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## **Submission: National Disability Insurance Scheme (NDIS) Costs**

March 2017

**To:**  
Productivity Commission  
Via email to: [ndis.costs@pc.gov.au](mailto:ndis.costs@pc.gov.au)

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## **About Blind Citizens Australia**

Blind Citizens Australia is the peak national representative organisation of and for people who are blind or vision impaired. Founded in 1975, our mission is to achieve equity and equality by our empowerment, by promoting positive community attitudes and by striving for high quality and accessible services which meet our needs.

We provide peer support, information dissemination, advocacy support and advice to community and government on issues of importance to people who are blind or vision impaired.

Our work is directly informed by lived experience of blindness and vision impairment. Our members, our Directors and the majority of our staff are blind or vision impaired.

## **Introductory Comments**

BCA appreciates the opportunity to highlight the issues experienced by people who are blind or vision impaired accessing the NDIS. BCA recognises the importance of insuring the economic sustainability of the NDIS. However, the associated costs of delivering the scheme are by no means the only consideration that should be taken into account when evaluating the efficiency and effectiveness of the NDIS. Assessment of the scheme's effectiveness through a purely economic lens does not account for the lived experiences of people accessing the NDIS, no matter which stage of the assessment or planning process they are working through. Merely cutting costs may in fact result in people receiving services through the NDIS that are not reflective of the best plan, support or equipment to meet their needs. In answering the questions in the issues paper, BCA will explore these factors and articulate the rationale for making investments which will insure long term, sustainable results. It should also be noted that a sole focus on cost is incompatible with the principles of choice and control, which are at the centre of the NDIS and its intended purpose. Being forced to receive a lesser quality support service or piece of equipment just because it costs less removes choice and control from the consumer, and often results in greater costs in the future which could have been avoided if high quality support or purpose built equipment were purchased in the first place.

## **Issues Arising in Relation to Current Planning Processes**

### **1. Plan meetings taking place over the phone**

At a recent Victorian Disability Advocacy Network meeting, a representative from the National Disability Insurance Agency (NDIA) confirmed that the agency's preferred method for undertaking planning was by telephone. Although people are able to ask for their planning meeting to be conducted face-to-face if this is their preference, many people are not aware of their options when receiving their first planning phone call and are therefore unable to properly exercise their rights.

While we understand that the agency is under intense pressure to meet the targets that have been agreed upon under the bilateral agreements between state and territory governments, meeting these targets should not come at the expense of the basic rights

and freedoms of people with disability. The NDIA's current approach to planning ultimately fails to uphold the principles that have been legislated under the National Disability Insurance Scheme (Plan Management) Rules 2013, which reflect rights set out in the Convention on the Rights of Persons with Disabilities. The rules state that:

- people with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports
- people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise informed choice and engage as equal partners in decisions that will affect their lives, to the full extent of their capacity
- people with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs
- people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves

Furthermore, we are increasingly concerned about the degree of contextual information that will not be available to planners in instances where plans are not conducted in a face-to-face environment. Conducting meetings over the telephone severely compromises the ability of people who are blind or vision impaired to demonstrate the difficulties they may face with completing tasks like reading, navigating the environment or household chores. The functional implications of Vision impairment can differ according to diagnosis and a range of other social and environmental factors. It can therefore not be assumed that every person who is blind or vision impaired will need the same supports and equipment to complete the same tasks. Face-to-face meetings would give a person with a vision impairment a chance to demonstrate the challenges they face in real time.

### **Recommendation 1:**

In order to maximise the active and informed participation of people with disability in the planning process, the NDIA must provide people with information about their rights in advance of planning meetings. Information must be provided in plain English, in formats that are accessible to people who are blind or vision impaired such as large print, Braille, audio and accessible electronic format. This process should aim to ensure that participants understand:

Complaints and appeals processes

The option of having planning meetings conducted face-to-face

The option of delaying a planning meeting where a participant does not feel they have had enough time to pre-plan

The option of having a family member, support person or advocate attend a planning meeting

## **2. Lack of specialist planning and assessment**

BCA is concerned about the efficacy of generalist planning and assessment processes in achieving positive planning outcomes for participants who are blind or vision impaired. From our interactions with NDIS participants, we have reason to suspect that this approach is failing many people and leading to higher administrative costs in the long-term; as people have no option but to appeal decisions and request formal plan reviews in order to receive a plan that properly articulates their support needs.

While we value the role of reference packages in assisting Planners to understand the range of supports that an individual who is blind or vision impaired may typically require, we are concerned that, given the fast-paced nature of the roll out, Planners are placing an increasing level of emphasis on reference packages without properly assessing each participant's individual needs and aspirations. This approach is contrary to the social model of disability; which recognises that people with the same condition or impairment can experience differing levels of functional limitation and participation restriction based on a number of social and environmental factors.

