

About Blind Citizens Australia

Blind Citizens Australia is the peak national consumer body of and for people who are blind or vision impaired. 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. As the national peak body, we have over 3100 individual members, 16 branches nationwide; in metropolitan, regional and rural locations. Blind Citizens Australia is also affiliated with 13 other organisations that represent the interests of Australians who are blind or vision impaired.

Blind Citizens Australia provides an individual advocacy service for people who are blind or vision impaired who experience unfair treatment or potential discrimination on the basis of their disability. We also develop policy, work with all levels of government to improve the rights of people who are blind or vision impaired and provide information and peer support.

To inform this review, Blind Citizens Australia held 12 forums around Australia and six teleconferences to speak with and hear directly from people who are blind or vision impaired. Members of Blind Citizens Australia were also encouraged via our email lists, website and weekly radio program to provide feedback on the recommendations of the draft report. In total, Blind Citizens Australia spoke and received feedback from 229 people. Blind Citizens Australia also spoke with 126 people in the lead up to the forums to raise awareness and gauge interest in the proposed National Disability Insurance Scheme.

This submission has been informed from the feedback we have received and has been developed in consultation with our National Policy and Development Council and Board of Directors. This submission exclusively focuses on the proposal for Tier 3 funded support, with a short focus on the proposal for a National Injury Insurance Scheme (NIIS). This submission has been prepared in sections, with quotes from our forums and teleconferences included throughout the submission. A complete set of our recommendations can be located in Appendix A. A complete set of the quotes included in this submission can be located in Appendix B. This submission is available in large print, audio, Braille and in electronic formats on request for access by people who are blind or vision impaired.

Executive Summary

Whilst this Inquiry and its proposal of a no fault national disability insurance scheme (NDIS) takes a very important step in the right direction, Blind Citizens Australia on behalf of people who are blind or vision impaired do not believe that this scheme, as proposed, will fundamentally address the full range of support needs of people who are blind or vision impaired. In this submission, we highlight a number of areas which require further clarification and amendment in order to meet the needs of people who are blind or vision impaired.

Firstly, Blind Citizens Australia is concerned about the exclusivity of the current proposal. Whilst we recognise that the scheme must be sustainable in the long term, we are equally mindful that the current proposal will create a situation of “have and have nots” purely on the basis of age and an arbitrary assessment of how desperately a person may require support. We are deeply concerned that people aged over 65 who acquire their disability later in life and individuals who are vision impaired will not only miss out on support through an NDIS, but

may be burdened with additional costs to access services that are currently provided for free or at low cost. We are also concerned that true cost of blindness has been under-assessed.

It is our assertion that all people who are blind or vision impaired must be able to access the supports that they need at a comparative level to people who may be eligible for the NDIS. At present, it is unclear who will be covered by the scheme and who will miss out. The extent of the blindness related supports which will be covered by an NDIS is also unclear. Blind Citizens Australia maintains that the supports provided by an NDIS must be tailored to the needs of people who are blind or vision impaired, as the majority of these supports, as they currently stand, are designed to assist people with profound physical disabilities. Likewise, the process of assessment requires further consideration to ensure that the episodic, but very necessary needs of people with sensory impairments are not missed or under prioritised.

Secondly, our focus is to ensure that high quality and accessible services are available to meet our needs, now and into the future, as outlined in our mission statement. The phasing out of block funding, whilst presenting opportunities for the development of innovative supports, may detrimentally affect the sustainability of specialist services in favour of more generalist services. Many of the people we spoke with do not believe that the current system for people who are blind or vision impaired is broken enough to warrant a complete reform of the entire disability system. Whilst some reforms could be beneficial, such as portable assessments and the ability to choose where supports are accessed, people who are blind or vision impaired expressed an overwhelming concern of the effect of phasing out of block funding on the quality and range of specialist services. Current services offered could be eroded by the introduction of generalist providers with limited knowledge of vision impairment and unqualified professionals offering very niche services. We also do not agree with the Productivity Commission's recommendation that formal training should not be required of all employees.

Blind Citizens Australia is concerned that the limited reach of the proposed scheme will lead people to embody dependence in order to access supports via an NDIS; which is contrary to our key message of empowerment.

Blind Citizens Australia calls for advocacy services which are independent of service providers and funded from a portion of the NDIS budget, rather than from an individual's support package. The provision of a well resourced and well informed information gateway is vital to ensure that individuals can make an informed choice, as is an independent National Disability Insurance Agency (NDIA).

Blind Citizens Australia agrees with the Productivity Commission's recommendation that an NDIS remain separate to the Disability Support Pension and recommend that this be legislated and extended to include reference to the Disability Support Pension (Blind). Whilst Blind Citizens Australia supports efforts to increase the workforce participation of people who are blind or vision impaired, this should not be enforced at all cost to the detriment of individuals.

To be inclusive of the needs of people who are blind or vision impaired, an NDIS model must provide assurances that those who fall outside the scheme will still have comparative and equivalent access to publicly funded care and support. One of our recommendations focuses on the continuation of some block funding to specialist providers to continue to provide core

services necessary for people who are blind or vision impaired. Refer to Appendix A for the full list of recommendations.

What is the true cost of blindness and vision impairment?

The Productivity Commission has estimated that \$6.2 billion is currently spent per annum on disability services, which includes services to assist people with sensory disabilities and has recommended an additional injection of \$6.3 billion per annum to meet unmet need. Whilst Blind Citizens Australia commends the recommendation to substantially increase funding, we contend that \$6.2 billion does not reflect true current spending for people with disability as this figure relates exclusively to government funded services. This figure excludes vital services offered by unfunded community services, not for profit organisations, services provided by non-funded or only partially funded disability service providers and volunteer run services such as support groups.

Historically, the level of government funding to blindness rehabilitative services has been poor when compared to funding for the physical and intellectual disability sectors. The numbers of people experiencing blindness has also traditionally been smaller than other sectors. As such, people who are blind or vision impaired have been reliant on the charitable dollar to access the services that they need.

At present, most service providers who provide services to people who are blind or vision impaired only receive a portion of their funding from state or federal governments which ranges between 5% to 35% of total operating budgets. Many of these providers are heavily reliant on charitable donations, grants and bequests to continue to provide a range of rehabilitative and early intervention services to people who are blind or vision impaired. Importantly, most people who are blind or vision impaired currently receive free or low cost access to specialist services irrespective of the severity of their vision impairment or their age. Timely service access is however dependent on agency waiting lists, geographic boundaries and reach and resourcing, including staff and financial resources.

“There's no [funded] place in Tas to teach me to cope and live on my own. About four years ago, I went to a place in Kew, Victoria (Guide Dogs Victoria) and paid them to teach me to live and cope on my own and they taught me how to fill a mug of tea without burning myself. This cost me several thousand dollars all up”. Female, Launceston.

Blind Citizens Australia is concerned that the true cost of blindness has been under assessed and therefore could potentially be under funded within an NDIS. Blind Citizens Australia is particularly concerned that an NDIS, as currently proposed, will only support people who have been long term blind and those who are legally blind and will fail to support people with vision impairments who are currently accessing supports at no or low cost.

To what extent does blindness and vision impairment fit within the currently proposed NDIS?

It is proposed that Tier 3 of the NDIS will cover 360,000 people who experience core activity limitations with mobility, self care and communication. Whilst Chapter 14 does make reference to ‘sensory conditions including vision, hearing and speech’ and Appendix H (Health conditions used to estimate Tier 3 criteria) does reference eye conditions, it remains

unclear where the line of eligibility will be drawn. Furthermore, it is noted in Appendix H that ‘...a positive listing of a given condition...does not necessarily mean that any given person with that condition would be eligible for funding under the scheme.’ This leads to greater uncertainty as to who will be in and will be out.

