

Level 3

Ross House

247-251 Flinders Lane

Melbourne Victoria 3000

Telephone: 03 9654 1400

Toll Free: 1800 033 660

Fax: 03 9650 3200

Email: bca@bca.org.au

Website: www.bca.org.au

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Blind Citizens Australia

### Submission to The Aging and Disability Commission – Disability Advocacy Review

#### NSW Ageing and Disability Commission

#### PO Box 40

#### Parramatta NSW 2124

#### October 2019

1. **About Blind Citizens Australia**

Blind Citizens Australia is the peak national representative organisation 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.

Our organisation provides peer support, information and advocacy to people who are blind or vision impaired across Australia. We also work to influence change on systemic issues impacting on people who are blind or vision impaired, and provide support and advice to community and government on issues of importance to our members.

Our work is directly informed by lived experience of blindness and vision impairment. Our membership, our Board of Directors and our staff are all made up of people who are blind or vision impaired.

#### 1.1 Introductory Comments

BCA is pleased to have the opportunity to make a submission to the review of advocacy funding model for NSW. Questions relevant to our operation and the future of advocacy will be addressed, with justification for the continued funding of diagnostic specific disability advocacy organisations provided. A commitment by government to continue providing advocacy funding is essential to the wellbeing of all people with disabilities. It is clear that the National Disability Insurance Scheme (NDIS) will not meet every need for people with disabilities. There are many issues which fall outside the scope of the scheme that will continue to require advocacy, consultation and monitoring

Prior to merging with BCA, Blind Citizens NSW was funded for over a decade to provide advocacy. This funding has continued following the merger with BCA which occurred in 2018, and has proven to be of great value in enhancing the lives of people who are vision impaired through both individual and systemic forms of advocacy. BCA strongly recommends that the NSW government continue funding organisations such as BCA who provide diagnosis specific expertise about issues which affect specific cohorts.

1. **Advocacy Principles**

BCA agrees that the stated principles are the right ones to apply. It is of critical importance that advocacy is not regarded by government at any level as a taboo topic. Advocacy is essential not only to prevent instances of blatant discrimination or neglect. It is necessary to highlight issues which are unintentionally overlooked by government, which will inevitably occur. Advocacy services should therefore be funded to provide advocacy in its purest form, and not be expected to couch grant applications in terms which governments feel comfortable with, such as merely providing information and referral, or peer support for example. There are times when issues which create a level of political discomfort must be raised in order to promote and protect the rights of people with disabilities to fully participate in and contribute to society, and there can be no escape from the truth that the voices of people with disabilities represents. Advocacy therefore needs to be regarded as a necessary and legitimate activity in and of itself.

1. **Identification of Trends and Needs**

To accurately identify changing needs among people with disabilities, it is critical for diagnostic specific disability advocacy organisations to continue to have access to adequate funding. In recent years, governments have tended to favour funding cross-disability groups for advocacy.

While there is no doubt that various groups of people with different diagnoses share issues in common, there are many more specific issues which are unique to each diagnosis. To ensure that advocacy efforts capture these issues and that governments are alerted to them, only people with lived experiences of the issues can provide the expertise required to highlight what needs to be done and the most appropriate solutions.

For example, as our population ages and life expectancy increases, BCA has identified a significant and growing gap between those people who are blind or vision impaired who are comfortable in using available smart and adaptive technology, and those who are unable to access this technology or do not have the fundamental skills to use it to its full potential. This is particularly the case for people who lose their vision later in life and did not have foundational technology skills to begin with due to age and the rapid developments that have occurred within the past ten years or even less.

In addition, many people who are over age sixty-five and do not have access to the NDIS experience a great deal more difficulty getting access to funding for technology which is often expensive and essential for their quality of life and participation in society. It is this disparity alone that makes it necessary for advocacy groups to be funded to highlight this inequity.

The issue of technology and those who cannot access it is raised here because technology is used in such a variety of contexts, from transport to banking to accessing personal government records. As technology continues to develop, the necessity to design it in a way that is accessible continues to grow, as does the need to insure that those who are unable to use technology have ways which enable them to manage everyday tasks which have become more difficult as older methods of completing them are abandoned in favour of online platforms.

As a result, government departments and companies alike need to be constantly reminded of the needs of people who cannot use systems based on platforms that are reliant on familiarity with technology such as smartphones or computers with screenreaders such as Jaws, Voiceover or NVDA. The role that diagnostic specific advocacy services play in providing feedback for consultation processes is therefore critical, in order to ensure that the needs of all groups of people are taken into account when products and services are being designed. Advocacy services have the ability to bring people who live with disability into these consultations so that the very people who are using these products and services on a daily basis can explain what it is that they need well before products and services are released.