To mitigate the risks associated with generalist assessments, especially in an environment where the NDIA is under enormous pressure due to time constraints, people should have the option of undertaking a specialist assessment to be conducted by a subject matter expert on issues relating to blindness and vision impairment. Specialist assessments would be particularly beneficial for people with newly acquired vision loss and people whose condition is of a degenerative nature. Many people who are blind or vision impaired, particularly those who have been blind for a long time, typically know what supports they need. So it is crucial that people are not forced into receiving a specialist assessment if this is not their personal preference.

#### **Recommendation 2:**

The NDIA or LAC agencies should be required to create new positions for subject matter experts on blindness and vision impairment, or contract subject matter experts on a needs basis. These new positions would exist for the purpose of undertaking specialist planning and assessment and plan reviews for participants who are blind or vision impaired who request this approach. These staff should also have delegated responsibility in relation to the approval of reasonable and necessary supports.

### **3. Adjustments required for people with episodic needs for support**

There are still a number of structural issues with the planning process that continue to impact upon the under-utilisation of plans amongst participants who are blind or vision impaired. BCA asserts that The current planning process is ill-equipped to meet the needs of people whose support needs are largely episodic. Until such time that a more responsive process can be put in place, it is likely that many people who are blind or vision impaired will miss out on receiving the supports they need in a timely and effective manner, thus impacting upon their participation in social, cultural and economic life.

When it comes to services like orientation and mobility training, it can be very difficult for a participant to calculate how much support they might require over a 12-month period. If, for example, an individual suddenly has to relocate or learn how to get to a new workplace, they may require intensive orientation and mobility training to enable them to navigate these new environments safely and independently. Support for transport costs may also need to be increased for the period during which the individual is still learning how to use public transport to access their workplace, local shopping and other community services and amenities. While these supports will not be ongoing, ensuring they are received in a timely manner is critical to the dignity, independence and wellbeing of the individual. Without this initial investment in higher level support, the costs of supporting an individual who has not been supported to function to their full capacity will be significantly higher in the long-term.

The learning of new travel routes is a naturally stressful process, as it takes a high degree of concentration and is highly dependent on the nature of the relationship between the instructor and the learner for a successful outcome. To add financial pressure to that scenario by asking someone to predict how many hours will be needed to become competent at travelling a route is unhelpful.

It could actually lengthen the amount of time it takes for a person to become confident in travelling alone because of the extra stress and anxiety added if they feel that they are under pressure to become competent at travelling within a certain amount of time.

While the above is true for people who have been blind or vision impaired for a long time, and whose vision is stable and not subject to change, the picture is often very different for people with degenerative conditions. The following statement from a BCA member, illustrates the complex and fluctuating nature of her support needs:

“I have Retinitis Pigmentosa and in the past couple of years I have lost my remaining sight. It seems to me that over this period especially, but probably for many years, life has been an almost continuous series of ‘episodes’ requiring new learning, new devices, and a lot of training. I’ve found that the transition from having a little sight to none at all has been the most intense in this way, although the degenerative nature of RP means that changes occur frequently and over a long period of time. At the moment, I feel that my life consists of many different kinds of new learning – new guide dog, preceded by several months of cane training, almost a year of adaptive technology training, continuous work to develop Braille reading skills, and then there are just the many kinds of adjustment and reorganisation in order to live reasonably without sight. I don’t even know how to begin to think about what is an ‘episode’ because the change is so global, and one period of adjustment and learning blends into the next one.

I think that people with degenerative conditions don’t necessarily have neatly delineated ‘episodes’, but rather are in a continuous state of flux. So, somehow, this needs to be accommodated in the support for those fortunate enough to access the NDIS”.

This example highlights the unpredictable nature of peoples’ support needs. In light of these circumstances, when it comes to supports such as orientation and mobility training, there is currently a need for individuals to plan for over and above what they might actually need based on a worst case scenario of the episodic needs that are likely to arise within any 12-month period, as an underestimation will mean they cannot access the support they need without requesting a full plan review – ultimately preventing them from accessing this support when they need it most. This anomaly is sure to be contributing to the under-utilisation of plans, as participants may not use all supports that have been committed in any 12 month period. Whilst this may be the case, it would also be a mistake to assume that people might require less supports in their plan the following year. Personal plans and the availability of supports need to be flexible enough to accommodate for sudden changes which are likely to lead to sporadically higher costs.

It is our understanding that the NDIA will no longer approve any new supports without a full plan review – a process which can take several months. A number of scheme participants who are blind or vision impaired have already reported having to seek a review almost as soon as their first plan was in place, as new support needs had emerged that could not have been foreseen at the time of planning.

