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**Australian Blindness Forum submission:**

**Joint Standing Committee on the**

**National Disability Insurance Scheme: Issues of sector concern**

**August 2018**

**About the Australian Blindness Forum**

The Australian Blindness Forum (ABF) is the peak body representing blindness, low vision and rehabilitation in the Australian blindness sector. It is a partnership between consumers and service providers; seeking equity in access for people who are blind or vision impaired.

ABF and its member organisations support every person’s right to participate in education, employment and contribute to the community. This includes all people who are blind or vision impaired having the right to access services and technology, to enable dignified and independent access to, and participation in their community and to live independently, inclusively and with dignity.

ABF’s position is consistent with:

* the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
* National Disability Strategy 2010-2020 (NDS)
* the Disability Discrimination Act 1992 (DDA).

We recognise that critical to these rights is the capacity to make decisions and choices that affect the way people with blindness or vision impairment choose to lead their lives. Inherent in this capacity is the provision of quality supports and services delivered along a continuum of care and accessibility that is efficient and effective.

Our close engagement with consumers means that we are an important advocate for those impacted by blindness or vision impairment and as such we are well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

As Australia’s representative to the World Blind Union, the ABF has strong connections with the international blind and vision impaired community, and seeks to undertake best practice internationally and regionally.

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**Introduction**

At the ABF’s members meeting in June 2018, the Chair of the Joint Standing Committee, the Hon Kevin Andrews MP invited the ABF to make a submission to the committee on key issues of concern to the sector.

The ABF formed a working group to consult with members on key issues and to provide solutions.

**Preliminary remarks**

The introduction of the National Disability Insurance Scheme (NDIS) has meant that many different services and programs need to interface with the Scheme. Whilst the intent and potential of the NDIS is a valuable opportunity for people with disabilities to access necessary supports and services, the opaque demarcation and cost shifting between jurisdictions and various departments creates significant challenges for current and potential NDIS participants and service providers.

In terms of the blindness and rehabilitation sector the transitional arrangements to the NDIS have impacted significantly on those people who are blind or vision impaired and their families.

Vision loss has a significant functional impact in many ways. It can mean losing freedom and independence through the loss of a driving license, difficulty maintaining or gaining employment, not having access to information in useable formats or being unable to safely move around one’s home or community.

For too long, people who are blind or vision impaired have been unable to access comprehensive and specialist supports in a timely manner which subsequently impedes the retention or regaining of confidence and independence.

With the right supports, however, capacity building, and connection to the community, people who are blind or have low vision can make the most of the NDIS. At present, accessibility of information, inconsistency of supports, and other issues associated with the NDIS rollout are preventing this from being achieved.

Whilst we recognise the NDIS is in its relative infancy and substantial work continues to occur to review and amend policies and processes there continues to be far too much inconsistency.

As a sector, we regularly encounter consumers who have been refused funding for supports and services but for which another consumer, with very similar need and circumstance, has had approved. In both these instances, comparable standard of specialist assessment and accompanying evidence had been provided to demonstrate the need for recommended supports.

Additional to regular inconsistencies within the NDIS plans, we see many examples of plans where it is clear the recommendations of specialist and or the preferences of NDIS participants themselves are not reflected. Far too many plans are still not tailored to the complex and specialised needs of people who are blind or vision impaired and often not designed for the periodic nature of support required by participants. Further, the lack of specialised knowledge is acerbated when planners do not understand adaptive technology or, mobility solutions, including dog guides.

These incomplete or insufficient plans and the funding contained within them has a substantial and lasting impact on people who are blind and vision impaired and their families by creating barriers to social participation, employment, education, health and positive ageing, transport, and childhood development.

By drawing from the experience of consumers and service providers operating within the NDIS environment over the last five years, the ABF provides the following recommendations:

**Recommendation 1**

That the National Disability Insurance Agency (NDIA) ensures assessors have the specialised knowledge and competencies to undertake assessments that are specialised and individualised providing the best quality plan for people who are blind or vision impaired, and to ensure accurate plans and appropriate supports are recommended within plans. Communication between the NDIS and the participant should be in their format of choice in a time equivalent to the printed word. And people’s verification of their blindness status (under the social security act) should be recognised by the NDIS.