1. **Types of Advocacy**

It is important to distinguish between the various types of advocacy, as there are different activities which support each type. For example, to promote self-advocacy to our members would not be reasonable unless BCA provides resources and training to enable people to develop the skills to engage in self advocacy. This requires the employment of staff to oversee projects which are designed to provide these resources, as well as potential transport costs and expenses related to infrastructure, such as videoconferencing facilities or venue hire.

Individual advocacy requires the employment of a staff member who has the skills to support people who may have difficulties with articulating their needs due to literacy issues, or a more recent loss of vision which leaves a person unable to use technology which would enable them to act independently for example. People often find themselves too upset to be able to articulate their situations in a manner which will be taken seriously by a third party. Hence, the support of a professional advocate can be vital in such situations. This can include employment related issues, NDIS appeals, educational settings and others.

Systemic advocacy involves a large amount of consultation with BCA’s members to ensure that the position articulated in any submission or consultation process accurately reflects that of our members overall. While there will always be differences of opinion amongst our membership, the position which is held by the majority, or that which reflects a compromise agreed upon by the membership, must be arrived at and faithfully delivered by representatives. Again, it is necessary to employ staff to coordinate this work, which is quite different from individual advocacy and which is difficult to combine into one role. Staff specialising in individual advocacy spend their time attending meetings with clients or members, writing letters on their behalf or adding to what members have already written themselves, and maintaining relevant records. Staff concentrating on systemic advocacy often represent the organisation on access advisory groups, attend government consultations, and collate feedback from the broader membership in preparation for submissions made to government at state and federal level. It is therefore not practical to expect one staff member to be able to complete all of these activities.

1. **National Approach to Advocacy Funding**

Ideally it would be preferable to have approaches to advocacy funding and provision aligned in all states, particularly for a national organisation such as BCA. Until this occurs however, and the approach is agreed upon by all parties, the principles which best serve the needs of organisational members and constituents should be what is aimed for when considering the future of advocacy in NSW. Approaches which limit the capacity of organisations to advocate for their members and constituents are counterproductive, and could result in much larger economic costs to government in the long run. For example, the failure of the Queensland government to consult with advocacy groups prior to introducing Queensland Rail’s New Generation Rolling Stock trains in 2014 led to massive cost blow-outs as a result of having to “retro-fit” train carriages to meet the needs of people with disabilities. Had genuine consultation occurred in the design phase, the cost of supporting advocacy groups would have been hundreds of millions of dollars less than the cost of remodelling the carriages. (<https://www.news.com.au/technology/innovation/bill-to-fix-queenslands-botched-new-trains-blows-out-to-336-million/news-story/e9c36ca982fa04831b210467fb2c820e>)

<https://www.abc.net.au/news/2018-12-10/queensland-rail-inquiry-new-trained-failed-from-day-one-forde/10600554>

The Queensland government at the time not only demonstrated great disrespect towards people with disabilities, but failed to recognise the value of advocacy groups in choosing not to consult in favour of perceived economic savings. This demonstrates that a holistic picture is required when determining the future of advocacy. No one perspective should be emphasised over another, with all factors being regarded as equally important.

1. **Measuring Outcomes**

It is easier in many respects to measure outcomes associated with individual advocacy, as cases are resolved within a relatively short timeframe, (often within 3-6 months, and usually within a year at most). Outcomes are easily recorded and feedback from clients can demonstrate the success of the outcome.

BCA is funded for individual advocacy in Victoria, and reports to the Department of Health and Human Services every three months. Provided records are kept adequately, this is not too big a task to manage.

BCA initiates projects often which are not funded, but which nevertheless have a positive impact on the lives of people who are blind or vision impaired. For example, BCA has dedicated a staff member to assisting people to make submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disabilities. From stories gathered and emerging trends, BCA will then make its own submission on a broader level.

Taking into account the outcomes of work such as this demonstrates unmet need in terms of what funding is available. Hence, it appears to be important to measure non-funded advocacy activities.

Systemic advocacy however, is more complex to measure, as often issues can take years to be resolved with no short term outcomes achieved. Audio description is a case in point. BCA has lobbied successive Federal governments for 25 years for legislation similar to that which underpins compulsory captioning on free-to-air television with no result. Yet it cannot be said that the fault lies with BCA. Records demonstrate that BCA has made tremendous efforts to continually raise this issue with politicians and convince them of its legitimacy. Perhaps then, it should not be the outcomes which are measured when considering systemic advocacy, but the quality of strategy development and implementation by organisations in their efforts to create systemic change.

In regard to what assists or prevents outcome measurement, it is essential that the processes for measuring outcomes and lodging results are accessible to people who are blind or vision impaired. The majority of BCA employees are blind or vision impaired. Hence, it is critical that our staff are able to complete the tasks associated with their responsibilities with a minimum of difficulty caused by inaccessible websites or documents. The accomplishment of such tasks is something which sighted people take for granted. So it should be for people who are blind or vision impaired.

