



# **Blind Citizens Australia Submission on the National Disability Insurance Scheme Bill Exposure Draft**

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This submission is available in large print, audio, Braille and in electronic formats 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 is a unique charitable organisation that is solely made up of and represents people who are blind or vision impaired. All of our Board of Directors and our committees are required by our Constitution to be people who are blind or vision impaired. Many of our staff are also vision impaired. We have over 3000 members around Australia who are all people who experience blindness. This is why we are best placed to comment on the necessary changes that are needed to improve access to services to enable people who are blind or vision impaired to live their lives with dignity and independence.

Blind Citizens Australia is funded by the Federal Government as the national secretariat to represent the consumer viewpoint of people who are blind or vision impaired and is not a service provider. In addition to our role as the national peak consumer body, Blind Citizens Australia provides information, support and assistance to people who are blind or vision impaired to advocate successfully for their needs.

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 welcomes the opportunity to provide comment on the National Disability Insurance Scheme (NDIS) Bill. Our submission is informed from the direct experiences of people who are blind or vision impaired and their vision of how access to disability specific and mainstream services can be improved to best meet their needs.

Blind Citizens Australia has chosen areas of the Bill for comment where our expertise extends. The following comments follow the order of the Bill for ease of the Committee, rather than the importance Blind Citizens Australia places on the issue.

### **General principles guiding actions under this Act**

Blind Citizens Australia is broadly supportive of the proposed principles of the Bill and the explicit recognition of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).

In addition to the recognition of international instruments, Blind Citizens Australia recommends that national instruments are also cited in the final legislation, specifically the national Human Rights and Anti Discrimination Consolidation Bill (once this has been formally adopted), the National Disability Strategy and the National Disability Advocacy Framework which establishes the entitlement of people with disability to access independent advocacy.

**Recommendation 1: Blind Citizens Australia recommends that the final NDIS legislation also cite national legislative instruments including the Human Rights and Anti Discrimination Consolidation Bill (once legislated) and other instruments, as appropriate, which protect or serve to enhance the rights of**

**people with disability such as the National Disability Strategy and the National Disability Advocacy Framework.**

## **How information is communicated and accessible formats**

Clause 7 of the Bill indicates that:

The contents of any notice, approved form or information given under this Act, the regulations or the National Disability Insurance Scheme rules to a person with disability must be explained by the giver of the notice, approved form or information to the maximum extent possible to the person in the language, mode of communication and terms which that person is most likely to understand.

- (2) An explanation given under subsection (1) must be given both orally and in writing if reasonably practicable.

Access to documentation in an independently verifiable and accessible format that meets the specific needs of a person with disability is critical to the transparency of the NDIS.

While Clause 7 appears to cover the provision of information in accessible formats for people who are blind or vision impaired, its wording could be open to misinterpretation. The majority of people who are blind or vision impaired will have the capacity to understand information communicated verbally (as worded in the clause) but it is the independent access to this information in a format which is accessible to the person (such as large print, audible formats, electronic formats and Braille) which is critical. People who are blind or vision impaired should have the same access to information as any other participant in a timely manner, consistent with the caveats of the current Disability Discrimination Act 1992 (Cth). This applies to a number of elements specified in the Bill, including but not limited to participant plans, information provided to nominees, information relating to debts and methods of notification by the CEO.

**Recommendation 2: Blind Citizens Australia recommends that Clause 7 of the final legislation is reworded to specifically include the words ‘ in a format that is accessible to the participant’ to ensure the clearest interpretation of the Clause.**

## **Access requirements and restrictions**

### **Age**

The proposed NDIS entrance cut-off of 65 years of age continues to be a major concern amongst people who are blind or vision impaired.

Put simply and as noted in our submissions to the Productivity Commission, the adoption of this threshold is likely to create a situation of ‘have and have nots’ purely on the basis of age - 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. As one of our members notes:

“If this scheme is going to be all it is proposed, there should not be an age cut off. Many disabilities are not age related. Either we have a much heralded scheme or we don't.” Male, Victoria.