**Recommendation 2**

Maintain a minimum level of mobility support for travel to ensure that people who are blind or vision impaired have the same access and opportunities to social participation, employment, and personal development as do other Australians. The NDIS must ensure that all travel supports are consistent, equitable and meet participant’s reasonable and necessary support needs.

**Recommendation 3**

Improved and guaranteed funding for children with a vision impairment to reduce the risk of developmental delays. Provide resources for adaptive technology, and therapies to support children in their childhood development within their family environment.

**Recommendation 4**

Program funding is provided to ensure that early intervention, and service provision for those, who have significant vision loss is available.

**Recommendation 5**

The NDIA and COAG must urgently address interface issues which are affecting people who are blind or vision impaired. These include supports in the education system, health, and aged care.

Our recommendations stem from our experience with our primary ongoing concerns more thoroughly explained below.

**1 The inconsistencies of the NDIS**

*Assessment and plans*

Many NDIS plans that have been developed for people who are blind or vision impaired have demonstrated that the generalist planners and assessors have a lack of understanding of blindness or low vision. This includes the impact of vision loss and the particular equipment and supports that are required, such as assistive technology and the adaptation of mainstream technology to support people.

Currently, NDIS plans that have been developed for people who are blind or vision impaired are often inconsistent and not tailored to specialised needs. In particular, ABF recommends that the NDIA develop a consistent approach to the way that assistive technology equipment is defined as ‘reasonable and necessary’, which accurately takes into account the specific needs of different disability cohorts. This should include clearer guidance around the specialist function of what might otherwise be considered everyday equipment.

Under the NDIS plans, there is an emphasis on ‘one size fits all’. This ‘one size fits all’ approach reflects the lack of understanding of the assessor and the inflexibility of the assessment process. The assessment process does not allow for the specific personal needs of clients to be met. Nor does the process have inherent flexibility that allows for minimal change over time or intermittent support, which are often the requirements of people who are blind or vision impaired.

For example, in relation to intermittent or periodic support, (which is about varying and different needs at varying and different times), people may need one off support to move house or jobs or because their vision loss has changed.

*Communication*

Further to this it must be noted that the NDIA continues to provide participants who are blind or vision impaired with information and materials, including their own plans, in formats that are not accessible to that participant.

*Eligibility*

Under the NDIS people who are permanently blind are expected to undergo a verification process. This is un-necessary as under the Social Security Act these people have already been assessed as legally and permanently blind. ABF is of the view that they should not have to verify their blindness status twice, once to social security and secondly to the NDIS, but rather their status under the social security act as legally blind be recognised by the NDIS via their Centrelink customer reference number.

**Recommendation 1**

That the NDIA ensures assessors have the specialised knowledge and competencies to undertake assessments that are specialised and individualised providing the best quality plan for people who are blind or vision impaired, and to ensure accurate plans and appropriate supports are recommended within plans. Communication between the NDIS and the participant should be in their format of choice in a time equivalent to the printed word. And people’s verification of their blindness status (under the Social Security Act) should be recognised by the NDIS.

**2 Transport**

The future of schemes such as the mobility allowance and taxi subsidy schemes are currently being either withdrawn or reviewed as the nation transitions to the NDIS.

Under the NDIS participants frequently see unequal and inconsistent transport allowance support. Where there is a loss of funding, people who are blind or vision impaired are significantly less able to independently participate in employment, education, community and family activities. The potential inclusion of taxi subsidy schemes within the NDIS may exacerbate inconsistencies for participants, or across states and territories. The promise of the NDIS was that no one would be worse off, however, all too frequently this is occurring. ABF believes that any changes to transport subsidies introduced under the NDIS should be equal to or greater than what was available prior to the NDIS.

Further there is a Bill before Federal Parliament to withdraw the mobility allowance. As the NDIS is only available to those under 65, a person who is blind or vision impaired is over 65, and is working or volunteering, will lose the mobility allowance that they are currently receiving once it is transitioned into the NDIS. There is also no information about continuity of support for the mobility allowance, or if it will be available in any form after 2020.