Demographics

In Australia in 2009, there were almost 575,000 Australians aged 40 or over with vision loss. Of this entire population, around 66,500 people were blind. By 2020, it is projected that there will be 800,000 people who will be blind or vision impaired.¹ These figures do not take into account people who are blind or vision impaired under the age of 40. It is obvious that not all people with a vision impairment will be covered by the proposed scheme. Furthermore, the estimate of 360,000 people does not seem to take into account the expected and projected growth of sensory disabilities within the next ten years.

As recommended in our initial submission to this Inquiry, Blind Citizens Australia recommends that an NDIS should cover all people with a vision related disability who require disability related support. At minimum, people who are legally blind and those with a visual acuity of less than 6/18 should be covered by an NDIS, with an open process to assess individuals who may fall beneath these levels but have demonstrable needs for support.

RECOMMENDATION 1:

That all people with a vision related disability who need disability related support should be able to access the supports that they need through an NDIS.

Blind Citizens Australia supports the Productivity Commission’s recommendation that the assessment of an individual should take into account a person’s individual goals in addition to medical criteria. We strongly assert that eligibility should never rest on medical details alone, but be determined through a transparent process that places trust in the person with disability to speak honestly about what supports are needed to enable meaningful participation.

Age related restrictions

A key area for concern amongst people who are blind or vision impaired is the proposed entrance cut off of 65 years of age. We are mindful that this requirement has been set by the Federal Government in the Terms of Reference for this Inquiry.

Figures from Access Economics indicate that over 70% of people who currently experience vision loss are aged 70 and above, with macular degeneration the leading cause of blindness and vision impairment².

Whilst the 65 age cut off has been proposed to ensure the sustainability of the scheme for those who are eligible, this age restriction is likely to create a situation of ‘have and have nots’ purely on the basis of age. Put simply, whilst a person aged 64 might be able to access the scheme and the supports they need, another aged 65.5 would not, even where both have the exact same needs.

¹ Access Economics (2010) *Clear Focus - The economic impact of vision loss in Australia in 2009*, Canberra, Australia
www.vision2020australia.org.au/resources.cfm

² Access Economics

As stated in our initial submission, separating two people with the same condition on their age alone is inequitable and in direct contravention of the UN Convention on the Rights of Persons with Disabilities (UN CRPD), which makes no distinctions based on the age of a person. Furthermore, the separating of ageing and disability ignores the fact that some people who are over the age of 65 and losing their vision may still be paying taxes towards a scheme that they will not be able to access. The proposed NDIS, as it currently stands, will only address a very small proportion of all people who experience blindness but fail to address those who may have legitimate needs. This would appear to contradict the Productivity Commission's statement that people would not be worse off with the introduction of an NDIS.

"Eligibility has nothing to do with age but everything to do with disability...I don't think there is any evidence that when you reach pension age your needs, in a financial sense, decrease or you become wealthier. I cannot imagine any other reason why they would be suggesting that means testing suddenly become applicable at that age (at age 65)", Female, Sydney.

"I've been going to Dr Vernon for years, I don't want to go to someone else. I can stay in town overnight when I visit him but I can't afford to do that now. When you are over 65 who pays for that? Female, Launceston

The draft report notes that memorandums of understanding would be reached between relevant sectors, including the aged care sector, to ensure that people do not fall between the cracks. We do not believe that the current aged care system, the reforms proposed to improve the system (as proposed in the Caring for Older Australians draft report) nor the promise of a memorandum will address this shortfall.

"When the nursing homes for the blind closed down, it was said that all other nursing homes would cater for the blind and vision impaired people. We have come to realise that the promises made by these nursing homes in the end did not meet all the requirements of the blind and vision impaired'. Male, regional Victoria.

"I see a great need for [an NDIS for] people with severe disabilities. Speaking for myself, I live in the city and get lots of support from the Association of the Blind WA even if there is a waiting period. At least it is there. There is nothing much for regional people and I'm not too sure about the facilities available to the aged. Personally looking at the age where I am now, it looks terrible getting old in Australia and it's a sad sort of area to go to. I am not looking forward to it as the system seems to be struggling rather than keeping along with the community. The aged are almost a forgotten group of people." Female, Perth.

Blind Citizens Australia recently presented at the Caring for Older Australians public hearing and made a written submission to the Federal Government's Senate Inquiry into people ageing with disability. Older people who are blind or vision impaired have consistently noted that the aged care sector is currently ill equipped to provide

- equitable access to low and high tech aids and equipment
- expertise and practical understanding of the effects of blindness and vision impairment
- early and timely referrals to service providers specialising in blindness, particularly in instances where sight loss may be under played by an individual to not create "a fuss" or be viewed as part of the natural ageing process by staff and support workers
- accessible facilities and settings, with activities which actively include people who are blind or vision impaired

- more than basic home and community care assistance to continue to enable individuals who are blind or vision impaired to live independently in their homes

Blind Citizens Australia asserts that professionals working within the aged care sector often have little or no experience working with people who are blind or vision impaired and are often ill equipped, untrained or unwilling to provide direct support which is inclusive. There is often a reliance on individuals to “speak up” and self advocate their needs, however many individuals remain silent due to the fear of compromising what little service they receive.

The needs of people who are blind or vision impaired will not be fully met until reforms are made to the aged care sector, which include the development of a well skilled, trained and resourced workforce who have a good working knowledge of disability and the provision of increased funding to provide equitable access to the supports that older people need to negate their disability.

Most people aged over 65 at our NDIS forums did not believe that the aged care system would meet the comparative needs which would be offered under an NDIS. Most who had acquired their sight loss later in life were not aware of the aged care services that were available to them or noted that the services on offer, whilst helpful, do not address their vision impaired specific needs. Many older attendees noted that they were “so lucky” to have their adult children to drive them to appointments or received some good infrequent service through HACC programs which assisted with shopping and cleaning. Not one recipient aged over 65 was able to access necessary aids and equipment.

“They are saying a person aged over 65 doesn’t have the same needs, but they have a right to the same lifestyle as everyone else”, Member, Brisbane.

Many older people who are blind or vision impaired require specialist episodic support, such as assistance to improve their orientation and mobility, targeted occupational therapy, the provision of some adaptive equipment or low tech magnification; the provision of information in accessible formats and community access, such as peer support networks and flexible transport. Whilst it is envisaged that many of these supports would be funded by an NDIS for people who are eligible, there is currently no guarantee that a person who developed their sight loss after 65 years of age would receive the same access to the supports that a person under 65 could access. It is important that this is reassessed as it has been shown that access to timely supports can improve wellbeing, independence and allow individuals to live in their own home for longer.

Furthermore, whilst the draft report proposes an additional injection of \$6.3 billion to disability services, there has been no additional funding allocated to the aged care sector to meet the support needs of people above 65 who are not eligible. There is an implied expectation that people with “less severe disabilities” and people aged over 65 will continue to access the services that are available now in the same manner. This is unlikely to be the case, particularly if block funding to service providers is phased out (which is detailed shortly in this submission).

A secondary concern is that individuals with “age related conditions” will not be eligible within the proposed NDIS. Whilst conditions such as macular degeneration may be considered to be connected with “natural ageing” rather than “disability”, we are aware of many individuals who have acquired significant sight loss and legal blindness before the age of 65. Despite the

intention to look beyond medical criteria, the exemption of age related conditions creates a situation where a person's medical diagnosis will dictate access to supports. Whilst a condition such as retinitis pigmentosa (a degenerative condition which often does not present significant symptoms until middle age) would likely be included within a NDIS, a comparative condition such as macular degeneration, would not.

