

Vision Australia submission

NDIS ECEI Implementation Reset

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Submission approved by: Karen Knight, General Manager Client Services

# Early Childhood early intervention (ECEI) Implementation Reset

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## Introduction

Vision Australia is pleased to provide this submission to the National Disability Insurance Agency (NDIA), as part of the Early Childhood Early Intervention (ECEI) reset. This review has the potential to improve access pathways and availability of early intervention supports for children and families. We do, however, have major concerns about the introduction of independent assessments for children under 7. If not implemented with due care and consideration, these assessments have the potential to severely disadvantage children who are blind or have low vision and lead to poorer developmental outcomes overall.

## Recommendations

* Vision Australia has a number of current clients who would benefit from increased access to short-term early intervention outside of the NDIS, however, we feel it is unlikely that ECEI partners will possess the specialist skills necessary to provide all of these services. Any modifications to the STEI access process must be supported by a clear pathway for families. Parents often have limited knowledge of the services available at their child’s point of diagnosis, and they need to be supported with a referral process that operates effectively across both the health and disability sectors.
* Vision Australia is broadly supportive of the proposed age increase for early intervention services, as it may provide additional time to finalise a diagnosis for some children. It may also allow for improved consolidation around assistive technology and compensatory skills, as the need for these often increases as activities at home and school become more demanding.
* It is important to ensure that children and families are not prematurely shut out of the NDIS because their need for support fluctuates. Even if children and families are transitioned out of the scheme, ongoing monitoring must occur to ensure they can continue to access relevant supports and that they have a pathway to re-enter the NDIS if required.
* It is important that families are encouraged to play an active role in setting goals, as well as having input into whether they have been met. Reporting and goal setting processes must be able to accommodate families with varied levels of engagement.
* Vision Australia believes there is value in collaborative early childhood reporting, however, if this is mandated, funding must be provided for it as a stated support in the child’s NDIS plan. Families should not be expected to cover reporting from a child’s therapy funding, and many are currently reluctant to do so, due to the limited support hours available to them.
* There would be value in early childhood partners having greater involvement in helping families to understand local resources, particularly in regional and remote areas. Funding that would allow specialist service providers such as Vision Australia to build the capacity of local providers in remote areas would also be worthy of consideration.
* Vision Australia has grave concerns that some of the assessment tools that have been identified are unsuitable for use with children who are blind or have low vision. The PEDICAT in particular, tends to result in poor outcomes for children who are blind or have low vision. Given the lack of suitable standardised assessment tools that are appropriate to young children in this cohort, we would prefer to see the introduction of a guided referral pathway to ensure families are able to access the supports they need.
* Vision Australia is concerned about the implementation of additional accreditation requirements and the impact this would have on thin markets associated with low incidence disability cohorts such as blindness and low vision. It will not be beneficial for children and families if an already restricted pool of specialist providers is limited further.
* We are broadly supportive of mandatory registration of NDIS providers who are operating in the ECEI environment. This would afford additional protections to families who are often vulnerable at this point in their journey.

## Discussion topics

### Increased focus on STEI Outside of Access to the Scheme

Vision Australia has a number of current clients who would benefit from increased access to short-term early intervention outside of the NDIS, however, we feel it is unlikely that ECEI partners will possess the specialist skills necessary to provide all of these services. For example, we work with several children experiencing delayed visual maturation. These children are generally aged under 3, and often do not qualify for access to the NDIS because their vision is able to be corrected, through contact lenses, removal of cataracts, and other treatment options. It is nonetheless important for us to work with these families so that they can understand how to provide the best possible environment to stimulate the child’s vision. A child’s vision will generally continue to develop until around 8 years of age, and the way in which they use it changes as they become more mobile and need to access visual information at greater distances. It is vital that they work with specialist providers such as vision Australia, to ensure that level of vision and its use in daily routines is monitored and is continuing to develop. Sometimes these children are later diagnosed with a permanent condition that qualifies for NDIS access, and sometimes they are not, but in either case their access to short-term early intervention services is crucial in ensuring that they meet development milestones. Any STEI services that are provided must be both appropriate and timely. Due to the impacts of vision impairment on all areas of development, it is essential that children are able to access services without delay. Any modifications to the STEI access process must be supported by a clear pathway for families. Parents often have limited knowledge of the services available at their child’s point of diagnosis, and they need to be supported with a referral process that operates effectively across both the health and disability sectors.