On the one hand, the Government is encouraging people to work past 65, and raising the pension age, but on the other, it is reducing the amount of support for people who acquire a disability and wish to meet these expectations of an individual's working life.

The withdrawal of the mobility allowance will prevent people over 65 who are blind or vision impaired from volunteering, increasing social isolation and reducing the ability for people to contribute to the community. This is one of the side effects of the NDIS, where withdrawal of existing services not covered by the NDIS have serious and unintended consequences.

**Recommendation 2**

Maintain a minimum level of mobility support for travel to ensure that people who are blind or vision impaired have the same access and opportunities to social participation, employment, and personal development as do other Australians. NDIS must ensure that all travel supports are consistent, equitable and meet participant’s reasonable and necessary support needs.

**3 Childhood development**

Issues in access to the NDIS, and a lack of understanding about specialist supports for early childhood intervention services for children who are blind or vision impaired place, children at an unacceptable risk of developmental delays. It is vital that children with a permanent impairment receive the supports they need as early as possible. Early intervention targets the strategies that young children, who are blind or vision impaired, need in order to manage their disability as opposed to intervention that alleviates the disability.

It is also important that children who are blind or vision impaired not be supported in isolation, but in the context of their families. It is also critical that the impact of blindness and vision impairment on parents and siblings and wider support networks be recognised.

Support for families in the early years helps build the knowledge, confidence and capacity of families so that they are in a position to make the right decisions for their children and themselves in terms of identifying the supports needed and the most appropriate services with which to engage. Supporting families as whole entities provides the strongest foundation for a child’s capacity building, and a family’s quality of life.

The prompt and straightforward access to the NDIS enabled by the early childhood early intervention approach, in theory, will optimise a child’s learning, development and well-being, and their capacity to participate meaningfully in family and community life. However, we are deeply concerned that early childhood partner planners and assessors, the first point of contact for young children and families, lack an understanding of the specialised needs of young children who are blind or vision impaired, a general understanding about different types of disability is insufficient.

There are instances where a child’s vision impairment may not be easily identified by their medical professional, greater awareness and understanding of specific needs, and a guaranteed base level of support funding for all children with a vision impairment, is urgently required.

Children who are blind or vision impaired require adaptive technology and therapies to reduce the impact of vision loss to be able to actively and independently participate in education, community activities and family life. Technology that allows them to do this is often technically sophisticated and expensive and needs to be supported via the NDIS in order that each and every child who is blind or vision impaired has equal access to, community and interaction with family and friends.

**Case Study**

An ABF member submitted an assistive technology request for an NDIS early intervention early childhood participant with no vision.

The application included a combination of vision impairment and physical impairment related resources and equipment. The physical impairment related resources and equipment were all approved whereas all the vision impairment specific ones were declined. This includes the most basic tool for a young child to access literacy, a Perkins Brailler. This is akin to denying a sighted child access to a crayon and paper to draw. A Perkins Brailler is the only way a vision impaired child can learn the early cause effect of ‘writing’. When the child uses a key on the Perkins Brailler, the child can feel the dots that is formed on the paper. This is like a sighted child seeing the thick lines they draw with a crayon. The young child is otherwise unable to develop pre-writing skills.

Other important equipment, for which funding was refused, were the Little Room and Resonance Board. Both of these items are very specialised equipment for babies and young children with vision impairment. The Little Room and Resonance Board are designed to facilitate independent upper limb, spatial, tactile and auditory exploration for children with little or no vision. The acoustic properties of the resonance board can help a child locate different objects using hearing. The position of carefully selected objects facilitates upper limb exploration and hand play. A vision impaired child is able to learn important cognitive concepts like cause effect, object permanence through upper limb play and exploration. This is an important first step to helping the child be more aware of their world and be independent in play.

Funding for the above vision impairment specific resources and equipment has been rejected without any consultation with the therapy team and prescribers. On the other hand, funding for physical impairment related resources and equipment in the same application were approved.