Blind Citizens Australia maintains that the provision of supports required by people with visual age related conditions would be minor as compared to people with severe and profound disabilities. Supports needed are likely to include access to episodic rehabilitative services and the provision of low tech equipment, such as magnifiers, which can vastly improve a person's quality of life and independence.

RECOMMENDATION 2:

People who lose their vision after the age of 65 should receive the same access to services and supports as people under that age. Blind Citizens Australia recommends that the NDIS be open to people aged over 65 as this provides the best chance of preventing discrimination and inequality. If two schemes are adopted, Blind Citizens Australia recommends that both schemes must apply the same rules for access, provide equivalent access to supports and deliver resources proportionate to the numbers of people requiring access in each scheme.

RECOMMENDATION 3:

Blind Citizens Australia recommends that visual age related conditions be included within the final NDIS model presented to the Australian Government.

Who will benefit from early intervention?

Research has shown that early intervention for people who are blind or vision impaired can lead to improved wellbeing, quality of life and a reduction in depression. Sensory impairment is referenced in Tier 3 c) which is estimated to cover 80,000 people. Chapter 14 indicates that the early intervention category would cover 'people not already captured under significant core activity limitations' and would cater for people who experience schooling or employment restrictions. The draft report explicitly references coverage for people who experience autism, acquired brain injury, cerebral palsy, multiple sclerosis, Parkinson's disease and sensory impairments.

Blind Citizens Australia believes that there are a number of areas which require further review:

- Five other disabilities in addition to sensory impairment are highlighted. Taking all of these disabilities into account, it appears that the projected number of 80,000 people is too low. This would only address the needs of a very small number of people with acquired vision impairment.
- Schooling and employment restrictions have been explicitly highlighted as areas where early intervention can improve outcomes. As highlighted above, a significant proportion of people develop vision loss later in life and currently receive low cost of free tailored support, such as orientation and mobility, occupational therapy and teaching of daily living skills, to adjust to their sight loss. Under the early intervention proposal, almost all people who acquire sight loss later in life would miss out on early intervention, as these learned skills would not be used to access schooling or employment.

- The Productivity Commission states that the timing and duration of early intervention will need to be informed by good evidence and will depend on the particular disability, type of intervention and individual circumstances. Whilst we support the benefits of individualised assessment, it is imperative that the early intervention eligibility guidelines are clear and transparent.

RECOMMENDATION 4:

Blind Citizens Australia recommends clear and transparent eligibility guidelines for early intervention which include people who acquire significant vision impairment, irrespective of age.

Phasing out of block funding to current specialist providers

An overwhelming proportion of the people we spoke with were very concerned about the proposal to phase out block funding to specialist service providers. Whilst this reform could increase competition and improve choice for people with disability, Blind Citizens Australia has reservations about the complete phasing out of block funding, especially for specialist services that address the very specific needs of people who are blind or vision impaired.

The introduction of an NDIS would lead many disability service providers to review their core services to determine which services should be provided for a fee. Whilst people eligible for an NDIS support package would be able to “purchase” and choose the supports that they need at no personal financial cost, people with significant impairments who are ineligible for the scheme would be required to pay for a service that has been previously provided for free or at low cost. Needless to say, this could significantly increase the cost of accessing services for people with a vision impairment and people aged over 65 who may be solely reliant on the Aged Pension. Once again, this does not sit comfortably with the statement that no person with disability would be worse off by the introduction of an NDIS.

Blind Citizens Australia is also concerned that the introduction of fee for service may lead to a reduction in the numbers of older people who seek the assistance of rehabilitation services. Anecdotally, we are aware that many older people with vision impairments are reluctant to seek the services of a blindness agency due to the perceived shame of “going blind”. The introduction of a fee for service model may mean that already tight pension money is prioritised elsewhere.

The phasing out of block funding also presents a number of other considerations, including opportunities and challenges:

Introduction of generalist rather than specialist providers

Blind Citizens Australia believes that the opening of the market could lead to the development of innovative approaches, such as the development of services which are responsive to a local community (such as more flexible and regular community transport), provide greater flexibility in how and when support is accessed (including greater potential for one to one tailored support) and could potentially provide better access to a greater range of disability supports in regional and rural areas. We also see that there are a number of general supports, such as home and community care, community transport and recreation providers, which could benefit from an open market and lead to increased quality and choice of services.

A number of our members were optimistic and viewed the NDIS as an opportunity to create more competition in their state. Some stated that this would “shake up” service delivery and force all providers, including specialist providers, to provide higher quality, tailored services that could meet currently unmet needs, such as better recreational access and access to adaptive technology training.

“I think it’s a good idea to give you money to have the choice of where you would like to go. If you had the choice to take money to another service provider, it would keep costs down and it would be a better service and more competitive”, Male, Perth.

“It wouldn’t necessarily be a bad thing to take away the money from the charities. We are marketed as poor, pitiful, blind people”, Member, Brisbane forum.

Whilst there are definite benefits to the introduction of competition in the disability services sector, this approach may not be suitable for all services which are currently provided to people who are blind or vision impaired. Services such as orientation and mobility (which teaches an individual who is blind or vision impaired how to safely navigate an environment independently using their remaining sight or an aid, such as a white cane or dog guide), training in the use of adaptive equipment and training in daily living skills are only three supports which are specific to people who are blind or vision impaired. These skills are currently taught by a handful of service providers around Australia who specialise in vision impairment only.

Furthermore, service providers are often currently responsible for providing professional development to train instructors and specialist staff in the specific skills needed to support people who are blind or vision impaired. It is our concern that generalist providers will not have the specific knowledge of vision impairment, which may impact on the quality of the service that a person receives and the skills they learn.

“Vision Australia and Guide Dogs offer more than practical support, there is also emotional support, a group of people working together, sharing skills, feelings, experiences. These skills which have been built up over time are hard to quantify. I am concerned about the loss of these important things”, Male, Mudgee.

People who are blind or vision impaired noted that the phasing out of block funding could lead to

- a decline in the number of skilled professionals available to teach blindness related skills due to the loss of job security
- the establishment of generalist providers who might offer similar services but who are not equipped to provide the same quality of training to an individual and may not be appropriately trained themselves. Blind Citizens Australia is concerned that this could lead to poorer outcomes, and in the instance of orientation and mobility, could compromise personal safety
- sustainability issues for current disability specialist providers, particularly small operators. We are concerned that many current providers may find it difficult to allocate a budget for the same services that are currently offered due to uncommitted funding. Whilst the Productivity Commission has argued that providers should be subject to competitive risk like other markets, this may mean that service providers lose qualified staff and may be forced to reduce specialist services.

- people new to losing their vision may be misled by the credentials of a generalist provider or may receive service access which is inappropriate to their needs.
- a risk of “over-servicing” by asking clients to come in again and again

In order to remain sustainable, many specialist providers may need to re-focus where and who services are delivered to. Service providers may choose to direct their attention to the lucrative age care market by delivering more age tailored services and supports for a fee. This could impact on the types of services offered to younger people and individuals who are legally blind who make up a much smaller percentage of the vision impaired pie.

“Agencies will change their criteria for delivery of their services and that will change what we will be able to access”, Female, regional Victoria.

Establishment of more services may not lead to more choice

Many of our members noted that whilst more choice would be available for certain supports, such as access to recreation which can be accessed by a range of people with disability, supports that people who are blind or vision impaired require are only provided by one or two service providers in each state. Whilst it is true that new providers might establish themselves within the market, many people we spoke with were unconvinced that this would provide any more choice than what is currently on offer. A underlying theme at all of our forums focused on whether people who are blind or vision impaired are currently getting access to the services that they need. Whilst gaps in service provision were raised, for the most part people stated that core services are being met.