### The Proposed Increase in Age Range for the EC approach from under 7 to under 9 years of age

Vision Australia is broadly supportive of this approach, as it may provide additional time to finalise a diagnosis for some children. It may also allow for improved consolidation around assistive technology and compensatory skills, as the need for these often increases as activities at home and school become more demanding. It is noted, however, that it can often be difficult to deliver early intervention services for children once they commence school. Sessions must generally be run outside of school time and this can be challenging for parents and families to accommodate.

If the proposed increase in age range is implemented, it will be necessary to have increased clarity and greater collaboration between ECEI partners, the NDIA and state and Territory education systems. For example, assessments conducted by education providers are currently not shared with service providers that work with the child in their home and community environments. This renders it difficult to integrate strategies that are being used at school into the therapy that is provided at home. This creates complexity when teaching compensatory skills, because many of the supports that children need at home will cross over into education. For example, a child learning assistive technology skills might use those to complete school work and homework tasks, but could equally utilise the same skills for recreation, to connect with peers or use social media.

### The desire to see more successful Transitions from the scheme to the next State of Life

It is important to ensure that children and families are not prematurely shut out of the NDIS because their need for support fluctuates. We work with some families with young children who access early intervention supports for a time and subsequently go through periods where fewer services are needed. Often, when those children commence a new life stage, such as preschool or school, however, their support needs, both in the home and education environments, will increase significantly. It is important that, even if these families are transitioned out of the scheme, that ongoing monitoring occurs to ensure they can continue to access relevant supports and that they have a pathway to re-enter the NDIS if required.

### Helping Families to Understand NDIS Terms such as Best Practice and capacity building

When families receive the information that their child has a disability, acceptance of this may take time. Moreover, parents are unlikely to understand terms such as capacity building, and in the case of young children, tend to think more about giving them experiences, rather than skills. Vision Australia feels that families would often benefit from greater support with goal development throughout the NDIS planning process. This would enable them to better understand what best practice might mean for them. Initial planning discussions for families often appear to be highly focused on services, without necessarily looking at how these influence outcomes for the child. Moreover, parents and carers often think about supports for their child individually, without necessarily being aware of how a variety of therapies or supports can integrate in a holistic and transdisciplinary approach, with several providers working collaboratively towards the same goal. It is important to realise that families do not always know what aspirations they can, or should, have for their child, particularly where diagnosis of a condition is new and unfamiliar. It would be helpful to emphasise the role of family coaching during planning sessions, so that parents and carers understand that therapists will work with them to foster their child’s skill development using a family centred approach that considers the family’s routines, significant family members, values, culture and priorities.

### Tracking Goals and Mandatory Early Childhood Reporting

It is important that families are encouraged to play an active role in setting goals, as well as having input into whether they have been met. Reporting and goal setting processes must be able to accommodate families with varied levels of engagement. Some parents conduct their own research and are able to understand how to make systems work well for their child, whereas others have more limited capacity to do this.

Vision Australia believes there is value in collaborative early childhood reporting, however, if this is mandated, funding must be provided for it as a stated support in the child’s NDIS plan. Families should not be expected to cover reporting from a child’s therapy funding, and many are currently reluctant to do so, due to the limited support hours available to them. Often, where families work with a number of service providers, reports from each organisation will be completed separately. This is seldom efficient, however, if the Agency wishes to promote collaboration between providers, funding must be allocated for it accordingly. As with reporting, many families are unwilling to spend funding on case conferencing between providers. One option may be for ECEI partners to take on a more substantial role in coordinating appropriate communication between providers. We find that some organisations are unwilling to share information for fear of losing clients, and do not always work well together, particularly if they feel they are potentially competing for services. It is, however, important to ensure that families are not given conflicting information and that providers are working towards common goals to the maximum extent possible. It may be valuable for the NDIA and ECEI partners to promote the value of collaboration among providers, and to set aside or encourage the use of funding specifically for that purpose.