It would be far more cost-effective for there to be a more streamlined process for seeking approval for changes in support needs where supports are required episodically rather than on an ongoing basis. Rather than requesting a full plan review everytime a new support need arises, participants who have been identified as having support needs that are of an episodic nature should be able to request a "support adjustment". This would allow for funding to be allocated quickly to fulfil support needs that emerge at different points in time.

Additionally, Section 6.3 of the NDIS (Plan management) Rules 2013 stipulates that:

"Some supports in the statement may be described generally, whether by reference to a specified purpose or otherwise. For such supports, the participant will have a high degree of flexibility over the implementation of the supports."

Section 6.4 goes on to explain that when deciding whether the support should be described generally or more specifically in the participant's statement, the CEO is to have regard to the following:

- (a) the cost of the support;
- (b) any expected return or saving in costs from providing the support;
- (c) any risks associated with the supply of the support such as the need for the support to conform to State or Territory laws;
- (d) whether achievement of other goals in the plan or the effectiveness of other supports is contingent on a particular support being procured or used;
- (e) whether the participant's disability requires a specialist, evidence-informed support provided by a qualified person or a particular delivery mode;
- (f) whether the participant accessed the NDIS by satisfying the early intervention requirements.

At present, this section of the rules does not reference supports that may be required by the participant on an episodic basis.

Problems associated with the under-utilisation of plans would be further diminished by orientation and mobility training being identified as a core support rather than a capacity building support (which is currently the case). Funds that are allocated to core support activities are able to be shifted around to pay for other vital supports and services such as transport, Consumables and daily activities relating to social, community or civic participation. Because orientation and mobility training is currently identified as a capacity building support, funds cannot be shifted across to any of these activities, and participants are generally hesitant to access supports that would contribute to genuine capacity-building for fear of being left without enough funds to cover vital orientation and mobility training.

### **Recommendation 3:**

Section 6.4 of the NDIS (plan management) Rules 2013 must be amended to recognise the need for supports that may be of an episodic nature, such as orientation and mobility training, to be described generally rather than specifically identified in a participants plan.

### **Recommendation 4:**

Rather than requesting a full plan review every time a new support need arises, participants who have been identified as having support needs of an episodic nature should be able to request a "support adjustment". This would allow for funding to be

allocated quickly to fulfil support needs that emerge at different points in time. At full roll out, support adjustments should be able to be processed within one week of the initial request. The NDIA should work with service providers currently delivering specialist blindness services to determine how much funding the agency should set aside per year for supports such as adaptive technology training and orientation and mobility training.

#### **Recommendation 5:**

The NDIS price guide should be adjusted to recognize orientation and mobility training as a core support rather than a capacity building support.

## **Issues arising in relation to plan implementation**

### **1. Self-management**

Since the scheme commenced full roll out in July 2016, we have received an increasing number of complaints relating to the inaccessible nature of information provided by the NDIA. Complainants have reported issues with the accessibility of:

- Personal plans
- Generic information that is provided to self-managing participants about registered providers
- Information about the complaint process, and the complaint process itself
- Information on the NDIS website

Many people who are blind or vision impaired would be happy to self-manage their plans, which would in the long term, amount to a significant saving for the NDIA. However, all processes, including the logging of expenses, keeping receipts in an accessible format, and creation of invoices etc., must be accessible for all. The lack of accessibility for such processes at present prevents people who are blind or vision impaired from independently self managing their plans, and creates fear and anxiety for people about attempting to take on this task. Hence, the option of self management is not considered as a viable prospect for many people who are blind or vision impaired at present.

Another factor which may be impacting on the numbers of people taking on the task of self-management is that planners may not be discussing the option of self management with people with disabilities. This can occur if planners have low expectations for people with disabilities about what they are capable of achieving independently. Low expectations are a factor that is a common barrier for many people with disabilities preventing them from reaching their full potential. The creation of accessible self-management processes would be a very practical measure in addressing the tendency by society to have low expectations of people with disabilities. This step may also positively influence outcomes in other areas such as employment for example, once others understand that it is the accessibility of processes that impacts most upon the ability of a person to complete tasks efficiently and independently.

### **2. Support coordination**

The Productivity Commission's issues paper asked organisations responding to the inquiry to provide reasons that may account for the under-utilisation of plans during the

trial period. We have already outlined some of the reasons for the under-utilisation of plans in section 3.3 of this submission, however it is also likely that there are transitional issues associated with some of these outcomes.

BCA suspects that some people are still not taking full advantage of their plans due to the shift in mind set that is required with the transition to an individualised funding model. This observation is supported by data from the NDIA's 2015/16 annual report, which showed that participants utilised more support in their second plans compared to their first plans.