“Why is the government now wanting to dismantle what it has taken us so long to already build when it can help us improve what we already have?”...This approach is going to come across to a lot of people as “We’re going to tell you how we’ll help you and it’s going to be good for you”, Female, ACT

It therefore needs to be questioned whether a full reform of the system would lead to better outcomes for people who are blind or vision impaired, particularly when taking into account an NDIS proposal which is not seeking to cover all people who are blind or vision impaired.

“Flexibility of spending money where you choose is a good and strong point of the whole scheme. I am however still questioning if it is not possible to build this in the existing scheme? Even for funding for the autism children fund, I have heard of parents saying that they could only use certain registered people, professionals needed to then register and they then lost 10% of funding to the registration body. This could happen again. Professionals could also charge twice as much as other professionals.”
Member, via teleconference.

Impact on the charitable dollar

Many individuals that we spoke with noted concern that donations to charities, such as guide dog organisations and blindness service providers, would decrease upon the introduction of an NDIS, particularly if the NDIS were to be funded by an increase of marginal tax rates. This is particularly a concern for agencies who receive very little or no government funding and are solely reliant on donor generosity. As the current NDIS model does not propose to cover all people who are blind or vision impaired, there is a significant risk that the current spending on blindness rehabilitative services across Australia will decline. As one member noted:

“Even if we are excluded from the NDIS, the public will still think that we are covered. Why would you donate money if you are having to pay taxes as well?”

RECOMMENDATION 5:

Blind Citizens Australia recommends the continuation of block funding to blindness specialist providers for the provision of core services, including but not limited to, orientation and mobility, training in adaptive equipment, orthoptists, occupational therapy specific to people with vision impairment and information access (for example, the provision of audio books and reading materials in accessible formats). The continuation of block funding for core services will ensure equitable access for people who are blind or vision impaired, irrespective of their level of vision loss or age.

Supports available under an NDIS

People who are blind or vision impaired have very different support needs to most people with disability. For the most part, most people who are blind or vision impaired require episodic supports (eg. orientation and mobility training) and some regular supports (eg. home and community care) to get on with life.

Most of the supports cited in the draft report are relevant to people with high support needs or intellectual disability; most are not relevant or used by people who are blind or vision impaired. Whilst the draft report does cite many of the general supports that people who are blind or vision impaired need (such as aids and equipment, home and community care, employment support, community participation and counselling), it remains unclear to what extent these services would be tailored to the specific needs of people who are blind or vision impaired. Eligibility, once again, is a major concern. Many members expressed concern that an arbitrary “upper limit” would be developed which could significantly impact an individual.

“How accessible will the supports be? Once a person has been allocated a quota of 10 talking books, what do they do if they want an 11th? What about Braille if it is seen to be more expensive? Someone who isn’t blind can go to the library or bookshop, but options are limited for people who are vision impaired.” Female, Melbourne

Aids and equipment, specifically adaptive equipment and low tech equipment

As per our first submission to this Inquiry, Blind Citizens Australia maintains that adaptive equipment is a crucial inclusion within an NDIS. Whilst reference is made to aids and equipment, it is currently unclear from the draft report whether adaptive equipment, such as screen reading software, text enlargement software and devices, and Braille notetaking devices, would be available under the scheme. This is particularly important as aids and equipment for people who are blind or vision impaired are not currently funded by state and territory aids and equipment programs. In WA, individuals may be fortunate to receive adaptive equipment through grants by LotteriesWest.

As an example, a braille notetaking device can cost anywhere from \$3000 for the most basic display through to \$11,500. Global positioning systems (GPS) which assist people to independently navigate an environment can cost up to \$2000. A daisy book reader to enable a person to read audio materials in their own home is around \$600. Computer based software, such as screen reading software, text enlargement or braille translating problems can range from several hundred to a thousand dollars for licencing and renewal costs. These estimates do not take into the account the need for supplementary technology such as a

computer with adequate memory, a mobile phone which has the capacity to run speech software, software renewal costs and other items, such as magnifiers, to make living a quality life possible.

“I had a braille given to me by someone who could no longer use it because of arthritis. I am always concerned about the high costs of equipment that people who are blind need to use. It is disappointing that everything is centred, or has been centred, around working.” Female, SA via teleconference

“A (electronic) reader would be good but I can’t afford it. It would be beneficial when I go shopping and when I go to the post office and need to read smaller print. People are reluctant to help. This would help me to live independently”. Female, Smithfield, SA.

“Technology, readers, scanners - if you are on a low fixed income you can’t access funding for the equipment and technology you need. I either have to take out a bank loan or mortgage to get that technology”. Male, Hobart.

At present, only individuals who are undertaking employment are eligible for adaptive equipment to use within the workplace through JobAccess. This presents an anomaly as an individual may be unable to become workready without sufficient skills and access to their own equipment, which compromises their ability to seek meaningful employment. This has significant flow on effects for people who wish to volunteer, people who are reliant on technology to live within the home and individuals who just want to remain connected to the world. As one male member in metro NSW noted:

“I have been blind for 16 years and I’m finding that my sight is now nil. I’m depending more on more on equipment and finding that my current use of Windows 7 is totally inadequate. I’m worried about learning, the costs of JAWs and who is going to teach me now that the guy at Vision Australia Sydney is gone. I am getting quite scared about losing contact with the rest of the world.”

The inclusion of aids and equipment within the scheme would not only benefit and increase the independence of individuals, but could also reduce the need for additional supports. Many older people who are blind or vision impaired are reliant on family, friends or community volunteers (through HACC programs) to assist with reading mail, accessing print materials and using household items which may be inaccessible. The provision of adaptive equipment could alleviate much of this need and improve independent living. This would also provide cost offsets in the provision of direct support to individuals and lead to long term costs savings for the NDIS.

Many members noted that the cost of equipment is prohibitive to ordinary pensioners, with equipment providers currently charging what they wish. One suggestion from a forum attendee centred on the development of a system similar to the Pharmaceutical Benefits Scheme (PBS), where individuals would have the option to purchase a range of adaptive equipment at a more affordable rate through the NDIA who would be eligible for group purchasing discounts due to bulk purchasing. This could also provide incentives for technology providers to create innovative products. Individuals who are not eligible for the NDIS could purchase equipment outright at a much lower cost.

Blind Citizens Australia sees merit in this suggestion and recommends that the NDIA, once established, investigate the development of an equipment scheme which is available to people within and outside of an NDIS. In the development of a scheme, it is imperative that safeguards are put in place to ensure that equipment manufacturers do not artificially increase the costs of equipment – see quote below - and that individuals are provided with a reasonable choice of high quality equipment to meet a range of needs and uses.

“I recently had a hearing exam done and they classified my hearing loss as moderate. They referred me to a service provider who showed me some hearing aids which the government would pay for. What the government could provide were no good to me. What actually was going to help me was going to cost me \$8000”. Male, Hobart

We also agree with the recommendation that the NDIA actively work to support innovative development and research and believe that adaptive technology is one area which would benefit.

RECOMMENDATION 6:

Blind Citizens Australia recommends that the National Disability Insurance Scheme include and fund aids and equipment specific to people who are blind or vision impaired, including adaptive equipment and low tech aids (such as magnifiers) to increase independence and meaningful participation. Blind Citizens Australia recommends that the NDIA, once establish, investigate the development of an equipment scheme which is available to people in and outside of an NDIS.

Community access

Community participation is a key area where supports are needed. Many of the people we spoke with wanted better access to recreational options, more flexible transport options and more inclusion within mainstream pursuits.

