**Blind Citizens Australia Submission:**

**NDIS Proposed criteria for Eligibility and Reasonable and Necessary Supports**

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Council of Australian Governments (COAG)

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Submitted Via email at: NDISenquiries@fahcsia.gov.au

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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

# About Blind Citizens Australia: Who we are and why we say what we say

Blind Citizens Australia’s unique point of difference is that our organization is solely made up of and represents people who are blind or vision impaired. Our Board of Directors and our committees are required by our Constitution to be made up of people who are blind or vision impaired and we have over 3000 members Australia-wide, all of whom share a lived experience of blindness; whether they be a parent, professional, job seeker, volunteer or student. This is why we are best placed to comment on the specialist needs of people who are blind or vision impaired.

We are driven by our mission 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.

Blind Citizens Australia provides the following consumer driven advice in relation to the proposed criteria for eligibility and for reasonable and necessary supports. Below this advice are our further considerations in response to the discussion questions.

# General Comments

The discussion paper notes that feedback on the discussion paper can be provided via email or via the federal or state advisory groups. Blind Citizens Australia would like to document its concern about the transparency of these groups, which has been highlighted by our members who have noted that it has been very difficult to provide independent input in their states and territories. We also note that there are no mechanisms provided to enable people to phone in with their feedback, or to text or use National Relay to provide feedback

# Proposed eligibility criteria

People with disability are within the scope to receive support that is funded under an NDIS if:

1. *The individual resides in Australia and is:*
	1. *an Australian citizen; or*
	2. *the holder of a permanent residency visa; or*
	3. *a New Zealand citizen who was an Australia resident on 26 February 2001 (SCV holder); and*
2. *The individual is less than 65 years of age on entry to an NDIS; and*
3. *The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment, or a combination of impairments; or is a child with a global developmental delay; and*
4. *The impairment/s:*
	1. *is permanent or likely to be permanent; and*
	2. *results in a substantially reduced functional capacity of the individual to undertake activities of daily living; and*
	3. *impacts on the individual’s participation in the community or employment; and*
	4. *may be of a chronic episodic nature and result in the need for ongoing or long term episodic support; and*

*5. the support needs will persist for the foreseeable future and are not more appropriately met by other systems including education, health* *and/or palliative care.*

**Age**
Blind Citizens Australia maintains that people who are blind or have significant vision impairment should have access to the disability specific supports that they need, when they need them, whether this be within or outside of an NDIS.

While the proposed cut of age is consistent with the recommendation made by the Productivity Commission, Blind Citizens Australia remains extremely concerned that there is no clear pathway or provisions (both of funds and resources) within either the proposed NDIS or within the scheduled aged care reforms to fund the specialist needs of people who are blind or vision impaired aged over 65. At the time of writing this submission, Blind Citizens Australia was not aware of any work released publicly by either the Federal government or State and Territory governments regarding how the interface between the proposed NDIS and the aged care reforms will work.

Blind Citizens Australia remains unconvinced that the aged care sector has, or will have, the disability specific expertise, resources and funding to provide comparable access to the reasonable and necessary supports that older people who are blind or vision impaired require in order to remain independent within their community. While Blind Citizens Australia agrees that the NDIS should not duplicate the supports offered by other service systems, we note that there is minimal provision of disability specific supports for people who are blind or vision impaired within the aged care sector. The ACAT assessment is just one example of an assessment process which does not adequately measure the level of functional impairment resulting from vision loss for a person who is aged and may therefore also have other restrictions.

With 70% of blindness service provider clients aged over 70 years of age, there will be a significant proportion of people who are blind or vision impaired who will not benefit from an NDIS, but still have an identified need/s for support. Simply saying that these needs will be met by the aged care sector, without funding dollars attributed, is not enough, particularly in light of allied health evidence that suggests that the costs of providing rehabilitative services offset health costs down the track.

To ensure that the NDIS remains fair and equitable, Blind Citizens Australia recommends that the Select Council gives careful consideration to one or more of the following policy options which have been discussed within the sensory sector:

1. Remove Criterion 2, which states that the disability specific needs of people over 65 will be funded via the Age Care budget. The NDIS should instead cover all people who are blind or vision impaired with the eligibility criteria remaining the same regardless of age or when the onset of disability occurred. We wish to reinforce that this is the only fair and non-discriminatory option and that the inclusion of people who are blind or vision impaired over 65 would not be costly when considering that most interventions accessed by older clients are episodic and are of low cost, such as a magnifier or the development of orientation and mobility skills.