This data is unsurprising when considering that until recently, people with disability have had little or no control over the services they receive. While the principles of choice and control are crucial to the NDIS, further support is required to build the capacity of people with disability to adjust to this monumental shift and ensure plans are being utilised to their full capacity. Due to the speed of the roll out, we are increasingly concerned that participants are not always being made aware of the full range of options in regards to plan management and support coordination and as such, their plans do not always include the support that will enable them to put their plan into action. Such support is especially crucial for participants who may have difficulty self-managing due to the requirement for funds to be managed through the online portal; as there are still many people who do not have access to, or do not feel comfortable using this technology.

**Recommendation 6:**

Support coordinators need to be located in close proximity to participants and should have specialist understanding of particular condition or impairment.

## **Issues arising in relation to scheme boundaries**

### **1. Ensuring adequate support for people with disability aged 65 and over**

#### **a. People who were born with or acquired disability before the age of 65**

The terms of reference for the Productivity Commission's 2011 inquiry into disability care and support indicated that the proposed scheme was:

"intended to cover people with disability not acquired as part of the natural process of ageing".

In other words, if a person is over the age of sixty-five but acquired a disability earlier in life, they should not be discriminated against based upon their age at the time of application for the scheme. Despite this fact, however, people with disability who are aged 65 or over when the NDIS rolls out in their area are not currently eligible to receive an individually funded package of supports under the scheme.

The Parliamentary Joint Committee on Human Rights has expressed concern with the age 65 cut-off under the NDIS from the outset. In its report on the NDIS Bill 2012, the Committee noted the following in relation to the age 65 cut-off:

"This assumes that the aged care system does or will deliver all the forms of assistance and support required, and is organised in accordance with the principles and operates



in compliance with the obligations set out in the CRPD and the NDIS. While the incidence of disability may increase with age, the assumption that a person who has lived with disability for many years can transition without difficulty to a different system that may be organised around different principles deserves further examination.”

As correctly identified by the Parliamentary Joint Committee, the aged care system is organised around very different principles to those which fundamentally underpin the NDIS. The Productivity Commission has made a similar observation, with appendix 3 from the 2011 inquiry report stating:

“...in the aged care sector, a major goal is to minimise the rate of loss of autonomy of the person, and preserve people’s links to their current home, familial supports and social networks. This recognises too that people have come from (at least the opportunity of) living a full life.”

The assumption that those accessing the aged care system will have had the opportunity to live a “full life” may be applicable to people who acquire vision loss after the age of 65. People who were born with or acquired disability early in life, on the other hand, have often been subjected to a lifetime of discrimination and exclusion and have not had the same opportunities to accumulate wealth over the lifecycle.

The aged care system was ultimately set up to accommodate the needs of people experiencing deteriorating health due to aging– not people with lifelong and severe disability. It therefore focuses on a far more medicalised model of disability than that which is advocated by our organization and the people whom we represent. Since the introduction of the National Disability Insurance Scheme in 2013, BCA has been approached by several older people with vision loss who have expressed frustration at the lack of disability awareness across the aged care workforce. This lack of awareness is further exacerbated by negative attitudes and misconceptions towards blindness which can be extremely demoralizing for the consumer. As noted in Appendix C from the Productivity Commission’s 2011 inquiry report:

“...the kinds and persistence of disability presenting in the disability system are more varied than in the aged care system, requiring a greater diversity of responses. They involve a large mix of conditions (and co-morbidities), a wide span of intellectual capabilities, complex behaviours and support requirements.”

In its report on the NDIS Legislation Amendment Bill 2013, the Parliamentary Joint Committee on Human Rights referred to the need to review the age 65 cut-off under the NDIS, in addition to the general exemption from the Age Discrimination Act, as part of the two-year review of the NDIS Act. Submissions to the two-year review of the NDIS Act concluded at the end of 2015. When the Department of Social Services was questioned about its revision of the age 65 cut-off as part of this review, it was stated that this fell outside the terms of reference of the review and as such, had not been explored. It is our hope that the Productivity Commission will give careful consideration to this issue as part of the current inquiry, and put forward recommendations that will promote a greater level of equity for older people with disability into the future.

#### **Recommendation 7:**

The eligibility criteria outlined in the NDIS Act 2013 should be amended to allow any person who was born with or acquired disability early in life (not through the process of aging) entry into the scheme.