As has been noted in many submissions, many people with disability would benefit from improvements to the built environment and within communities. People we spoke with in Launceston and Smithfield, South Australia, noted that public transport access was insufficient, leaving people with no choice but to rely on family and friends, use the limitedly available system, rely on HACC funded transport or simply stay at home.

“If my daughter can’t help me I have to book a community car or bus 3 weeks ahead. If they weren’t available to me, I’d panic. I try everybody, I call my other daughter. It is an ordeal trying to get a hold of someone. It’s not easy using the phone either. They come and put large print numbers on my phone but it’s still hard to use it”, Female, Launceston.

Education

At the time of writing this submission, the Federal Government had undertaken a review of the effectiveness of the *Disability Standards for Education 2005* (Cth) and a separate review focusing on schooling funding arrangements. Blind Citizens Australia made submissions to both of these reviews which will shortly be available at www.bca.org.au.

Whilst we agree with the Productivity Commission that sectors such as health and education should be required to continue to meet their obligations under the *Disability Discrimination Act 1992* (Cth) and meet the costs of reasonable adjustments, there are many instances where

crossover between an NDIS will and should occur. For example, a student requiring a laptop with speech software for school needs the same equipment to allow them to complete homework - however education providers funding a student's supports often apply restrictions on home use. Where a student moves schools or has finished their schooling, there is no guarantee that the student will be able to retain the equipment; even if this means that it will sit in a school cupboard unused (which we are aware has happened many times). This leaves families with no choice but to make multiple, unnecessary purchases at their own cost due to a lack of flexibility.

Likewise, a student undertaking orientation and mobility training may need to learn how to get around independently within a school setting. Whilst orientation and mobility training is currently free and therefore unfunded by education departments, the introduction of an NDIS will impact on supports that are necessary within an education setting.

It is imperative that supports are viewed as whole of life tools and that NDIS assessments do not simply focus on one dimension of life – such as provision of supports in the home – to the detriment of support which is necessary for the whole of the person's quality of life. Yes, education providers must meet reasonable adjustments but there will need to be a necessary blurring of lines in how supports are provided.

Transition programs are also vital for students transitioning between school settings and into employment and must be considered as a component within the NDIS.

“There are no occupational therapists specialising in low vision. No services beyond year 12. No one to show us how to use a computer with assistive software. If you are 25 years old in Tas, if you lose your eyesight, you can't learn to read and write. It is not the university's responsibility to teach people to read and write. There is also a real deficit in computer training for older people”, Male, Hobart

Employment services

A 2007 survey by Vision Australia revealed that 63% of people who are blind or vision impaired of workforce age were unemployed or underemployed³. At many of our forums, stories were shared of the difficulty in seeking meaningful employment and being given a chance. Many individuals noted the importance of having a choice as to where to access support to gain employment. Many noted that access to employment support within an NDIS should not be restricted to the purchase of disability employment services (DES) support only, but should include mainstream services where this may be in the client's best interest or their direct choice.

Information access

The supports, as currently cited, do not reference information access which is one of the most significant barriers experienced by people who are blind or vision impaired. Estimates state that only 5% of the world's information is available in an electronic format. Whilst adaptive technology can alleviate some of the difficulties in accessing material, this only goes part of the way.

³ Vision Australia, 2007, *Results and Observations from Research into Employment Levels in Australia* via http://www.visionaustralia.org.au/docs/news_events/Employment_Details.doc

At present, major blindness service providers around Australia provide reading materials in a range of accessible formats, including talking books, to people who are legally blind and vision impaired. Whilst public libraries are continually increasing their range of accessible materials, the supply of accessible materials is not keeping up with demand. Many of the people we spoke with were worried that the phasing out of funding to blindness organisations would leave a significant gap in how and where people with vision impairment would be able to access these materials. As one person noted:

“Thing is, only 5% of books actually get read out. If you want it on audio, Vision Australia will say yay or nay re whether they’ll do that for you. If you want to go get it done professionally, it’ll cost you \$4000 dollars to get it read out. What’s this system (NDIS) going to do for that?” Male, ACT

RECOMMENDATION 7:

Blind Citizens Australia recommends that funding continues to be provided to specialist service providers to produce reading materials in a range of accessible formats.

Transport subsidies

The draft report notes that state and territory based taxi subsidy schemes would be included within the proposed NDIS. The inclusion of state run taxi subsidy schemes within a national scheme could present benefits such as fairer and consistent access to the scheme (at present an individual in Melbourne has a \$60 trip cap, whilst in Adelaide this is a \$30 trip cap) and a consistent application of non-means tested access. It is imperative, however, that the nationalising of individual schemes does not lead to a lowering of entitlements currently offered by some states in favour of reaching a national consensus. As an example, people who are legally blind in Victoria receive an uncapped annual subsidy and a higher per trip subsidy.

“The \$25 cut off for the taxi subsidy has not changed since 1984. If you get assessed and are able to get more for medical transport, you only get access to an extra one for medical use per week”. Female, Perth

RECOMMENDATION 8:

Blind Citizens Australia recommends that state and territory taxi subsidies should remain outside of an NDIS, but be subject to a review to ensure greater consistency between schemes. This will ensure that subsidy criteria does not inadvertently become tied with NDIS eligibility criteria.

Coverage of guide dogs and assistance dogs

Whilst most current users of guide dogs we spoke with were in support of the inclusion of guide dogs and assistance dogs with the scheme, particularly the recognition of veterinary costs, there were some reservations regarding who would cover the cost of initial training of the dog and ongoing training of the team (individual and dog). The ongoing viability of current highly skilled organisations was also queried.

Many guide dog organisations around Australia provide a complementary range of specialised services in addition to the provision of guide dogs. Services include orientation and mobility to people using a white cane and other mobility devices, occupational therapy, teaching daily living skills and working with babies and young children to maximise their

functional vision and independence. The bulk of these services are currently funded through charitable donations from the public; donations which are often sourced from the marketing of guide dogs and improving the independence of a person who is blind. As noted earlier, there is a significant concern by both members and organisations that core services currently funded through charitable dollars could disappear if donations decline.

In addition to guide dogs, it is imperative that other mobility tools are also referenced and made available through an NDIS. Only a very small proportion of people who are blind or vision impaired use a guide dog, with many individuals using aids such as a white cane, identification cane or technological aids such as navigation devices to get around safely and independently. These aids are just as fundamental as the provision of a guide dog. It is imperative that individuals have a choice in using the mobility aid that is most suited to their needs rather than assume a one size fits all approach.

“Guide dogs were mentioned, but there is no mention of orientation and mobility for cane users. It’s no use offering me funding for a Guide Dog when I don’t want or need it.” – Female, Perth

“It takes six weeks to get an O&M out for one hour. You have forgotten the training information by the time the person comes out again six week later. If you are in a forgotten area than the services are not being met”. Member, Toowoomba.

Self directed funding

As a consumer body, Blind Citizens Australia supports the proposal for self directed funding, as this ultimately places decision making in the hands of the individual. For self directed funding to be successful, it is imperative that increased information about how self directed funding could work and could be used be made available prior to and during the introduction of the proposed scheme. Many of the individuals we spoke with were suspicious of the proposal, concerned about fraudulent use and uncertain how this could be applied in their own lives. This reinforces the need for a well equipped information gateway as the one stop information source.

Development of a well resourced and well connected information gateway

People who are new to sight loss (and even those who have been vision impaired for some time) have noted that it is difficult to know what services are out there, the types of services they may be eligible to receive and how to successfully apply. Blind Citizens Australia supports the proposal for a second tier within the NDIS which aims to provide information and warm referrals to mainstream service and community groups. For this to work, it is imperative that there is a cohesive database of the full range of services offered in each state which may or may not be disability specific. Peer support networks are a key support which must be included. This will require more significant mapping that what has previously been undertaken.