1. **Factors in the Design of a New Advocacy Funding System**

As mentioned, both diagnostic specific and cross-disability organisations need to be funded with a sense of equality in stature for all organisations. There will be times when diagnostic specific organisations will join with cross-disability organisations to advocate regarding issues which affect people with multiple types of disability, but it cannot be assumed that cross-disability organisations will have the expertise to advocate well for people with specific needs and issues.

Secondly, while BCA welcomes funding for specific advocacy projects, general funding should be available to use as the organisation sees fit to contribute to advocacy on issues which are not recognised by the guidelines around existing project briefs. Again, audio description is one example of an area of advocacy which has never been funded, yet it is a critical issue for our constituency and something which the organisation must find resources to lobby for.

1. **Integrating Advocacy with Service Provision**

BCA is a member driven organisation, formed precisely because there was a high level of dissatisfaction among people who are blind or vision impaired with the way services interacted with them. After many years of instilling a shift in culture, BCA now has several memorandums of understanding with key service providers in the blindness sector.

One thing BCA is adamant on however, is that it will never itself become a service provider. BCA regards the provision of services and advocacy by one organisation as a real conflict of interest. One cannot advocate independently regarding the practices in the provision of service if one is also providing that service. BCA maintains that to be truly independent as an advocate is of paramount importance. Consequently, BCA argues that service providers should not be permitted to provide advocacy services at an individual level.

There are times when BCA will collaborate with services to advocate at a systemic level where it is important that the sector as a whole takes a united approach to an issue, (audio description being a good example). Service providers however do not regard advocacy as a full time activity, and BCA usually strives to be the lead organisation in a systemic advocacy effort, supported by service providers.

1. **Supporting CALD and Regional and Remote Communities**

#### 9.1 CALD Communities

To be able to gain a full appreciation of the issues faced by these communities, it is necessary for advocacy organisations to be resourced with the funds to take the extra steps required to truly engage with community members. Easy read English material must be developed, and interpreters may be needed for individual and group meetings. It cannot be assumed that videoconferencing will be an appropriate platform to meet with groups of people from these communities. They may not have the technological resources to make this viable. Even teleconferencing may present communication barriers if English is not the language participants feel comfortable using primarily. Hence, face-to-face meetings may be the only way to gain the trust of these groups and to fully grasp the issues they face which require advocacy.

#### 9.2 Regional and Remote Areas

The lack of infrastructure in these areas can be a barrier to holding group consultations, or for people to have regular contact with organisations based in metropolitan areas. The advocacy issues in these areas can involve matters which are not relevant in the city due to the infrastructure available, such as transport availability, telecommunications and support for blindness specific skills such as orientation and mobility or training in adaptive technology use.

This again demonstrates the need for diagnostic specific advocacy organisations to receive funding that is reflective of our level of expertise and the resources required to advocate for people in a variety of situations.

1. **Technological Advances**

The advance of technology in the last five years has meant that BCA has been able to become a truly national organisation. Where once all staff were based in Melbourne and anyone wishing to work for BCA outside of Melbourne had to relocate, our staff are now spread across four states and work from home apart from two staff who live close to our national office.

Our phone system allows us to transfer calls between staff in any state, and we can provide support to members in any state.

It must be remembered however that technology comes at a cost, which thankfully BCA has been able to afford. The investment was not funded through state or federal advocacy funding. Not all organisations have been as fortunate as BCA in experiencing the level of growth which the organisation has in the last five years. Organisations need to have technology and infrastructural costs factored into advocacy funding so that everybody has an opportunity to provide the coverage which BCA is able to achieve for their specific cohort.

1. **Resources**

As mentioned, technology which is innovative and efficient is a must for an advocacy service to provide high quality advocacy over a large geographic area today, as well as file storage and security measures, computers which are up-to-date and reliable internet.

While teleconferences and video-conferencing are an effective way of delivering workshops or conducting consultations, face-to-face forums provide an opportunity for participants to meet and learn from each other. Venue hire, effective audio systems and hearing loops which ensure everybody is included, and the cost of hiring sufficient staff to coordinate such activities need to be factored in. Advocacy workers are often already at capacity, and do not have the time to organise logistical matters. High quality administration staff are essential to the smooth running of any advocacy organisation.

1. **Conclusion**

BCA enjoys a good relationship with many government departments in NSW. It is important that the value this relationship brings is recognised through ongoing funding which is reflective of the knowledge and expertise which people who are blind or vision impaired bring to the development of truly inclusive and accessible initiatives, services and infrastructure by government. Advocacy will always be required by people with disabilities, including those who do not have access to the NDIS. NSW has an opportunity to become a leader in inclusive practice by providing a level of funding to advocacy services which allows for their smooth operation, growth and sustainability.