## **b. People who acquire vision loss after the age of 65**

While BCA asserts that people who were born with, or acquired vision loss before the age of 65 should be grandfathered into the NDIS, According to Vision 2020 Australia, around 80% of vision loss in Australia is caused by conditions that become more common as people age. Ensuring that the aged care system is adequately set up to meet the needs of people who acquire vision loss through aging will therefore become more pertinent in years to come; with one in every four Australians projected to be 65 years of age or older by the year 2056.

We are aware that some people who are blind or vision impaired have had to wait up to 12 months to receive a proper assessment of their needs within the aged care system, while the maximum turn-around time for an individual to start receiving support under the NDIS is up to six months from the date of application. Without timely support, people who are blind or vision impaired are far more likely to experience declining health due to factors such as social isolation and loneliness, depression and anxiety and potential falls. We assert that people with permanent disability, including people who are blind or vision impaired should be properly recognized as a “special needs” group in the Aged Care (Living Longer Living Better) Act 2013, with individuals within this “special needs” group being placed on a priority wait list to ensure they are able to access the support they require in a timely manner.

At the heart of the inequity between people who can access the NDIS and those who are forced to access the Aged Care system despite having a long term disability, is the fact that while people under the NDIS are not subject to co-payments for services which are specific to their disability, people with a disability under the Aged Care system are subject to co-payments for these services. BCA members over sixty-five have reported that services they genuinely require such as garden maintenance and cleaning have risen up to 500% since the introduction of My Aged Care. BCA calls for such inequities created by co-payments for people over the age of sixty-five with disabilities to be removed.

### **Recommendation 8:**

The Aged Care (Living Longer Living Better) Act 2013 must be amended to include people with permanent disability (including people who are legally blind) as a “special needs” group.

### **Recommendation 9:**

The rules for co-payment under My Aged Care should be reviewed, with an exemption being applied to specialist services and supports that are uniquely required by people with permanent and profound disability.

### **Recommendation 10:**

The government must commit to a comprehensive education strategy to provide older people with disability with up-to-date information about aged care services. This information must be provided in plain English, and in alternate formats that are accessible to people who are blind or vision impaired.

### **Recommendation 11:**

Staff working across the Aged Care Contact Centre and Aged Care Assessment Teams must undertake mandatory training on disability awareness. This training must be based

on the social model of disability and must be delivered by people with lived experience of disability. The training must also aim to inform staff about challenges that are specific to different diagnostic groups, such as people who are blind or vision impaired.

## **2. NDIS as a scheme of last resort**

The issues paper that was published to help form the basis of this inquiry questioned whether there should be a scheme of last resort for people whose needs would otherwise not be met, and whether this should fall to the National Disability Insurance Agency to administer. Such an approach would provide an important safety net for people with disability who currently fall outside the NDIS. This approach would also align closely with recommendations put forward by the Productivity Commission in its 2011 inquiry report. The report noted that In exceptional cases, the scheme should also include people who would receive large identifiable benefits from support that would otherwise not be realised, and that are not covered under the eligibility criteria for the scheme. The Productivity Commission also recommended that guidelines be developed to inform the scope of this criterion.

Additionally, we refer to the NDIS Information, Linkages and Capacity Building Framework which states:

“The NDIS should have capacity to provide ease of access to one off low cost supports or low cost equipment where it is sufficient to facilitate independent living or social and economic participation, or reduce potential future support costs and requirements.”

There may be instances where people who acquire vision loss after the age of 65, or who would otherwise not meet the eligibility criteria for the NDIS could benefit from the provision of one-off supports; such as a talking barcode scanner, a stand-alone talking scanner to enable them to read their mail independently or other aids and equipment. In these instances, it would be beneficial for the NDIS to fund these supports.

The NDIA could also play a key role in providing assessments for older people with permanent disability and complex needs for support. Peak body, National Disability Services has previously acknowledged that when older people are being assessed by an Aged Care Assessment Team, the person undertaking the assessment may have difficulty understanding what level and types of support a person with permanent disability may require. While the supports might ultimately be funded by the aged care system, there could still be a role for the NDIA to play in providing specialist assessments that focus on the individual’s disability-related needs.

### **Recommendation 12:**

People with disability accessing support under My Aged Care should be able to request a specialist disability assessment through the NDIA in instances where their support needs are not being adequately addressed through the aged care system.

### **Recommendation 13:**

The NDIA should reserve a pool of funds for the purpose of providing one-off or low-cost supports for people who are ineligible for the NDIS who would benefit from such interventions, and whose support needs would otherwise remain unaddressed. Information about the nature and type of supports to be funded by this approach should be clear and transparent, and should be developed in close consultation with people with disability and their representative organisations.