As a case in point, Blind Citizens Australia met with staff of Royal Guide Dogs Tasmania during our Tasmanian consultations. Staff advised that in 2 years only one referral had been provided by the state’s disability referral service despite significant growth in the numbers of people developing sight loss. At our Launceston forum, many of the attendees stated that

they had learned more about the services available in their region from each other at the forum than they had from referral services.

“Not a lot of people know what is available now so how are people going to know with the NDIS?” Female, Launceston

“I don’t really know what’s available to help me. Royal Guide Dogs Tas have helped me with a stick and talking books, my husband has to do all my reading. I have two magnifiers but there’s only certain days I can use them. I always lose my place when I am reading and I get tired. I have never seen a CCTV so I don’t know what’s around for me” Female, Hobart.

As the gateway will be a large entity, it is imperative that

- a) Referrals are relevant and tailored to the disability specific needs of the individual - the provision of incorrect information or non relevant referrals can create more confusion and possible apathy to accessing services in the future
- b) Information and referrals which are provided are ‘intuitive’ – eg. meeting the expressed information need of the individual– such as information about local community transport options in the person’s region – but also unexpressed but likely needs such as providing information about the companion card program or state based taxi subsidy programs.
- c) Information and referrals are provided by well trained staff (which should include qualified people with disabilities) who have strong knowledge across a range of disabilities - as a member in Brisbane put it “any administration is only as good as the training that is provided, if the staff are not trained they will not act appropriately”.
- d) referrals and information provision does not fall into the trap of promoting the more well known providers (generally with the bigger advertising budgets) at the expense of smaller qualified providers, not for profit and community groups.

It is imperative that individuals are assisted to navigate what could be a minefield, particularly with the introduction of new service operators. We believe that peak consumer bodies could play a significant role in this area due to their expertise and current role in advising and supporting individuals with disability to make informed choices.

Workforce issues

As outlined in the section on age restriction, it is imperative that there is a well skilled workforce in place to support the aims of the NDIS which is to improve quality access to supports. Blind Citizens Australia is concerned about the recommendation made by the Productivity Commission that formal training should not be compulsory for all employees. Whilst we appreciate that there are some roles where formal training may be less necessary (for example cleaning), it is imperative that the supports offered through the proposed scheme offer a high standard of service, with personnel who are equipped with the skills to work with a range of people with different disabilities and respect the dignity of individuals.

Cost of supports now and into the future, introduction of an excess and long term funding of an NDIS

An additional consideration is the cost of supports now and into the future. Many members were concerned that whilst the provision and types of supports to an individual may remain constant over many years, the cost of such supports would increase and could lead to out of

pocket expenses and “gaps” to meet the shortfall. Comparisons were made to the Medicare system, where the availability of bulkbilling has declined.

“I want to go learn Moon (a writing system for people with sensory disabilities) which has been around for some time. There is no facility that actually teaches it at the moment. If I find somewhere and they say it costs \$180 a week to do the course, do you allocate me that money every week to do Moon? Six months down the track they say they need an extra \$30-40 per week. Do I go back to you and ask for that because it’s gone up or do I have to pay that out of my own pocket?” Male, ACT

Many individuals were also concerned about the \$500 excess proposed to gain supports under the NDIS. Whilst the Productivity Commission has indicated that this would not apply to all individuals and would take into account the amount of support provided by natural supports, many people who are blind or vision impaired would be impacted due to the less intensive nature of their disability and the need for less direct intervention from family and friends. Pensioners noted that an excess would create a significant dent in their pensions for potentially little gain, particularly if an individual only requires specialist supports a few times in a particular year. A number of our older members noted that they would not access the scheme if there was an excess.

Cost blowouts and the long term sustainability of the scheme were also significant concerns raised at a number of our forums, particularly at a time where governments across the world are cutting back on budgetary spending. It is imperative that the planning of the scheme can provide a level of guarantee to eligible individuals that the supports which are promised can be delivered into the future, particularly for individuals whose needs are episodic and could be seen as less warranted if funding cuts are necessary.

“What happens at the moment is a rationing type process, even in aged care, as the budget does not allow it. What sort of guarantee will they be able to make to those eligible?” Male, Adelaide.

“How are we going to persuade the public when there is already a climate levy and a carbon tax levy?”, Member, Brisbane forum.

As highlighted at the beginning of this submission, Blind Citizens Australia is concerned that the true cost of providing a comprehensive scheme to support people with profound disability related needs has been undervalued. The Disability Investment Group report, *The Way Forward* (2009) proposed terms of reference for a feasibility study which would look into a need/gap analysis, data collection across a range of disability types, the creation of a strong evidence base and the development of revenue projections. We believe that there is still a need for a feasibility study to be undertaken to understand the true costs and to appraise how support needs can continue to be met in the long term.

Assessment

“I understand why they want to talk about assessing people, but I just hope it can be a smooth process because at the moment you have to re-apply for every single service every time and get the same reports. I have not been able to see since I was 2 years old but I still need an ophthalmology report. I think it just needs to be a bit more streamlined, particularly for me and Malcolm who are two blind people living on our

own together. We don't have a lot of support and that is fine except for filling in forms for services." Female, Sydney

Blind Citizens Australia supports the proposal for assessments which are portable, forward looking and are tailored to the individual. Blind Citizens Australia does wish to make a number of recommendations based on concerns raised by our membership.

Many of our members were extremely concerned that the implementation of an assessment process would undermine their self determination to access services when and how often they choose.

Secondly, the 'toolbox of assessment tools' as proposed will focus on assessing suitability for a range of supports, rather than assess the person's disability type. Whilst Blind Citizens Australia agrees that this places the individual at the centre of the assessment, we are concerned that allied health professionals acting as assessors:

- a) may not have sufficient awareness, experience or expertise with specific disability types and may therefore underestimate or miss the full support needs of a person. This could pose an issue for individuals who are new to vision loss and unaware of what services they need and should ask for.

"I'm currently going through an absolutely useless process with Commonwealth Rehabilitation Services. And I have people who are qualified in physiology and sports movement allegedly being qualified to voice opinion about what technology should be beneficial. I'm telling them the names of agencies and the people that they need to talk to. If they are talking about you being assessed by certain people, I'm afraid I don't have high confidence in these so called professionals. Having qualifications in sports movement etc doesn't qualify them to advise me on what equipment I might need." – Male, Northern Territory via teleconference

"If I was assessed I would probably be assessed as someone who is coping pretty well as I have a lot of support. But if I was assessed two years down the track and I don't have my dog, it would be completely different". Male, Adelaide.

- b) incidental and episodic needs may be overlooked or may not be viewed as "reasonable and necessary". The incidental needs of people who are blind or vision impaired are often picked up during in home assessments or through ongoing discussions after an initial support/s has been provided. As an example, a client recently had changes to lighting made in her home after a recommendation was made during an adaptive technology consultation. The client noted that she would not have thought to ask for this.
- c) Some people may need to be assessed frequently under the proposed scheme due to the deteriorating nature of their vision loss to ensure access to the correct amount of supports. Some individuals with deteriorating conditions noted that this could be burdensome in comparison to the current system where individuals are able to access blindness specific supports without continual reassessment.
- d) current assessment tools, such as forms for welfare entitlements often ask disability specific questions, with no acknowledgement of people who experience vision impairments. As an example, the Mobility Allowance application form includes sections

for people with intellectual disability and physical disabilities but no section for sensory impairment. Whilst these forms may take into account physical restrictions such as being able to walk 50 metres, they omit other mobility barriers such as the inability to read signage, independently navigate an unfamiliar station, view timetables, hear announcements and so on. A person's need for assistance is physically present, but is not evident or recorded in these tools. For example, a person with photophobia (extreme glare sensitivity) may be able to see under certain circumstances but not in others – current assessment forms make it difficult for individuals to know how to fit within a 'box' which is clearly not designed for them.

