
- Promotion of the NDIS at other touchpoints for vulnerable children (E.G. family violence, mental health or financial assistance organisations).
- Funding of internet access for children with vision loss and their families where other barriers render it inaccessible.

Tailored Independent Assessments Approach

Consultation Question: Do you have any feedback on this recommendation and/or any suggestions on how this proposed approach would work best for young children and their families/carers?

The vision sector has consistently seen and reported that in cases where knowledge of vision loss is insufficient, participants have often received sub-optimal supports, or even been denied supports recommended or prescribed by specialists.

The introduction of independent assessments (IAs) is the most significant change to NDIS eligibility and planning processes since the scheme's inception. As previously mentioned, some children with vision loss have been denied supports because assessment processes have not demonstrated developmental delay.

The creation of a tailored IA process for children with vision loss represents an opportunity to ensure that assessments recognise the value of avoiding such developmental delay through the introduction of supports when they will produce maximal benefit.

It is understood that IAs for the ECEI cohort are to be conducted by Early Childhood partners themselves rather than the independent assessment workforce proposed for other participants. Vision 2020 Australia strongly supports this approach. To create a system wherein IAs can capably measure functional capacity, and capture early intervention opportunities, children with vision loss should wherever possible have their independent assessments performed by experts in blindness and low vision.

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.

While it is envisaged the second pilot of IAs will yield information about how the assessment tools for intended use in the general scheme will work for this cohort, appropriate testing of the tools intended for use in the ECEI process hasn't yet been conducted.

Vision 2020 Australia's members recommend that a pilot process, similar to that conducted for the general scheme, be completed before IAs are introduced into the ECEI process, and that the NDIA ensure that children with vision loss are included in this pilot.

Vision 2020 Australia seeks further discussion with the agency so that we can pool our expertise to ensure the final tools are suitable for use with children with vision loss.

Greater Transparency on Providers for Best Practice

Vision 2020 Australia and its members support the NDIA's intention to ensure that service providers are delivering best practice.

The consultation paper notes the necessity for "appropriately qualified professionals" to deliver services and supports. Vision 2020 Australia reiterates that due to the low prevalence of blindness and low vision, best practice for this cohort must involve treatment and recommendations from people qualified to understand their needs.

It is understood that provision of all supports by these specialists is not possible, but the NDIA must work with the blindness and low vision sector to facilitate this wherever it can be achieved. Priority areas include:

- The delivery of independent assessments for children with vision loss by specialists in their disability
- Facilitation of travel by children and their families or by specialists such as occupational therapists and orientation and mobility instructors for training purposes
- Continued flexibility to allow provision of training via telehealth, where the delivery method will not impact the quality of training.

Children who are blind or have low vision are often supported by a number of service providers working in collaboration. Vision 2020 Australia has found that a crucial element of best practice, especially for young children, is consistent communication between these service providers. This communication would ensure that:

- A. A child's supports and needs are accurately recognised.
- B. Families do not face the extra burden of acting as a liaison between stakeholders.
- C. Work is not replicated.
- D. Supports are complementary and work toward the same goals.

Unfortunately, service providers in the vision sector have found that this communication has not always been sufficiently funded by the NDIA despite its essential contribution to the effective support of the child.

Vision 2020 Australia recommends that the ECEI process include communication between service providers as one of its principles of best practice, and prioritise improving funding for this communication in the development of the new ECEI process.

Consultation Question: Who would be best placed to lead the development of, and manage, any additional complementary mechanisms?

Vision 2020 Australia believes the NDIS Quality and Safeguards Commission is the agency best equipped to oversee the improvement of best practice delivery within the ECEI process.

Consultation Question: What do you think of the following ideas for potential mechanisms? What are the benefits or concerns with these potential mechanisms?

- **Provide greater information to families about the benefits of using providers registered by the NDIS Commission.**

This would be largely beneficial, with the qualification that particularly in rural and remote areas, no NDIS providers exist. Participants should clearly understand that using other service providers in these instances is permissible.

- **Establish an industry-led 'best practice accreditation system'.**

This would seem to replicate systems already in place. All allied health professionals already must demonstrate their accreditation and ongoing professional development and ideally, any additional quality assurance arrangements would leverage existing processes rather than duplicating them.

It would be important that the cost of any additional reporting or accreditation obligations for service providers be reflected in increased funding to meet these costs, as these systems add to the cost of service delivery.

- **Establish a 'quality feedback / rating system'.**

In our submission regarding the NDIA's access and eligibility policy, Vision 2020 Australia recommends an innovative system wherein participants can offer positive feedback about their independent assessors.

Such a system could potentially also be used to provide feedback around service providers. This would be in keeping with the principles of choice and control which are fundamental to the NDIS, and would offer a unique channel via which families could ensure children are receiving the best possible service.

- **Make registration with the NDIS Commission mandatory for all providers operating in the EC space.**

This could be restrictive because some service providers, particularly in rural and remote areas, may for a variety of reasons not have capacity to register with the NDIS.

Vision 2020 Australia recognises the importance of ensuring all service providers are held to similar standards, but given the problem of thin markets, it is vital that children not be unable to access necessary supports because of where they live.

- **Require self and plan-managed participants in the new Early Childhood approach to use only registered providers.**

While it is vital to ensure children are receiving appropriate quality services, Vision 2020 Australia believes this step would be restrictive for people who are blind or have low vision.



There are some low-cost AT items which can be purchased from mainstream settings, which has previously been possible through the consumables category in a participant's budget.

It is vital that this flexibility be retained, so that children with blindness or low vision don't face inefficient wait times for inexpensive but essential equipment.

Additionally, as mentioned above, while it would be ideal for all supports and services to be offered through registered NDIS providers, it must be acknowledged that this may not yet be possible, particularly in rural or remote areas. While ensuring that children receive best practice services is essential, Vision 2020 Australia recommends that the NDIA does not impose restrictions on children and families which might arbitrarily limit their ability to access the supports they need as quickly as possible, in keeping with the priorities of the Early Intervention process.