### **3. Interfacing arrangements between the NDIS and the Health system**

NDIS participants who are blind or vision impaired have reported substantial difficulty obtaining funding for essential low cost items such as white canes and magnifiers. This appears to be due to inconsistencies regarding decisions over what should be funded by the NDIS and what should be funded through the health care system. The NDIA has explained the decisions about what should be funded under the NDIS by saying that items which relate only to function should be funded under the NDIS. This position is certainly not clear for the consumer, and the Department responsible for funding such items is of little concern to someone who simply needs a piece of equipment that could dramatically improve their quality of life.

Additionally, although the NDIS was introduced to create a more nationally consistent approach to the provision of disability services, there are currently differences in the supports that are approved in different roll out areas. A planner in one part of the country may not question the NDIA's role in providing a particular item,

While a Planner in another part of the country may refuse to fund the support based on an assumption that it is the responsibility of the health system. This demonstrates that criteria can be interpreted in a number of ways depending on peoples' individual value bases.

Equipment such as white canes and magnifiers are essential products that are key to the independent functioning of people who are blind or vision impaired. They enable people to complete daily tasks efficiently and are vital tools that aid people to overcome environmental barriers that prevent them from participating fully in social and economic life.

Oral melatonin, which is used to address the issue of non-24 hour sleep/wake disorder amongst people who are blind or vision impaired, is a good example of a product which causes controversy when it comes to making decisions around what will and will not be funded in borderline cases where the difference between health and functional benefits is not clear cut. This product is not typically approved as a reasonable and necessary support at present, as it is deemed to be a health-related therapy and therefore, not the responsibility of the NDIS. It could be argued however, that while it is true that melatonin is a health-based intervention, there are many other examples where the NDIA has approved medical therapies under NDIS plans. there is also extensive evidence available to demonstrate that non-24-hour sleep/wake disorder is a direct manifestation of blindness which has an enormous impact on an individual's level of functional limitation and participation restriction. Some individuals have described this unconventional sleeping pattern as being the "second most burdensome aspect of blindness"

Melatonin is still not recognised under the pharmaceutical benefits scheme and as such, remains out of reach of many people who are blind or vision impaired. In light of the fact that the NDIS was established with the intention of increasing the inclusion and participation of people with disability, it is worth considering the social and economic impacts of failing to fund such a vital support. One BCA member told us:

"I can't tell you how having Melatonin has so revolutionised my existence! It sounds like a sales pitch, but every word is true, and I would hate to continue a situation in which

people are not able to access Melatonin due to cost. It is essential in my view for people's sense of well being, not to mention their productivity levels if we really have to comment on its economic benefits! But it is true that being alert throughout the day makes the world of difference, and it's something that most of us take for granted."

**Recommendation 14:**

The NDIA should enter into a memorandum of understanding with the health system to clarify which supports are to be provided by which Department. This memorandum of understanding must be publically available, so that it is able to be used as an advocacy tool by participants attempting to access support under either system.

#### **4. Interfacing arrangements Between the NDIS and the Education System**

The Australian Blindness Forum and the Disability Reference group for the Victorian Department of Education have noted that the relationship between the NDIS and the education system is fraught with issues. The matter of who should take responsibility for what has become politicised and centred around costs. As a consequence, children and their families are receiving mixed messages about different interventions and who is responsible for funding them.

Education departments refuse to take responsibility for the provision of services such as braille or equipment that children desperately need both at school and at home, because they believe the NDIS should be responsible for these supports. All this bickering between departments does is put the education of children with disabilities in great jeopardy. Education comes at a cost.

It is imperative that teachers and therapists employed by the education department work in conjunction with therapists contracted by the NDIS to ensure that holistic plans are developed for each child in order to avoid potential contradictions in interventions. An holistic approach involving all parties provides the opportunity to determine what areas education departments in each state will address, and what the role of therapists contracted through the NDIS will be. It is also essential that staff from all state departments of education understand and acknowledge their role in accommodating the needs of children with disabilities, and carry out these responsibilities to their full extent. Every professional in a child's life must embrace disability and provide the necessary accommodations.

BCA acknowledges that the federal government has not delivered the needs based funding recommended in the Gonski report for children with disabilities. Both governments and professionals in the education system must understand that the NDIS should not be seen as the only scheme solely responsible for catering for the needs of people with disabilities. Education departments have a critical role in insuring that a child who is blind or vision impaired reaches their full capacity, and should be funded appropriately at both state and federal levels to carry out their responsibilities, external from the NDIS. The provision of services such as material in accessible format, and specialist teachers to help children learn essential skills such as braille and orientation and mobility techniques are clearly the responsibility of education departments, as they are skills which are required for literacy, social participation and independent living.