As stated in our two submissions to the Productivity Commission, separating two people with the same condition on their age alone is inequitable, discriminatory and in direct contravention of the UN CRPD, which makes no distinctions based on the age of a person. Furthermore, this proposal is inconsistent with the draft Human Rights and Anti Discrimination Bill 2012 and the current Age Discrimination Act 2004 (Cth) which makes it unlawful to discriminate against a person on the basis of age. The separating of ageing and disability also 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. As another member notes:

“In many degenerative conditions of vision impairment, the degenerative changes may be detectable long before clinical symptoms are present or noticed, so when is the person deemed to have acquired the disability? And in the case of conditions which are genetic in nature, is the person deemed to have acquired the disability at conception, or when medically diagnosed, or at some other point in their life trajectory? Eligibility should be based on need, not on arbitrary (bureaucratically determined?) criteria such as chronological age. And the choice of 65 years as the cut off point seems to be based on completely outmoded and inappropriate assumptions about ‘retirement’, both from employment and from life in general”, Female, NSW.

Furthermore, parallel reform in the aged care sector which has placed its focus on supporting people who are older to continue to live in their own homes (arising from the recommendations of the Productivity Commission’s Caring for Older Australians final report) **has not been linked to additional funding to support ageing Australians with disability to access the comparable supports offered by an NDIS**. These supports are vital for older Australians with disability to be able to live independently and with dignity comparative to their peers who will likely be funded by an NDIS. As one of our members noted in response to the Productivity Commission inquiry:

“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.

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 underplayed 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
- access to information in accessible formats

While Blind Citizens Australia is aware that fiscal sustainability has been the driver behind this clause, we note that the financial benefits and cost offsets of providing early intervention and low-cost supports far outweigh the direct cost of providing services through an NDIS. Many people aged over 65 who experience vision loss continue to have some remaining functional vision, with only a small proportion of people experiencing total blindness. Supports, including access to episodic rehabilitative services (such as learning how to perform everyday tasks with reduced sight) and the provision of low tech equipment, such as magnifiers and screen enlargement software, can vastly improve a person's quality of life and independence, and lead to long term cost savings in other government spending areas such as in the health portfolio and aged care placements. Blind Citizens Australia is concerned that short sighted cost cutting in an NDIS could lead to substantial increases in costs in other government portfolios.

Moreover, the argument resoundingly comes back to dignity – all people with disability have a right to live a quality life, not just people under the age of 65.

**Recommendation 3: Blind Citizens Australia recommends that people who are blind or vision impaired who require disability related support should have access to the services and supports that they need, when they need them, irrespective of age. Blind Citizens Australia recommends that the final legislation removes the age requirement in its entirety.**

Blind Citizens Australia notes that the costs to the Federal, State and Territory governments for the inclusion of people with disability over the age of 65, and the projected participation of people with disability over this age is only speculative, particularly for people who are blind or vision impaired who may only require low cost and episodic levels of support. As the launch sites are designed to test how an NDIS will work in practice and are limited in their geographic coverage, Blind Citizens Australia views this as an ideal opportunity to examine the effects of the inclusion of people over 65 within an NDIS.

**Recommendation 4: Notwithstanding Recommendation 3, Blind Citizens Australia recommends that one or more NDIS launch sites include applicants aged over 65 to be assessed for NDIS eligibility and where eligible, provide funded NDIS support. This approach will assist in determining the long term sustainability of extending the NDIS to participants who have been assessed as having disability related needs.**

**Disability requirements**

**Permanency of a disability**

Blind Citizens Australia recognises that parameters need to be set within the final legislation in order to provide guidance for the establishment of the NDIS.