"The same tool for all disabilities is totally impossible. Blindness is different to physical to deafness, you both have personal care needs but for different reasons." Member via teleconference.

"You can't expect a person who is new to vision loss to need the same supports as someone who has been blind a long time. People would have totally different service needs." – Female, Perth

Whilst an assessor may provide an individual with the same range of supports that they receive under the current system, many members were concerned that the frequency of supports would be arbitrarily decided by the assessor and currently provided supports would need to be justified. As one person in Canberra noted:

"So we can't actually do these things for ourselves anymore? Sounds like our independence is being cut at the knees and its becoming "Come and see us first and we'll decide what you can have"." Female, ACT.

Older people who are blind or vision impaired noted that the NDIS proposal has a strong focus on employment and educational participation. Many noted that this was similar to the current system which minimises the importance of meaningful participation in other areas of life, such as recreation and peer support.

Demonstrating need

Many expressed concern that the assessment process would become bureaucratic, with a requirement to "prove how disabled you are". Furthermore, people that we spoke with expressed a significant concern that the needs of people who are blind or vision impaired could be overlooked in favour of people who present with more significant and profound disabilities. Many of our members were concerned that they would need to present their needs in a "worse light" to guarantee access to supports that are currently provided. It was noted that presenting as an empowered, independent and functional person could lead to the provision of less supports. As one member noted "I'm blind but I do not see myself as profoundly disabled".

"Statistically we are going to be compared to people with other disabilities – we are going to be bunched and disadvantaged. Maybe we aren't as physically as bad as everyone else, but in other areas we are", Male, Adelaide.

"If we say that we do not have a profound disability, then we all go to buggery", Male, Hobart.

A number of members made comparisons to the assessment process for disability employment services (DES), noting that a higher level of support to search for employment is

available “if you act like you can't do anything”. As one member put it, “my concern is that groups that need distinct funding are going to get it at the expense of those, say, like us, in the sensory disability area, who have more opportunity to be independent in our lives”.

Natural supports

The draft report recommends that natural supports, such as family and friends, should be considered when determining the amount of supports a person with disability may require as part of their package.

A number of our members noted that this could present issues for people who may live with others but be deemed as less ‘needy’ than a person who lives alone. As one of our female members put it:

“I have three sons and a husband, but that doesn’t mean that I get assistance with cleaning, or that when they do it, they do it to the level that I want them to”.

A woman in Melbourne, who lives alone noted:

“What an assessor deems as essential and what you deem as essential can be two different things. The assessment needs to take into account people who are on their own and don’t have access to same things as those with the physical support of another person and who have access to their funds as well as their own. All systems seem to rely on the fact that you each have a support person. I was told that a family member should be supporting me through their super and own funds. And the attitude is often, find someone to take an active role in your life. If they really love you, they will help.” Female, Melbourne.

This can also present issues for young people who may want to break away from overprotective families to live more independent lives.

A member at our Geelong (Vic) forum provided the example of two friends who have a young daughter who is blind, autistic and has high support needs. The carers allowance is used to pay for four family carers to assist the child. The member expressed concern that because the child is getting extra care, she may be assessed as requiring less supports.

The assessment process will require further tweaking to ensure that the needs of people who are blind or vision impaired are not under-assessed and to ensure that the process of assessment is not too burdensome on individuals. It is imperative that comparison against people with similar needs does not unfairly disadvantage a person with legitimate needs. It is also important that natural supports and individuals can choose re-assessment points – the ageing of a natural support is one important transition point amongst many.

RECOMMENDATION 9:

Blind Citizens Australia recommends that the assessment process

- a) **focus on the specific disability related needs, including episodic needs, of people with disability**
- b) **be undertaken by staff with demonstrable awareness, experience and/or expertise with specific disability types**
- c) **utilise assessment tools which assess the limitations experienced by people with sensory impairments (current assessment tools often focus on physical limitations only)**
- d) **be transparent at all stages of the assessment process**

- e) **minimise bureaucracy to ensure that people access the supports that they need in a timely manner without extensive need for reassessments**
- f) **be accessible, with forms and information to be available in alternative formats including large print, audio, e-text and Braille formats**
- g) **contain a clear and transparent appeals process (detailed shortly)**
- h) **consider the needs of natural supports and allow for the nomination of re-assessment points as decided by the individual or the natural support**

Implications on DSP Blind and other entitlements

Blind Citizens Australia agrees with the Productivity Commission's recommendation that the disability support pension should be viewed independently of an NDIS. We recommend that the Productivity Commission should also extend this to the DSP Blind.

Whilst this statement is clear within the draft report, Blind Citizens Australia does note that the Productivity Commission has highlighted areas of possible reform, most notably increasing the meaningful workforce participation of people who have less severe disabilities, such as sensory disabilities. Blind Citizens Australia supports efforts to minimise the current discrimination experienced by people who are blind or vision impaired when seeking and maintaining employment. It is imperative however that reforms of the DSP do not seek to force individuals into employment at all cost.

"Is this a situation where I would be encouraged to take up employment until the age of retirement? I am concerned that people would be forced under these new reforms to get employment at all costs, such as working in the workshop which can be detrimental and more harming to young people." Male, 60+, regional Victoria

"There seems to be a widespread conception amongst politicians that people benefiting from the DSP are sitting at home quite happy to accept the money. My experience is that people want work but find it extraordinarily difficult to obtain it", Male, Melbourne via teleconference.

We are mindful that the report also proposes a curb on long term pension reliance which could lead to cost savings in the provision of support to people with disability. As has been noted throughout this submission, the full needs of people who are blind or vision impaired are unlikely to be met through an NDIS. Whilst there may be scope for some reform, the DSP and DSP Blind must be recognised as important supports which provide quality of life, meet many of the non optional costs of blindness and assist many to live a life just above the poverty line. This should not be reduced or compromised as a result of the introduction of an NDIS.

"What's being taken away? Because we all agree you don't get something for nothing and somewhere along the line something will be taken away". Male, ACT'

RECOMMENDATION 10:

Blind Citizens Australia recommends that all forms of income support, including DSP and DSP Blind, remain independent of an NDIS and that enacting legislation for the establishment of an NDIS explicitly cite this distinction.

RECOMMENDATION 11:

Blind Citizens Australia advocates that all current entitlements, such as carers allowance, carers payment and mobility allowance remain as per status quo (external to an NDIS) until the projected NDIS review in 2020. This timing will allow for a review of the success of an NDIS and suitability of the inclusion of entitlements.

Establishment of Disability Support Organisations (DSOs)

Advocacy

The provision of advocacy has been cited as a role which can be performed by a DSO or a service provider. Blind Citizens Australia agrees with comments made in the Disability Advocacy Network Australia (DANA) submission that “advocacy is about standing by a person or people with disability and seeking to ensure that their voice is heard, understood and valued, and that their rights and interests are safeguarded and respected”. Blind Citizens Australia agrees with DANA that advocacy should be independent of service providers to minimise conflict of interest. Independent advocacy is particularly vital to ensure that the rights, needs and interest of people with disability are properly addressed in an NDIS and NDIS and that people with disability are appropriately supported to make choices and to communicate their needs and wishes.

“A lot of blind people and the elderly cannot advocate properly for themselves and are not aware of the Standards. It would seem that there would be a need for an advocacy service before the insurance people. One on one is just as important”, Male, Melbourne via teleconference.