The early intervention team is concerned that the external parties who were tasked to assess the equipment application do not have sufficient knowledge and expertise about vision impairment to make the funding decision. They are extremely concerned about the lack of consultation with the prescribers, that is the therapists, who work closely with the families, resulting in poor decisions and poor plans for participants.

**Recommendation 3**

Improved and guaranteed funding for children who are blind or vision impaired to reduce the risk of developmental delays. Provide resources for adaptive technology, and therapies to support children in their childhood development within their familyenvironment.

**4 Information, Linkages and Capacity Building**

ABF notes that the range and type of services initially promised to be funded under the Information Linkages Capacity Building program has changed substantially. The Productivity Commission recommended Tier 2 programs included a level of block funding and early intervention programs, and substantially greater funding. The goal of this was to continue to provide disability services to those who were not eligible for the NDIS and greater support for disability service providers to support the transition.

The ILC program, as introduced has a more limited range of supports, available for a limited time or on an ad hoc basis.

As noted by the Productivity Commission on multiple occasions, we have concerns relating to the current thin market of specialised services that is able to provide specific tailored supports and services that respond to disability specific issues. The viability of services in such a thin market must be considered and addressed. Low incidence disability cohorts such as vision impairment are particularly susceptible to the risks of a thin market: primarily those of geographic restrictions. Participants who are in rural or remote areas will struggle to access mainstream or alternative services (who even if present will have limited specialist vision impairment knowledge or capability) and will frequently be limited in the social and community supports they can access.

For specialist vision service providers, delivering supports into remote or rural areas is challenging. Frequently the demand for services is spread across distances that require service providers to shoulder the burden of travel to deliver services. However, for children who are blind or vision impaired, remote online service delivery is inappropriate.

Face-to-face services, such as occupational therapy and physiotherapy, delivered in a young child’s natural environment, are crucial. A child’s natural environment includes the home, daily routines, the community, early childhood education and care settings. Early intervention therapy for children who are blind or vision impaired includes developing their skills around activities like engaging in play, that enhances their inclusion in mainstream environments like education.

ABF urges decision makers to ensure relevant funding is included to enable services to be delivered to the relevant location. ABF believes it is unfair for families and service providers to be put in a situation where they are required to draw down on participants’ support budgets for purposes of travel as this may impede them receiving adequate supports.

It is unclear how the early childhood early intervention approach responds in order to meet the needs of thin markets when helping young children and their families access services, or trying to overcome the barriers to accessing services associated with these exacerbating factors and demographics. A failure to respond appropriately inhibits the goal of choice and control for families.

**Recommendation 4**

Program funding is provided to ensure that early intervention, and service provision for those who have significant vision loss is available.

**5 Interface with mainstream systems**

The boundaries between disability services and mainstream service systems such as aged care, health, and education are blurred. There is little clarity around the jurisdictional boundaries and responsibility for providing support is often avoided. For instance, in Aged Care, the promised continuity of support for all people with disability who are not eligible for the NDIS only covers a portion of the demand, not otherwise met in the aged care sector.

It is critical that interface issues facing people who are blind or vision impaired are addressed. For example, for children and youths, the different funding schemes of the education system and the NDIS means that the needs of children with vision impairment are not considered as a whole picture. Rather the child and their needs are separated between school and out-of-school. This is not a correct representation of the child as a whole person and their daily living. All key stakeholders who are involved with the child must have the opportunity access the same therapists and specialists supporting the child and their family. This will ensure supports are consistent and most effective across the child’s different environments.

The communication from the NDIA to both the health and education systems has been sporadic, uncoordinated and at high levels. Further, there are many cases where critical information is not reaching the people working directly with the participant.

**Recommendation 5**

The NDIA and COAG must urgently address interface issues which are affecting people who are blind or vision impaired. These include supports in the education system, health, and aged care.

**Conclusion**

ABF advocates for consistent supports for people who are blind or vision impaired across the disability and aged care systems. The ABF seeks to ensure that the NDIS and the aged care system are fair and equitable and meet the needs of people who are blind or vision impaired.

The right support for the complex and specialised needs of people who are blind and vision impaired will ensure that people are enabled to make the most of the opportunities available to them across education, employment, social participation and economic security.