In regards to permanency, it is imperative however that there is a provisional clause which grants the CEO power to make a discretionary decision in unique situations. This is particularly crucial in circumstances where a person may not have a condition which can be deemed to be lifelong but experiences debilitating effects to their quality of life without access to services and supports.

“Certain conditions are not permanent, but they can produce results which affect a person for the rest of their life. A serious disability which is temporary can impact on an individual's capacity to secure and keep employment, thus affecting their earning capacity, quality of life, relationships etc” Male, regional Victoria.

As an example, people with cataracts may be able to access surgery to restore their vision however access may be dependent on an extended wait for surgery. Without access to training in daily living skills to live independently as a person with significantly impaired vision, a person with cataracts may lose their functional capacity or place themselves in a position of personal danger (ie. unsafely crossing roads) while waiting for a medical ‘fix’.

**Recommendation 5: Blind Citizens Australia recommends the inclusion of a clause which provides the CEO with discretionary powers to allow the provision of NDIS funded supports where a person is deemed to experience severe functional limitations (compatible with 24 (1)(c)) as a result of their disability, which may not be lifelong in nature.**

#### **Requirement to re-prove a permanent disability**

Clause 26 of the Bill outlines that the NDIA could require participants to undertake a medical examination to substantiate the permanency of their disability. Blind Citizens Australia and other disability peaks note that this is an unnecessary and burdensome requirement for people with disability who have a condition which has already been shown to be permanent through earlier medical examinations. As one of our members has aptly noted “my eyes aren’t going to ^%&\*n’t grow back are they?”.

Furthermore, in the vast majority of cases, the existence of a person’s disability will have been established for other purposes, such as an application for Disability Support Pension, thereby limiting the need for additional medical assessments.

**Recommendation 6: Blind Citizens Australia recommends that Clause 26 is amended to require that the**

- a) NDIA seek the expressed consent of the participant to access medical information from a medical professional or from Centrelink (where the person is in receipt of disability support pension) where this is relevant or**
- b) NDIA seek that the participant, or their nominee, provide a copy of the most recent medical report outlining the permanency of the medical condition where permanency is in question.**

## **Matters that must be included in a participant's plan**

Blind Citizens Australia is broadly supportive of the proposed elements which will be considered in the development of a person's plan as part of Clause 33. Blind Citizens Australia would however recommend that considerations also extend to providing resources, as required and identified by a participant, to enable a participant to plan and identify their goals and aspirations.

“One of the key things in helping you put together a plan is to have access to the knowledge and experiences of other blind and vision impaired people. So an organisation like BCA which provides peer support is vital in this respect. Blind people know best what is practical and how to achieve personal goals, so the advice of other blind people is crucial. At the same time it's important to have input from blindness agencies and other service providers who can offer professional advice about things like adaptive technology.” Male, regional Victoria.

The types of support and information that will be needed may differ substantially depending on factors such as age, literacy, assertiveness and familiarity with the services available within the current disability sector. Goal setting can also be heavily influenced by knowledge and perceptions of what is possible and the capacity for individuals to think outside of and beyond the current suite of services offered by current providers. Many people who are blind or vision impaired who we have spoken with have expressed uncertainty and fear in the move to individualised planning. The need for independent information and advice, particularly from others with a lived experience of blindness or vision impairment, is therefore all the more crucial.

“Goals and plans can be viewed as a very seductive but simplistic perspective for the delivery of services for people whose life situations are dynamic, and where society constantly shifts around them... It will be important that participants have access to information about the variety and types of services from which they can choose to develop their goals and plans. The greatest amount of real choice needs to be available to consumers relating to the sources of services, and extent to which people wish to use informal supports and the capacity to adopt different services if life circumstances call for changes in plans and goals”. Female, Victoria.