2. Introduce a three year grace period to enable people with disability who are aged over 65 to seek assistance and coverage under the NDIS. This is particularly important for individuals whose disability related needs outweigh needs related to ageing and require support to continue to remain included within their community and in other activities such as employment. A similar measure has been adopted in New Zealand which sets a benchmark and model that Australia could implement.

At minimum, Blind Citizens Australia recommends that a launch site (preferably the Hunter Region, Barwon region or ACT which intend to cover a broader demographic of people with disability) be used as a model to test whether the expansion of the eligibility criteria to people with disability over the age of 65 (who meet all other eligibility criteria) will, in real terms, impact on the sustainability of the NDIS long term.

**‘Age related’ eye conditions and degenerative conditions**

In addition to the concerns that have previously been highlighted, , we are concerned that an age restriction could unfairly disadvantage individuals with eye conditions which may be deemed to be age related such as macular degeneration, and degenerative conditions such as retinitis pigmentosa which may not manifest until later in life. Both of these conditions can result in legal blindness and can impact on a person’s capacity to function within their home and community if appropriate supports are not provided at the time that the needs of the person are identified. While a person aged under 65 may be considered under the proposed eligibility criteria, it is unclear where a person aged over 65 will have the ability to access the early intervention and supports that they require.

**What happens to people who are diagnosed before 65 but do not access supports until after 65 years of age?**

Through the shared experience of our members, we know that many people who are new to legal blindness or a significant vision impairment can delay accessing the supports of a blindness service provider. This can be a result of shame about the loss of functional vision and ability, perceptions of what it means to be blind or vision impaired and the time needed to come to terms with learning how to do things in a different way, including “using technology that only blind people use”. This has direct bearing to the NDIS and the proposed age cut off point, particularly for people who may need supports in the short or long term but who may not be quite ready to take the next step to access rehabilitation services. While Blind Citizens Australia does not endorse a purely medical approach, it is important that people who have acquired their disability before the age cut off receive the supports that they need, even if they choose to access those supports after the age of 65.

**Recommendation 1:
As outlined above, Blind Citizens Australia recommends the removal of the arbitrary age restriction for older Australians who are blind or vision impaired through funding from the Age Care sector. In the instance that this change is not implemented, Blind Citizens Australia recommends that criterion 2 is amended to state: “The individual is less than 65 years of age on entry to an NDIS and/or has received medical advice of the presence of a condition consistent with Criterion 3 prior to the age of 65”.**

**Where does early intervention fit in?**

Early intervention for children who are blind or vision impaired as well as those who are new to sight loss is vital and for this reason, it is important that specific reference is made to early intervention within the eligibility definition.

**Recommendation 2:
Blind Citizens Australia recommends that the eligibility definition is amended to**

**“The individual has a disability that is attributable to an intellectual, psychiatric, cognitive, neurological, sensory or physical impairment or a combination of impairments; or is a child with a global developmental delay; or would benefit from early intervention for one or more of the above disabilities.”**

**Clarifying the term ‘episodic’**

Blind Citizens Australia is pleased that the term ‘episodic’ has been included within the proposed definition, however the current definition of this term within the discussion paper is restricted. On page 3 of the discussion paper, the following statement is made:

*“…Since an NDIS is intended to provide long term support, the eligibility criteria would need to consider whether the disability is permanent, or likely to be permanent. This includes impairments that are episodic, such as psychiatric impairments, where the level of impairment and support may vary but will be long term.”*

The proposed definition of eligibility also states:

*“The impairment/s
d) may be of a chronic episodic nature and result in the need for ongoing or long term episodic support”*
Blind Citizens Australia wishes to reinforce that for a person who is blind or vision impaired, the term episodic does not relate to the impairment itself I.E. people who are blind or vision impaired do not lose their vision for a period of time and then have a period of good sight. The term instead is used to refer to the frequency of when and how often people who are blind or vision impaired need to access key supports, such as training in orientation and mobility. Often these supports are not required on a regular and ongoing basis, although this may be the case if a person is new to vision loss. Instead, such services are required episodically; often when the individual experiences a change like starting a new job or moving house, or identifies a new personal goal, such as learning how to travel to the local supermarket independently.

While Blind Citizens Australia feels that it is important for ‘episodic supports’ to be clearly defined within the final eligibility definition to ensure that vital supports such as orientation and mobility training are not overlooked, we wish to reinforce that there may, in some cases, also be some non-episodic supports that would benefit a person who is blind or vision impaired in assisting them to live independently; such as assistance with transport and home maintenance.