### Supporting families to connect with funded and community Services

Currently, Vision Australia does a great deal of unfunded work to establish links with both disability related and community services for families. It is not always possible, however, to provide families with the level of support they need. It would be worthwhile to increase the capacity of ECEI partners to assist families to access appropriate services. Alternatively, providers must be afforded funding, as part of their key worker role, to liaise with other organisations and make appropriate referrals. Examples of situations where this is required include services that go above and beyond what Vision Australia provides, such as assisting parents to find an appropriate preschool or playgroup, referrals for counselling or behavioural support, and other therapies that are outside of our expertise or remit.

Funding should also be included in plans to work, not just with the child and their family, but with other mainstream service providers such as preschool teachers, in order to build their capacity. This is particularly important for low incidence cohorts such as blindness and low vision, where specialist knowledge is often required to upskill local providers or other key influencers in the child’s life.

### Effective Provision of early Childhood supports in remote Communities

In general, we find that families in remote areas tend to need higher levels of assistance with case management. The child may need to work with a number of local providers to establish a full suite of services, however, coordination among those providers is often lacking or challenging to manage. Parents rarely have the capacity to effectively take this on. There would be value in early childhood partners having greater involvement in helping families to understand local resources. Coordination of those resources must also be improved, whether that happens through funded support coordination, or an ECEI partner model that is better equipped to link families with local supports.

Funding that would allow specialist service providers such as vision Australia to build the capacity of local providers in remote areas would also be worthy of consideration. We currently provide face-to-face services in remote areas wherever possible, however, the provider travel arrangements that presently exist under NDIS often make this prohibitive for providers and families alike. Even where we can offer a mix of face-to-face and telehealth services, there may be circumstances where it is valuable to upskill a provider in the client’s local community to ensure continuity of support can be achieved. No funding exists for us to establish those relationships currently, and we are not otherwise resourced to viably provide that level of support. There is a role for ILC funding in building skills of the local community. However, because of the low incidence of vision impairment, in combination with remote and regional locations, it is often more effective to provide this support at the time it’s needed, and in the child’s natural setting. Including specific funding for this purpose in plans would obviate the need for the child’s own capacity building budget to be used for upskilling others.

### Supporting Peer-to-Peer Connections

There should ideally be greater opportunity to link parents and children together in a community setting to share experiences and provide informal peer connections. Role modelling and informal mentoring from others who are, or have been, in similar situations, can be highly valuable. Options to achieve this would include establishing digital platforms, or facilitating the running of events and camps to connect families together. While many providers such as Vision Australia are willing to run these types of events, it is often difficult to determine if, or how, they might be paid for through NDIS funding. The current funding environment means that many organisations across the sector are not resourced to develop these programs without the assurance of financial means to run them. Similarly, there are many ways to build the capacity of families, by allowing parents, siblings and other support people to connect through workshops or informal days, for example. It is often unclear whether plan funding can be used to support capacity building and development opportunities for parents, however, and without certainty around financial support for these programs, it is difficult to provide them, particularly where there are families who may need to travel from regional centres to participate.

### Reaching and supporting vulnerable Children and families

Vulnerable families may often have other touchpoints in the community, such as GPS, schools, or organisations that assist to address family violence. An improved focus on education may be needed so that these providers are able to use their connections with families to talk about NDIS supports where appropriate. This could be expanded beyond health and disability service providers to other community organisations more broadly, so as to generate referrals or encourage vulnerable families to initiate contact.

There is also an ongoing need to support translation of materials for families. While the NDIS relationship with TIS National allows for the use of interpreters, there are often materials and resources given to families throughout the planning process that are not available in an appropriate language or format. It may also be valuable to establish connections between ECEI partners and local cultural groups in the community, as these organisations are sometimes the first to become aware of participants, or potential participants, who are experiencing disadvantage or need support. Families who are new to Australia, or for whom English is a second language, will not always have an in-depth knowledge of the various Government support systems available to them, and may also have a reduced capacity to advocate for themselves or articulate the needs of their child for funding and planning purposes. It may be worthwhile to consider whether additional advocacy support could be offered, through avenues such as migrant services or utilisation of bicultural workers. A set number of support coordination hours could also be provided to help guarantee these families the additional support they need.