**Recommendation 7: Blind Citizens Australia recommends that the final legislation make explicit reference to the requirement to facilitate access to independent information and advice to enable participants to identify their goals and aspirations.**

## **Reasonable and necessary supports**

Blind Citizens Australia shares the concerns of the Australian Federation of Disability Organisations (AFDO) regarding Clause 34 which stipulates that the CEO must be satisfied that all of the criteria relating to what is deemed to be reasonable and necessary – eight in total – must be met prior to eligibility being approved. As noted in

our earlier example regarding cataracts, there are a number of conditions where individuals may experience significant functional limitations which can render a person housebound, yet low cost interventions could be denied on the basis that the person does not meet one or more criteria.

Furthermore, part c) which relates to value for money needs to consider value in the broadest of terms – the provision of a cheaper piece of equipment may not be the most effective solution when looking at the cumulative effect on a person’s life. It is vital that the NDIS does not lose sight of its intent – to provide people with the supports that they need to live a quality and dignified life. It is also important that the NDIS does not unfairly restrict people from using their NDIS funded support to explore innovative supports or solutions which achieve the same outcomes and are in line with their goals and aspirations.

Furthermore, it is also important that considerations regarding reasonable and necessary support consider the normative support that would be expected to be accessed by people without disability when considering its application to people who are blind or vision impaired. For example, all children, with or without disability, would be expected to rely on caregivers for support. However, not all adults rely on others for support. People who are blind or vision impaired should not be expected to rely on significant others in their life for support, particularly if the person is not reliant on support in their life before accessing an NDIS.

**Recommendation 8: Blind Citizens Australia recommends that Clause 34 is reworded and refined to ensure that**

- a) people with disability who have a legitimate need for disability related supports are not unfairly denied access to an NDIS if they are unable to meet all criteria and that**
- b) the full circumstances of people with disability with demonstrable disability related needs are considered upon application to the NDIS**

#### **Division 4: Reviewing and changing participants plans**

The current draft provisions within the Bill (Clause 47) stipulate that a new plan must be developed each time there is a variation in circumstances, rather than allow minor variations to a plan when a person needs to modify a support. While this proposal may be suitable for some people with disability who have regular requirements for the same supports and then opt to change goals or major supports, this approach could be very problematic – and add additional layers of red tape – for people who are blind or vision impaired who may only need to access support episodically (sporadic access).

The specific needs of people who are blind or vision impaired can change as their circumstances change – a person who is blind who is functionally capable can quickly need access to a new range of supports if they change employment, alter their living arrangements or identify through their peers another way to effectively manage a particular task which may not have been discussed at the last assessment with the NDIA.



Each service request, which may not be able to be predicted ahead of time, will need to go via the NDIA, which would lead to the development of a new service plan each and every time there is a change of circumstance – a process which is unnecessarily onerous.

“For people who have a degenerative condition, this could result in the NDIS tail wagging the life dog. But even for those with a ‘stable’ disability, what changes in circumstances will necessitate a changed plan? Unless this is limited to major (unpredictable?) changes in circumstances, the resources and energies of the NDIS could be absorbed by planning rather than delivery.” Female, NSW

As an example, one of our members moved home several times within 24 months due to a partner who was domestically violent. Using the blindness service provider in her state, she was able to access orientation and mobility training to learn how to safely and independently navigate new routes around her home each time she moved home.

This situation, and many others for people who are blind or vision impaired, do not fit neatly within the prescribed intent of this clause, particularly when an allocation of a particular support, such as orientation and mobility training is exhausted. In the above instance, it would appear that if this individual were to seek the support of an NDIS, she would need to approach the NDIA each time she moved home, make a new request for access to a particular support and wait for approval. This not only substantially increases red tape for people with episodic disability, but also compromises the privacy of individuals who may not want to disclose very personal information about their lives to a bureaucracy for the purposes of being assessed for an amended support that they have already been receiving. This can also compromise the timeliness of support – if a person isn't confident enough to leave a new place of residence on their own without having orientation and mobility training first, the need to wait for an assessment could severely compromise a person's functional capacity in the meantime.