**Recommendation 3:
Blind Citizens Australia recommends that the definition of “episodic” be clearly articulated in the final definition of eligibility to ensure that the vital needs of people with sensory impairments are not overlooked. It is imperative that people who require episodic supports are able to access the supports that they need in a timely manner, without being subject to reassessment.**

**What is defined as a sensory impairment?**Blind Citizens Australia supports the reference to sensory impairment in the proposed definition. While we are not supportive of solely using a medical definition for entry to the scheme, Blind Citizens Australia recommends that if a medical entry point is adopted, the World Health Organisations’ criterion of 6/18 should be considered for access to daily and non daily living supports as well as a functional definition. When a person’s visual acuity reaches 6/18, there is a profound impact on their functioning as they are no longer eligible to hold a drivers license, are unable to read standard print and may experience an increased risk of injury without having access to the appropriate supports.

Furthermore, access to early intervention should not be bound by the World Health Organisation definition, particularly for individuals with degenerative conditions where a person may still have good sight but would benefit from skill development to offset later issues.

**Recommendation 4:** **Blind Citizens Australia recommends that if a medical entry point is adopted, the World Health Organisations’s criterion of 6/18 should be considered for access to daily and non daily living supports as well as a functional definition. Access to early intervention should however, not be bound by the World Health Organisation definition. Instead, the presence of a medical condition which leads to a degradation in a person’s functional capacity should be the only criteria for access to early intervention support.**

**Permanence of vision impairment and legal blindness**While most visual conditions leading to legal blindness and significant vision impairment are permanent or likely to be permanent, there are some visual conditions, such as cataracts, which may be medically treatable in the longer term but may be subject to significant waiting periods of surgery. As an example, a person with cataracts may be impacted to the point of legal blindness, have substantially reduced functional capacity to independently undertake activities of daily living, be impacted in their ability to participate in the community and may need to learn blindness specific skills in order to continue to lead a normal life.

**Recommendation 5:
Blind Citizens Australia recommends that criterion 4a be reworked to
“Is permanent or likely to be permanent (until such time a medical intervention is available).**

**Substantially reduced functional capacity**Blind Citizens Australia, in principle, supports the inclusion of the terms “reduced functional capacity” within the proposed definition for eligibility as this moves away from a purely medical model of identified need. We do however have concerns about how “substantially reduced functional capacity” will be determined, the parameters of this definition and who will assess an individual’s capacity, particularly in instances where an individual may appear, on the surface, to fare better than a peer with a similar level of vision.

As an example, many of our members who have been blind from a young age are employed, are able to competently get to and from work, are engaged within their local community and have developed blindness specific skills to undertake a range of tasks. While a person who has acquired blindness related skills over an extended period of time is likely to be more confident in their environment, the functional capacity of that person is often context driven. This means that simply changing the location of the employee’s office or having a flat mate move in can result in well learned routines and in turn, the person’s level of independence being compromised.

An assessment reviewing “substantially reduced functional capacity” might view many people who fall into the above category as being functional and capable, concluding that they are ineligible to receive supports under an NDIS. It is therefore imperative that an assessment of functional capacity considers the following:

* The environment in which the person is assessed – a person may be highly functional in a familiar environment such as their own home, but have difficulties functioning independently in different light conditions, at different times of the day or in locations that are unfamiliar to them.
* Comparisons of the functional capacity of people who are blind as compared to people with other disabilities which may be more severe and profound – a person in the above circumstance may be viewed as “less needy” that a person with a significant physical disability with daily living needs, despite having very different needs
* Comparisons to people with the same visual conditions or similar levels of sight loss may create an unfair judgment on the level of need an individual has. By default, a person who receives limited supports due to their perceived high functional capacity could be placed in a position of skill degradation without the reinforcement of the skills they have and the addition of new skills along the way.
* The capacity of the assessor to think ‘outside of the square’ to assess beyond “disabling barriers” to look at barriers that enable an individual to continue to grow and be included in all facets of life
* The individual’s capacity and knowledge to articulate what they need and why they need it. This includes knowing what’s best in the first place.
* How a person’s attitude to their circumstances and capacity can frame the assessor’s response – a person who presents confidently and articulately as compared to an individual struggling to cope with sight loss could be assessed very differently even if their comparative needs are similar
* Change in an individual’s personal circumstances – moving homes, getting a new job or training to use a new piece of software within the workplace can mean that a person who is highly functional prior to these changes may struggle. While some people who are blind may be equipped with the blindness-specific skills of daily living that are needed, a demonstrable need for support may still be present.