### Tailored Independent Assessments

Vision Australia has grave concerns that some of the assessment tools that have been identified are unsuitable for use with children who are blind or have low vision. The PEDICAT in particular, tends to result in poor outcomes for children who are blind or have low vision. Children assessed under the PEDICAT may appear to be within normal developmental limits, particularly if we have already been providing services. It is not until the child would typically start to become more mobile and access visual information beyond arm’s length that we would start to see developmental delays widening and the significant impact of the child’s vision impairment on their learning and development. These children will still require early intervention supports in order to develop foundational skills so that they do not present with a developmental delay at a later time. It is problematic if assessment tools only look at the child where they are now, rather than considering the foundational skills they need to develop to prepare them for changes in their condition and /or functioning. The PEDICAT tool generally fails to pick up vision specific issues and assessors who have only generalist knowledge of developmental markers are unlikely to either. We are aware of several children who have been refused NDIS access through the use of this assessment. They are told to re-apply to the Scheme when a developmental delay becomes apparent. The purpose of early intervention supports is to alleviate the impact of a child’s impairment on their functional capacity, and to prevent the deterioration of that functional capacity. It therefore seems counterintuitive that families are being requested to wait until their child presents with a developmental delay, before seeking appropriate supports. This is unlikely to be remedied through the use of the PEDICAT as a standardised assessment tool for children who are blind or have low vision.

The NDIA should also be mindful that these assessments are likely to be difficult for families to go through, particularly where a child has complex behaviours or needs. It is often confronting for families to see how delayed their child is and it will be necessary to provide appropriate support to parents around this process.

Given the lack of suitable standardised assessment tools that are appropriate to young children who are blind or have low vision, we would prefer to see the introduction of a guided referral pathway to ensure families are able to access the supports they need. The vast majority of children who are blind or have low vision are born to fully sighted parents. As a result, families of children receiving a diagnosis of vision loss often have little, if any, knowledge of what is needed and the supports available to them. This is problematic, because the effective operation of the choice and control that underpins the NDIS is dependent on those exercising that choice being fully aware of their various options. There is also a significant risk that developmental outcomes for the child may be compromised if poorly informed decisions are made regarding early intervention therapies. Frequently, early intervention is time critical for children who are blind or have low vision in order to minimise the risk of ongoing disadvantage. The creation of a guided referral pathway would help to alleviate the difficulties in accessing services that exist currently. It would also reduce the potentially detrimental impacts for families associated with lack of knowledge or experience around available service options, as well as the lack of appropriate independent assessment tools for this cohort.

### Greater Transparency on providers of Best Practice

Vision Australia is concerned about the implementation of additional accreditation requirements and the impact this would have on thin markets associated with low incidence disability cohorts such as blindness and low vision. It is already difficult to recruit staff with the appropriate specialist skills and additional accreditation requirements are likely to render the costs of providing suitable training unviable. It will not be beneficial for children and families if an already restricted pool of specialist providers is limited further.

We are broadly supportive of mandatory registration of NDIS providers who are operating in the ECEI environment. This would afford additional protections to families who are often vulnerable at this point in their journey. While mandatory registration is likely to lead to better outcomes in terms of services, consideration should be given as to whether this would unreasonably restrict access to equipment that families purchase in order to facilitate delivery of early intervention supports. Much of this equipment is basic and would not always be purchased through registered providers currently.

Whichever approach is taken, it is important to emphasise to families that coordination is a key component of best practice service delivery. If families work with several providers who all give independent advice, with no linkages between services being established, this is unlikely to constitute best practice. Some level of coordination will always be required, whether that occurs through ECEI partners, or through provider commitments to work collaboratively and establish a key worker to operate across a team.

## 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.