**Recommendation 9: Blind Citizens Australia recommends that the final legislation provide a specific additional sub-clause within Clause 47 for people with disability who have episodic (sporadic) needs which allows for**

- a) flexibility for the individual to use their funded package in a way that best meets their episodic needs as they arise**
- b) variation/s to be added to the person's plan where necessary rather than be required to create a new plan**
- c) the creation of a new plan only where a person's goals or aspirations have changed. Participants should not be required to create a new plan for changes in their circumstances where the circumstances are not deemed significant enough by the participant to warrant the creation of a new plan.**

This recommendation is also pertinent to Clause 51 of the Bill which stipulates that a participant must notify the CEO of an “event or change of circumstances happens that affects, or might affect, his or her access request, status as a participant or plan” . .

## **Application to be a registered provider of supports**

The premise of an NDIS is that people with disability will be able to exercise choice about their goals and aspirations and where they can access the supports needed to achieve these. Blind Citizens Australia agrees with points made by Disability Advocacy Network Australia (DANA) that the degree of complexity of the registration process imposed for a provider should be commensurate with the risk posed by the service to the other human rights of the individual. This clause should not operate in a way which unnecessarily limits a person's choices about who delivers services.

Thinking outside of the box, there may be some instances where the delivery of a service may be more efficiently and effectively delivered by an individual with demonstrable skills rather than by a service provider, particularly in regional and rural areas where access to specialist services may be limited to infrequent visits.

As an example, there is a shortage of individuals qualified to teach Braille across Australia, particularly in regional and rural areas. The final legislation should allow enough flexibility to enable individuals to choose to learn a skill such as Braille through another person with disability who has the transferable, demonstrable skills and capacity to teach a peer in a paid capacity. This approach could open up innovative localised solutions and learning from peers who have developed their own successful skills. Further, this approach could, in some instances, better serve to meet a person's goals and aspirations as they may not need to wait an extended period of time for service, can access the service at a time which suits them and learn at a pace that works best. It is important to note that this will not be suitable for all services and would need to be assessed on a case by case basis to ensure that the support is of a low risk nature and to identify the benefits for an individual. Safeguards around quality would also need to be considered to ensure that the participant is getting value for money, but not so rigorous that it stifles the creation of small business opportunities by people with disability and localised innovation.

**Recommendation 10: Blind Citizens Australia maintains that the degree of complexity of the registration process imposed for a provider should be commensurate with the risk posed by the service to the other human rights of the individual. The final legislation should allow enough flexibility to enable individuals to access the supports that they need in new and innovative ways.**

## **Service providers acting as plan management providers**

Blind Citizens Australia notes that there may be a perceived conflict of interest in permitting the management of a plan by a funding manager of the NDIA or a service provider providing direct supports to an individual (Clause 69).

“There could certainly be a conflict of interest when service providers are assisting people to manage their personal plan. The advice of agencies is very important, as long as agencies are not making decisions for their clients. People need to be able to make decisions independently on the things which directly

affect them. The expertise of professionals working for blindness agencies should be utilised, but the experts should be on tap rather than on top". Male, regional Victoria.

While safeguards should be in place to ensure that people with disability can make their own informed decisions without coercion or undue influence, there is the potential that a participant who receives some of their funded supports from a service provider managing their plan may be led to believe that services offered from other brokers are ineffective, more expensive or not in the "best interests" of the participant. Some service providers may have a vested interest in the services which they provide which can inadvertently limit the scope of the advice offered to only supports that the plan manager is familiar with. This, in turn, could negatively impact on the innovation and flexibility of a participant's plan. It is important that the use of service providers as plan management providers is not automatically chosen as the default option for plan management, particularly where other independent planning options, including the expertise of Disabled Persons Organisations (DPOs), could be utilised.