**What supports would be considered in a one off NDIS package?**Blind Citizens Australia is concerned at the proposal for necessary equipment to be provided to a person who is blind or vision impaired as part of a one off package, as A persons technology needs may evolve over time depending on the nature of their eye condition, the stage of vision loss and how far they have progressed through the rehabilitation cycle. As an example, a person suffering from Macular Degeneration may immediately require the use of magnification aids, but down the track, might need to investigate alternative supports due to progressive vision loss. For someone who has recently acquired blindness on the other hand, the most immediate supports identified may relate to access to information, while other vital supports such as GPS software or a mini guide (to allow a person to mobilize independently within the community) may be entirely overlooked as the individual has not yet progressed to this stage of rehabilitation.

It is also important to consider that a one off package does not allow for new technological advances and for the constant update of software and equipment. For example, Jaws for Windows, the most widely used mainstream screen reading software for people who are blind or vision impaired is updated regularly by the software developer. These updates come at an additional cost to the individual and often, the most recent version of the software is needed to ensure compatibility with the most current operating system or version of an individual’s web browser. Providing a one-off funding package to cover the cost of technology for people who are blind or vision impaired would not ensure that these additional costs are taken into account.

**Appropriateness of other systems**

Point 5 of the proposed criteria notes the appropriateness of meeting the needs through other systems such as education, health and/or palliative care where this is more appropriate. Blind Citizens Australia maintains that strong safeguards need to be in place to ensure that systems which are identified as better placed or better resourced to support the needs of a person with disability are accountable and that people with disability are able to access the support that they need without added layers of bureaucracy or buck-passing. It is also critical that there is transparent and inclusive decision making on the suitability of other systems to meet the individual support needs of an individual.

**Focus question**

*Does this description of eligibility cover all the things that you think a National Disability Insurance Scheme would need to know about you to determine whether you should be eligible to receive support under an NDIS?*

In addition to our comments above, Blind Citizens Australia shares the concern of some blindness service providers that the assessment of eligibility does not consider the potential outcome of interventions and how these may lead to a substantial improvement in the independence and functioning of people with disability. In addition to consideration of eligibility criteria, it is also important that consideration is given to the anticipated outcome of a support covered by the NDIS and how likely it is that the support will aid in overcoming functional difficulties.

# Reasonable and necessary

Reasonable and necessary supports:

1. *are designed to support the individual to achieve their goals and maximise their independence;*
2. *support the individual’s capacity to undertake activities of daily living to enable them to participate in the community and/or employment;*
3. *are effective, and evidence informed;*
4. *are value for money;*
5. *reflect community expectations, including what is realistic to expect from the individual, families and carers; and*
6. *Are best provided through an NDIS and are not more appropriately provided through other systems of service delivery and support, including services that are offered by mainstream agencies as a part of its universal service obligation to all citizens.*

Blind Citizens Australia, in principle, supports the definition of reasonable and necessary with the following caveats:

**What are considered to be ‘activities of daily living’?**

The terms “activities of daily living” are often used by the disability service sector to describe one to one personalised care arrangements to assist a person with disability to function, such as assistance to shower, dress or prepare a meal. While Blind Citizens Australia recognises that the use of this term is designed as a “catch all” for all people with significant disabilities, it is imperative that the terms ‘activities of daily living’ are explicitly defined to include the development of

* personal care skills including being able to live and function independently within the home
* Skills allowing access to information, such as reading Braille or learning to use text-to-speech software on a computer.
* mobility skills, including developing skills to safely and independently navigate in the community
* Self advocacy skills to enable people with disability to identify and ask for supports to meet their needs.

**Recommendation 6:**

**Blind Citizens Australia recommends that the definition of “activities of daily living’ is redefined to consider the development of independent skills in addition to direct care support.**

**Defining “evidence informed”**

The provision of adaptive technology, the teaching of white cane technique and training in the use of a dog guide are all well recognised supports for people who are blind or vision impaired which have been shown to have direct benefits in improving functioning. Blind Citizens Australia recognises the importance of the inclusion of supports which are well established as proven interventions and have been shown to lead to increased functioning for people with disability. However, the strict application of evidence informed supports could unnecessarily restrict the intention of the NDIS which aims to ensure greater inclusion of people with disability.