The provision of advocacy by service providers raises considerations around the

- long term viability of independent peak consumer bodies and government funded services currently providing advocacy, including good service provided at a state level which is currently funded by state governments.
- take up of advocacy by people with disability would likely decline if this now needs to be paid for through an individualised support package. As one of our members noted, if people were to start to pay for advocacy they would be expecting high level representation and a higher skilled and legal workforce.

It is imperative that funding for advocacy services is not drawn from people’s individualised packages.

RECOMMENDATION 12:

Blind Citizens Australia recommends that a percentage of total NDIS funding should be allocated to consumer bodies and independent specialist advocacy services to enable independent individual and systemic advocacy.

Blind Citizens Australia supports the recommendation made by DANA that

“An identifiable, justifiable proportion of the total NDIS bucket of funding should be provided to an independently constituted statutory advocacy authority to administer and distribute to independent advocacy organisations so as to ensure that the strength and effectiveness of advocacy is assured and that the advocacy provided remains focused wholly on the rights, interests and well-being of the person with disability.”

In regards to systemic advocacy, it is imperative that improvements which might be obtained through self directed funding – such as the pooling of funds amongst a small group of people

with disability to purchase more flexible community transport – is not used as an “out” by governments and private providers to provide publicly accessible infrastructure as governed by the *Disability Discrimination Act 1992* (Cth) and its Standards.

The establishment of a National Disability Insurance Agency

Independent nature of the NDIA

Blind Citizens Australia supports the recommendation for the establishment of an independent Commonwealth statutory authority and an independent board to oversee the NDIA. Whilst we support the Productivity Commission’s recommendation that no particular interest groups should be represented on the Board, we strongly support the view that people with disability who have significant expertise should be represented on the Board.

The perceived independence of the NDIA and NDIS is just as crucial as its actual independence. It is important that the distinction between the NDIS and other schemes are maintained, particularly as there is concern and confusion amongst people with disability as to how an NDIS will work with the welfare and health systems. As an example, a number of attendees at our forums expressed concern that local NDIS offices may be co-established at Centrelink sites, similar to the co-location of Medicare. Whilst this may present a streamlined point of entrance, this can create confusion as to the true role of the NDIS and create a blurring of demarcation lines of which agency is responsible for what services, now and in the longer term.

Appeal and complaint mechanisms

We commend the Productivity Commission for its recommendation to establish an independent officer within the NDIA to oversee and resolve complaints, including complaints of merit.

We are however concerned that an additional recommendation has been made which states that complaints of merit should not be accepted by courts if a complainant’s case of merit has been denied by the independent officer.

Individuals who require support but miss out due to arbitrary classifications of need must have an external mechanism for recourse. Blind Citizens Australia maintains that the court system, specifically the use of the Administrative Appeals Tribunal, may not be the best mechanism for the resolution of complaints.

RECOMMENDATION 13:

Blind Citizens Australia recommends the establishment of a NDIS Ombudsman to review decisions made by the NDIA which are unable to be resolved by the independent officer.

This ensures that decisions can be viewed in a timely manner, are not subject to a bureaucratic legal process and can be resolved at no additional personal cost to the individual applying for access to Tier 3 of the NDIS.

Quality and control measures including the development of Standards

Blind Citizens Australia agrees with the recommendations to develop a service charter for service providers and disability support organisations. Blind Citizens Australia also supports

the recommendations for the development of nationally consistent guidelines and standards for delivery, the introduction of independent periodic auditing and the recommendation that the NDIA set efficient prices for reimbursement of service providers to ensure that individuals receive services at a set market price.

Implementation of an NDIS

Blind Citizens Australia agrees with the Productivity Commission that the implementation of an NDIS must include collaboration with support and advocacy groups to build the confidence of people with disability to exercise choice under the new proposed arrangements. We also support the recommendation of targeted consultation with people with disability and groups in the development of the scheme.

The recommendation to gradually phase in an NDIS has merit. We are however mindful that the introduction of an NDIS which covers people who are blind or vision impaired will be significant, particularly in light of the stark disparities in funding models and publicly funded support for sensory disabilities as compared to other disabilities. The rollout of an NDIS to people who are blind or vision impaired requires further consideration and finesse, particularly in light of the eligibility, supports and block funding issues raised in this submission. This is not to say that it cannot work, however further direct consultation with the sensory disability sector is needed to ensure that these specific issues are addressed for a smooth transition.

RECOMMENDATION 14:

Blind Citizens Australia recommends further direct consultation with the sensory disability sector to ensure that identified barriers (as included in this submission) are addressed in the development and rollout of the NDIS.

National Injury Insurance Scheme (NIIS)

Blind Citizens Australia supports the proposal for the establishment of a separate National Injury Insurance Scheme (NIIS) for individuals who acquire a catastrophic injury and agree that this should be built on existing state based models. We are particularly supportive of the Productivity Commission's recommendation that the scope of catastrophic injuries currently covered should be extended to include motor vehicle accidents, medical treatment, criminal injury and general accidents. We also support the recommendation that a secretariat should be established to ensure consistency in eligibility, definitions and assessment. The elimination of the requirement to use common law to fight for necessary supports is a welcome step.

Blind Citizens Australia hopes that the NIIS can close some of the current gaps experienced by people with acquired blindness as a result of a catastrophic injury. Blind Citizens Australia has received many calls over the years from individuals who have been unable to access compensation to meet their full disability related needs or have experienced layers of bureaucracy from their past employer, insurance provider and other parties.

As an example, a young 19 year old woman who was involved in a car accident whilst at work was refused necessary screen reading technology and equipment by her past employer for her new employment role, as this was viewed as "unnecessary". Due to the receipt of compensation, this young woman was unable to access Job Access work modifications. The woman's new employer, a not for profit, has paid for the equipment out of their own budget

after one year of unsuccessful negotiations with the employee's past employer and their insurance company.

In another case, a woman aged 60 who sustained a compensable back injury in the 1980s, recently lost her sight to macular degeneration, an unrelated visual condition. Despite the onset of an additional severe impairment and legal blindness, the woman was denied access to benefits available to others with legal blindness, including a pensioner concession card to access discounted eye treatments and other crucial services. The strict application of the *Social Security Act 1991* (Cth), coupled with the insurance company's rightful claim that her new costs were not related to her pre-existing injury, left the woman in a severely compromised financial state. During winter, she could not afford to turn on her heater due to the ongoing costs of her deteriorating health. The Federal government, in this instance, refused to recognise the impact of multiple disabilities due to her receipt of compensation for one of her disabilities.

RECOMMENDATION 15:

Blind Citizens Australia recommends that the NIS include a range of supports, including episodic and functional supports (such as aids and equipment) to people who are eligible for the NIS. As part of the implementation of the NIS, Blind Citizens Australia recommends a review of the current processes used by state and territory schemes and government entitlement schemes with the view to minimise the bureaucracy and burden currently experienced by individuals who are claiming supports.

Closing Comments

Blind Citizens Australia contends that the NDIS, as presently proposed, moves forward in the right direction, but does not safeguard the full and necessary needs of all people who are blind or vision impaired.

In order to do so, the proposal for Tier 3 supports must address concerns surrounding eligibility, arbitrary age restrictions for people who may have exactly the same needs as a younger person; the threat to the ongoing availability of very niche specialist services and ensuring that assessments take into account the full (which includes episodic) needs of people with disability. It is imperative that the true costs of blindness are calculated to ensure that the scheme, if implemented, does not undercut the people it is designed to assist. Blind Citizens Australia would welcome further involvement in the development of this scheme. One of our members in ACT sums it best.

"I agree with the concept in principle...but we need further discussion to protect our particular interest which is different from the interests of the people this is most designed to support. Let's not forget this is coming from people at the bottom end of the scale who are currently being left out. But we need to remain part of the discussion." Male, ACT