The concerns highlighted above are consistent with those expressed by the Productivity Commission and serve to further highlight the need for independent advocacy to ensure that people with disability are not coerced or unduly influenced into decisions which do not meet their interests. It also highlights the need for systemic monitoring and independent auditing to keep plan managers accountable.

Furthermore, it is vital that generalist and specialist assessments and plan management processes place participant's at the heart of decision making. People who are blind or vision impaired should be empowered through person centred planning to develop a plan which is creative, flexible and most appropriate to their needs.

"I believe there is a real risk of loss of service integrity and independence if plan managers are also service providers, especially in relation to their potential influence on service users to take up their services, restricting choice and innovation in service provision." Female, Victoria.

**Recommendation 11: Blind Citizens Australia recommends that other options for independent plan management should be considered within the final legislation to minimise perceived conflict of interest.**

### **Nominees**

Blind Citizens Australia is aware that there is concern amongst disability peaks regarding the role of nominees in assisting a participant to manage a package of funding. Blind Citizens Australia refers the committee to AFDO's submission for further detail.

It is imperative that the duties of a nominee are aligned to Article 12 of the UNCPRD. Blind Citizens Australia also recommends that nominee appointments which are made other than at a participant's request should be made by an independent body (external to the NDIA) having taken into accounts the views and interests of the person with disability.

Furthermore, the final legislation should provide an additional safeguard for people with disability when it comes to auditing. Documentation prepared by nominees must be required to be provided to people with disability (in accessible formats where necessary), particularly for people who are blind who may not be able to independently verify how NDIS funds have been spent. This is particularly important where a nominee has been given responsibility for the purchase of goods and services on behalf of a participant. In this instance, any statements supplied to the NDIA should also be available to a person who is blind or vision impaired in an accessible format to minimise discrepancies, fraud or mismanagement.

**Recommendation 12: Blind Citizens Australia recommends that additional safeguards are implemented relating to nominees, including the provision of information in accessible formats to participants.**

## Reviews and appeals

### Independent advocacy and complaint handling mechanisms

The move to person centred and self directed planning is an important and fundamental shift that recognises that people with disability have the capacity to make decisions regarding their lives as people without disability do everyday. Independent advice to enable people with disability to make decisions is an important element which is noticeably absent from the Bill.

“If we are to believe that this scheme is to run properly, advocacy should be totally independent of the NDIA. BCA and other agencies will have a permanent ongoing role from here on”. Male, Victoria.

Blind Citizens Australia is concerned that there is no reference to advocacy of any form throughout the Bill, particularly self advocacy which is vital in building the capacity of people with disability (both those eligible for funded NDIS support and those seeking information or referrals) to make their own decisions and to question decisions made by the NDIA. This is a serious omission and could inadvertently disempower people with disability in their capacity to make effective decisions and to exercise their right to question decisions that do not take into account their full needs or circumstances.

It is also imperative that independent advocacy is referenced and promoted within the final legislation. The National Disability Advocacy Framework, a document endorsed by the Federal Government, stipulates that people with disability have a right to access independent advocacy support; a position supported by the Productivity Commission who noted that advocacy would make an important contribution to the effective functioning of the NDIS and would assist in delivering the NDIS’ key objectives.

Furthermore, it is vital that access to advocacy should be available independently of the NDIA to ensure that people with disability can raise their concerns without fear that their package of funded supports will be compromised. Likewise, it is imperative that potential and actual participants of an NDIS are informed of the availability of independent advocacy support in any issues related to their access or participation in an NDIS,

including reviewable decisions as specified in the Bill. This is particularly vital for an appeal based on the content of a participant's plan, reviews of a plan, compensation requirements and debt recovery, to name just a few.