As an example, a person who is blind may want to develop skills in echolocation to help them mobilise in the community. Echolocation is the developed ability to detect objects within a person’s proximity by sensing echoes that are reflected by those objects. Some people who are blind use echolocation by creating sounds – such as making clicking noises with their mouth or using their white cane. The individual is then able to interpret the sound waves that are reflected by nearby objects and use this information to determine their approximate location and size. While echolocation is a valuable skill for people who are blind or vision impaired, many people who are blind or vision impaired learn these skills from other blind peers as formal training by a service provider can be limited.

It remains largely unclear whether an innovative solution such as the example above would be recognised as an ‘evidence informed’ support, despite its successful use by a group of people with disability. It is therefore imperative that what is deemed to be ‘evidence informed’ is clarified, with consideration of the following

* What is considered as evidence? Is evidence academically backed practice? Is it practice/s currently adopted by disability service providers?
* What evidence is recognised? Is this Australian based research or work being undertaken internationally in the field?
* Who is recognised to provide evidence?
* What needs to be supplied in terms of evidence to ensure that the support a person with disability identifies as important for their own circumstances can be provided?
* How can new innovations be included within an NDIS to ensure that the supports offered under the NDIS remain current and effective?

**Value for money**

Blind Citizens Australia recognises the importance of implementing a scheme which is sustainable in the long term. We are however mindful that what is deemed to be ‘value for money’ needs to be outcome driven and guided by what will best meet the identified needs of each person who is blind or vision impaired, rather than what is the most inexpensive option.

Braille is an essential tool for the development of literacy and can greatly enhance an individual’s prospects for employment. Braille is, however, far more costly than the provision of materials in audio format or a licence for screen reading software. While all three options enable an individual to access information, it is important that an individual has the ability to choose the format that will best meet their needs so as not to unnecessarily restrict the choice that has been inherently promoted as the selling point of the NDIS.

**Reflection of community expectations, including what is realistic to expect from families and carers**

Blind Citizens Australia would like to ensure that the guidelines regarding this criteria are sufficiently tight to ensure that a dependence model is not inadvertently reinforced. Encouraging independence, individual skill development (such as learning how to get to the shops, identify different products and advocate for your needs in favour of a personal shopping assistant) should be a strong focus of this criteria, where this is consistent with the objectives identified by the person with disability.

**Appropriateness of where a support is accessed from**

Criterion f discusses services that are offered by “mainstream agencies as part of its universal service obligation to all citizens”. In the guidelines it is necessary to clarify the types of organisations which are considered to be mainstream organisations and how much say people with disability will have in deciding where the support will most appropriately be provided from.

**Focus questions**

1. *Are there supports that you think are important to include in an NDIS that would be excluded by this description?*

While Blind Citizens Australia understands that many mainstream practitioners provide counselling services as part of a universal service obligation to all citizens, we are concerned at the generic nature of such services and the limited empathy that is often shown towards people who are blind or vision impaired in these circumstances. In the event that a referral for counselling services relates directly to a person’s disability, this should not be outsourced to a generic, mainstream provider in the first instance. Instead, care should be taken to identify whether there are any specialist service providers who may be better positioned to offer this support.

1. *Are there additional points that are needed to make sure that the support provided under an NDIS meets the reasonable and necessary support needs of people with disability?*

Blind Citizens Australia wishes to reinforce the importance of the points that have previously been raised; primarily the funding of services for people who are blind or vision impaired over the age of 65, the inclusion of episodic supports without the need for reassessment and the inclusion of adaptive technology which can greatly enhance a person’s independence.

1. *Does this description of reasonable and necessary supports, combined with the eligibility statement, help you to understand who will be supported in an NDIS and what supports might be provided to them? If not, how do you suggest that the description be made clearer?*

Blind Citizens Australia does not feel that the current information adequately conveys how the often unique, but very vital needs of people with sensory impairments might be covered under an NDIS and, as previously indicated, recommends the following:

* That the eligibility definition be revised to adequately reference early intervention as per recommendations 2 and 4.
* That the definitions of “daily living” and “episodic” be revised and properly articulated, as per recommendations 3 and 6.
* That further consideration be given to how an assessment of “functional capacity” may work in practice and that, if a medical entry point is adopted in addition to functional assessment, this be based on the World Health Organisation’s criterion of 6/18 for people who are blind or vision impaired as per recommendation 4.
* That further consideration be given to what may be considered a “permanent” impairment as per recommendation 5.
* That the term “evidence informed” be further clarified, to indicate the level of consideration that will be given to innovative supports.

**Closing remarks**

Blind Citizens Australia is available to provide further comment or clarification on the recommendations contained in this submission. For more information about Blind Citizens Australia visit [www.bca.org.au](http://www.bca.org.au/) or contact us on (03) 9654 1400.