At the tertiary level, BCA continues to receive complaints from tafe and university students about inaccessible digital learning platforms, accessible format material not being provided in a timely manner, and lecturers having no understanding of the accommodations they need to make for people who are blind or vision impaired. The roll-out of the NDIS has led to an increase in these complaints, as universities attempt to deflect responsibility for providing necessary accommodations to the NDIS. Again, meeting the needs of people with disabilities is everybody's responsibility. Attempts by universities to cut costs by deflecting responsibility onto the NDIS to fund necessary services and equipment is discriminatory and promotes the exclusion of people with disabilities.

As per BCA's recommendation in section 5.2 of this submission, the NDIS should be regarded by schools and universities alike as a scheme of last resort. As an interim measure, until appropriate levels of funding are provided to state education departments to cover the costs of providing services and equipment for children with disabilities, the NDIS should fund the unmet needs of students with disabilities. This should not however be a long term solution.

Block funding is still an appropriate model for specialist early intervention services such as the delivery of "Dots For Tots", a pre-reading program designed to introduce children under school age to the concepts of braille. The removal of block funding to services such as this vital intervention program could mean that children who are blind or vision impaired miss out on foundational literacy skills, and may struggle for the rest of their lives as a result. This would naturally result in significantly increased costs as children who grow up without these skills seek support to cope with an impact of their disability which could have been prevented if the certainty and security of these vital specialist services had been guaranteed.

## **5. Interfacing arrangements between the NDIS and the transport system**

The NDIS was established based on an understanding that all states would contribute to the costs of transport via the existing subsidies. That is, the state a person lives in provides half the cost of transport, and the NDIS would cover the second half of the cost. Similarly to areas such as health and education, however, the issue of transport for NDIS participants has become increasingly politicised.

State Governments are now claiming that they no longer have a need to provide subsidies for people receiving the NDIS for transport costs. Each state is taking a different position on this matter, making it difficult to provide people who are blind or vision impaired with accurate information about how they will be affected. Firstly, BCA calls for all states to pull their weight when it comes to covering their share of transport costs, and to desist from avoiding their responsibilities when it comes to supporting people with disabilities in partnership with the Federal government. Because of differing policies between states regarding taxi subsidies in particular, it is perhaps a good time to consider the formation of a national transport subsidy scheme, which would truly and adequately support the transport needs of people who rely on taxis as their primary method of transport. While Victoria offers its subsidy recipients half price fares up to the value of \$60.00 paid by the government, Queensland offers a mere \$25.00 half price subsidy. This has resulted in people who are blind or vision impaired being treated less favourably in some states, and leads to the perception that some states are more disability friendly than others. A national taxi subsidy scheme would mean that a

consistent level of support could be provided to people who are blind or vision impaired, and to others who depend on taxis for transport throughout the country.

People who access community transport are also being affected by the politicization of transport funding. Until recently, state based community transport programs were block funded. With the roll-out of the NDIS and My Aged Care has come the expectation from service providers that people needing to access community transport will have a package from which the cost of the service can be drawn. This means of course that people who are not accessing either of the schemes are missing out on the community transport services they rely on to attend essential appointments. The Productivity Commission's 2011 report recommended that Tier 2 of the NDIS would include the continuation of block funding to cover community services, such as community transport. This recommendation was not implemented, resulting yet again in gross inequity for people who cannot access the NDIS or My Aged Care.

**Recommendation 15:**

That block funding continue to be provided to organisations offering community transport so that every person who needs the service can access it, regardless of whether or not they are eligible for the NDIS or My Aged Care.

## **Issues Arising as a Result of the Current Approach to ILC**

### **1. Inadequate funding for specialist blindness services**

In the report from its 2011 inquiry into disability care and support, the Productivity Commission eluded to the fact that tier 2 of the scheme (now known as Information, Linkages and Capacity Building), would include a number of block funded programs to ensure the continuation of services for people who would not be eligible for the NDIS. Back in 2013, when the federal government introduced amendments to the NDIS Act, there was an acknowledgement that vision services might require such an approach. A joint press release that was issued by The Hon Jenny Macklin MP and Senator Jan McLucas at the time stated that:

“existing services for older Australians, such as hearing and vision services, that complement the assistance available through aged care will also continue to provide supports to people who develop a disability after age 65.”

The activity streams listed in the current Information, Linkages and Capacity Building framework do not allow for the continuation of block funding for services that are tasked with addressing the needs of the many people who are blind or vision impaired who will not be eligible for an individually funded package of supports under the the NDIS and as such, there is a very real risk that specialist blindness services will not be financially sustainable into the future. As demonstrated in section 3.1 of this submission, the vast majority of people accessing services from specialist blindness providers will not be eligible for an individually funded package of supports under the NDIS. Additionally, while some NDIS participants will continue to access these services into the future, many blindness-specific services are generally required episodically, or for rehabilitative purposes, and are not required on a long-term basis. This means that payments providers receive through individually funded packages is unlikely to be consistent enough to cover the costs of staffing and overheads.