**Recommendation 13: Blind Citizens Australia recommends the inclusion of a clause within the General Principles that establishes the right of people with disability to access independent advocacy support in relation to their access to, or participation within, the NDIS.**

It is also vital that the NDIS legislation recognises the importance of systemic advocacy to ensure that work to improve access to services outside the gamut of the NDIS is not hampered. While the NDIS could potentially make some very positive changes in the inclusion of people who are blind, it will not address access barriers which continue to exist in many areas of life, including the accessibility of public transport, access to health, education and employment where discrimination on the basis of disability continues to exist despite the protections afforded by the Disability Discrimination Act (Cth) and associated Standards. Independent systemic advocacy by people with disability for people with disability and by advocacy organisations needs to be recognised as a crucial component that can help to enforce a more holistic societal change. While an NDIS may be promising in some areas, many other areas of life continue to be closed to people who are blind or vision impaired, as noted by one of our members:

“My needs for instance are not daily ones, but now and then I need mobility assistance and I will be upgrading my dog in the next year. I also will need some more computer training and I'm always wanting equipment, so have to save up for this and that's ongoing for each new item. Will I still have adequate library services I wonder? Will I have adequate training assistance for learning new computer skills with speech programs? Will I be able to attend the gym which has been set up to cater for those with vision loss and has people aware of the assistance one needs? My local gym certainly isn't like that at all.” Female, WA

As the introduction of the NDIS will herald a significant increase in the numbers of people accessing individualised packages, it is vital that there is a well resourced and funded advocacy sector to support individuals with disability when and if they need advocacy support.

**Recommendation 14: Blind Citizens Australia recommends that the final legislation stipulate an assigned percentage of total NDIS funding to be allocated to the provision of independent advocacy support to assist people with disability and to support the continuation of systemic advocacy. Where funding is allocated, Blind Citizens Australia recommends that its administration is handled, distributed and administered independently of the NDIA to ensure that all advocacy is independent.**

**Where advocacy is unable to be funded through a percentage of the NDIS total budget, Blind Citizens Australia recommends that an allocation of funding is committed for the continuation of advocacy to ensure that the tenants of the National Disability Strategy can be fulfilled.**

Furthermore, as noted by Disability Advocacy Network Australia (DANA), the Bill does not establish independent complaints handling mechanisms in relation to the actions of service providers, leaving participants with little option but to continue to use State and Territory mechanisms which can be quite different in their application and effectiveness. As the Bill currently stands, it is however unlikely that participants will be able to make a complaint about the NDIA unless the NDIA subscribes to each mechanism in each state and territory.

### **Review process**

In regards to the review process, Blind Citizens Australia recommends that a “middle path” is developed which would sit between the proposed internal complaint resolution process within the NDIA and progression of a complaint to the Administrative Appeals Tribunal (AAT). There are a number of useful models which could be investigated including the Disability Services Commission model in Victoria or at a federal level, the Social Security Appeals Tribunal model.

In the first instance, individuals should be able to request that the contested decision be independently reviewed within the NDIA by a decision maker unrelated to the access request, similar to the role of an Authorised Review Officer. Where the complaint relates to eligibility or a request for reasonable and necessary supports, disability specific expertise should be sought. Where resolution cannot be reached, an appeals mechanism similar to the Social Security Appeals Tribunal, with Tribunal members with specific disability experience, should be convened to assess a matter prior to it being progressed to the AAT.

As noted in other submissions to this Committee, the AAT can involve a very legal process which can be intimidating for people with disability and may not be the most effective resolution process to address concerns relating to human rights.

**Recommendation 15: Blind Citizens Australia recommended that the final legislation provide a “middle path” for complaint resolution similar to or modelled on the Social Security Appeals Tribunal model or Disability Service Commission (Victoria) model.**

### **NDIA Board**

“To let non disabled people govern the scheme is to go back to the paternalistic model of disability care and that is a real step backwards”. Male, Tasmania

The NDIS has been designed to empower people with disability to take an active involvement in all parts of social and economic life. The NDIS should therefore, be majority driven by people with disability for the benefit of people with disability. At present, the Bill provides no minimum requirement for representation on the Board of people with disability.

People with disability should not fill positions simply because they have a disability, but because they have the developed skills and knowledge, as well as the first hand experience and the vested interest to comprehend the impact and consequences of decisions for both people with disability and the long term sustainability of the NDIS. At the very minimum, the Board should comprise two individuals who have lived experience of impairments which result in substantially reduced functional capacity.

“It would appear that, while an advisory council can advise, it lacks the power of a board to make final decisions, and it is significant and alarming that people with disabilities are again being relegated to advice givers with limited influence. Without an active preference for people with disabilities on both the Board or and Advisory Council of the NDIA, both groups will be dominated by the interests of financial managers and administrators and carers. While these groups have a valuable role, their perspective is not necessarily unified to that of people with disabilities. Therefore, I believe the Board should be opened to people with disabilities, and a clear and defined number of roles, (more than 2) be allocated to people with disabilities.’ Female, Victoria.

Further, clause 172 outlines that Board will be required to release an Annual Report. Blind Citizens Australia recommended the inclusion of a clause which requires the Board to report on the achievement of the Principles of the final legislation and to report on participant satisfaction with the performance of the NDIA. This report should be publicly available to ensure accountability.

## **Independent Advisory Council**

In regards to the Independent Advisory Council (IAC), Blind Citizens Australia recommends that the final membership comprise a majority of people with disability who have the capacity to represent the views and experiences of a broad constituency of people with disability. The IAC should also be required to seek the expertise of consumer groups and disabled persons organisations (DPOs) regarding the issues experienced by specific demographics in their access to, or participation in the NDIS to enable informed recommendations to be made to the Board on gaps in the provision of reasonable and necessary supports. This may help to ensure that the NDIS caters for the introduction of new and innovative supports that may be of benefit to people with disability. Blind Citizens Australia also recommends that the function of the IAC should extend to providing advice to the Board about the way the NDIA meets the principles of the final legislation, including UN CRPD compliance.

**Recommendation 16: Blind Citizens Australia recommends that there is proportional representation of people with disability, including people who are blind or vision impaired, on both the Board and Independent Advisory Council. At minimum, this should include two people with disability with the developed skills and experience to represent the lived experience and interests of people with disability on the Board and majority representation of people with disability on the Independent Advisory Council.**

## **Review of the operation of the Act**

A review of the operation of an Act which is designed to build the capacity of people with disability should also include people with disability in the heart of the review process.

### **Recommendation 17: Blind Citizens Australia recommends that the final legislation cite**

- a) that the Terms of Reference for the review should be co-designed with consumer and advocacy organisation representatives to ensure the holistic review of the NDIS**
- b) that the views of participants and people with disability are actively considered in the review of the NDIS, with accessible mechanisms provided to enable people with disability to raise their concerns.**

## **Amendments to the NDIS in the future**

As highlighted by DANA, the Bill does not rule out the future use of means testing and/or co-payment mechanisms. It is imperative that the final legislation makes explicit reference regarding the status of these two decisions.

## **Final Comments**

Blind Citizens Australia notes that the NDIS, as presently proposed in the Bill, appears to be moving in the right direction but requires some further modification to meet the full interests and needs of people with disability and people who are blind or vision impaired in particular. Further detail is needed to ensure that people who are blind or vision impaired, and people with disability, are afforded the capacity and ability to access the disability related supports that they need, as they need them, regardless of their age on a piece of paper.

People who are blind or vision impaired need certainty that they will be able to exercise choice and will be at the centre of decision making. People who are blind or vision impaired also need certainty that the NDIA will be accessible to them - both in terms of eligibility and in the information that is provided - and that their needs will not be bound in excessive red tape in order to access the supports that are required, including supports which are innovative and flexible.

Independent advice, information and advocacy are crucial to enable people with disability to exercise choice and to rightfully question a decision. And it is imperative that people with disability, including people who are blind are at the front and centre of decision making at all levels of the NDIS.