At a bare minimum, specialist blindness services that were receiving block funding under previous arrangements should continue to receive transitional funding to enable them to adjust to the new business environment leading up to full roll out of the NDIS. At full roll out, however, we assert that providers should continue to receive a proportion of the funding that was available to them prior to the introduction of the NDIS; in recognition of the fact that the vast number of clients accessing specialist blindness services will not be eligible for an individually funded package of supports under the scheme. The amount of block funding to be provided should be calculated according to the proportion of clients aged 65 and over who accessed specialist services during the previous financial year. This approach would be consistent with recommendations put forward in the Productivity Commission's 2011 report in regards to Tier 2 of the scheme.

We acknowledge that this is a complex issue, and urge the Productivity Commission to try to find a workable balance between providing choice and control for NDIS participants and ensuring the availability of specialist blindness services for those who fall outside the scheme. It is imperative that people who are blind or vision impaired who are eligible for the NDIS are not locked in to using block funded providers if this is not their preference, as is currently the case for some in kind services that are already being provided under the NDIS.

**Recommendation 16:**

specialist blindness services that were receiving block funding under previous arrangements should continue to receive transitional funding to enable them to adjust to the new business environment leading up to full roll out of the NDIS. At full roll out, however, providers should continue to receive a proportion of the funding that was available to them prior to the introduction of the NDIS; in recognition of the fact that the vast number of clients accessing specialist blindness services will not be eligible for an individually funded package of supports under the scheme.

**2. LAC agencies unable to meet the needs of the broader population of people with disability**

In 2015, the Council of Australian Governments published a document entitled: 'PRINCIPLES TO DETERMINE THE RESPONSIBILITIES OF THE NDIS AND OTHER SERVICE SYSTEMS'. This document states:

"The interactions of people with disability with the NDIS and other service systems should be as seamless as possible, where integrated planning and coordinated supports, referrals and transitions are promoted, supported by a no wrong door approach."

In order for a "no wrong door approach" to be effective, the focus needs to be on the needs of the consumer. The government has made it clear that Information Linkages and Capacity Building, or ILC, will play a crucial role in assisting people with disability who are ineligible for an individually funded package of supports under the NDIS to access the supports that will best meet their needs. It is our understanding that this work will fall largely to Local Area Coordinators; whose work forms the centerpiece of the ILC system.

According to the ILC Commissioning Framework, one of the primary responsibilities of Local Area Coordinators is to:



“Provide short term assistance to people who do not have an NDIS plan to connect into mainstream services and community activities.”

It is clear that the role of Local Area Coordinators was always intended to extend well beyond people with disability who are eligible for an individually funded package of supports under the NDIS. At present, however, agencies that have been tasked with undertaking Local Area Coordination are being inundated by work arising in relation to the roll out of the NDIS, which means their primary focus has been on the development of NDIS plans. While this is likely to be a transitional issue, This means there are still very few information and referral mechanisms available to effectively meet the needs of people with disability who currently fall outside the NDIS.

**Recommendation 17:**

The government should Commission an independent audit of LAC services at full roll out to ensure they are adequately resourced to provide information, linkages and referrals for all people with disability into the future.

## **Conclusion**

**BCA echoes the support for the NDIS which the Australian Federation of Disability Organisations (AFDO) expresses in their submission. The NDIS is the most important opportunity we have to level the playing field for all people with disabilities throughout Australia. It is however imperative that the efficiency and effectiveness of the NDIS is not purely measured in terms of financial costs. The positive impact both for individuals and society as a whole of providing a generous level of support to people with disabilities, regardless of whether they access the NDIS or other forms of support, must be regarded as a positive and fundamentally valuable outcome. If the emphasis remains on cutting financial costs however, the potential people with disabilities have to contribute enormously to society in many ways, (including financially), may never be realised, as people**

**continue to be short-changed by solutions which might be cheaper, but which do not fulfil the needs of people as well as higher cost solutions could do. BCA also recognises that service providers are struggling to adjust to a brand new model of service delivery, and believes that there are benefits to continuing block funding to some extent for both consumers and service providers in the longer term. This should not however, limit the choice and control consumers have over how they access services. Finally, it is critical that the interfaces between the NDIS and state-based departments such as health and education are streamlined so that strong relationships are formed without political interference between the NDIA and vital services run by the states. Children and people who are vulnerable will continue to suffer a lack of services and support as long as there are arguments about who should be funding what interventions, services and equipment. Memoranda of understanding which clearly spell out agreements about these matters need to be developed quickly and in good faith by all parties.**