Blind Citizens Australia
Submission to the Productivity Commission Inquiry on Disability Care and Support

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About us

Blind Citizens Australia is the peak national consumer body of and for people who are blind or vision impaired. Our mission is to achieve equity and equality by our empowerment, by promoting positive community attitudes and by striving for high quality and accessible services which meet our needs. As the national peak body we have over 3100 individual members, 16 branches nationwide; in metropolitan, regional and rural locations and 13 affiliate organisations that represent the interests of Australians who are blind or vision impaired.

This submission has been developed through feedback received at in person forums held throughout Australia, teleconferences, discussion on our email lists, direct member feedback and consultation with our National Policy and Development Council and Board of Directors.

General Comments

People who are blind or vision impaired experience vastly different levels of service provision, depending on their age, location, or whether they have any other disabilities and whether they are from a Non-English Speaking Background (NESB). For that reason, there are a range of views in the blind and vision impaired community about whether the disability support system really needs to be reformed or not.

Among those in major cities, there is a strong feeling that services are already working well, and that there is a range of choice in the services which are available. “If it ain’t broke, then why fix it?” is a common refrain. Many are concerned that the introduction of a disability care and support scheme would simply add more complexity and bureaucracy. Outside the capital cities the experience is vastly different, with often little or no access to services, and a much stronger desire to reform the system.

Ultimately, all people who are blind or vision impaired want social inclusion and participation through the timely and adequate provision of supports such as aids and equipment, training, employment support, home support and counselling. These elements all add up to the right to have an ordinary life, a goal supported by the various articles of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). In ratifying the UN CRPD, Australia has agreed to meet this right to the fullest possible extent.

Given the concerns expressed by members, Blind Citizens Australia offers support for the introduction of a disability care and support scheme based on a National Disability Insurance Scheme model with the following caveats:

1. That people with disability are given the choice to access individualised funding, or to simply elect a service provider to direct funding and provide services;
2. That the scheme creates eligibility for all who need it;
3. That the scheme reduces bureaucracy and hands choice over to the individual; and
4. That the scheme is overseen and administered by people with disability themselves as employees, administrators, decision makers and volunteers.

Eligibility

Blind Citizens Australia believes that any person who is blind or vision impaired and requires support under this scheme should be able to receive it. This inclusive definition of disability is supported by the United Nations Convention on the Rights of Persons with Disability (UN CRPD).

In general, the medical cut-off for defining vision impairment is 6/18, or 10 degrees of vision, though definitions used in Australia do vary[1]. These measurements are done using anything that helps correct a person's vision, such as glasses or contact lenses. It is the firm belief of Blind Citizens Australia (BCA) that vision impairment which can be corrected through the use of glasses or contacts, such as myopia (short sightedness) or hyperopia (long-sightedness), should not be covered by a disability care and support scheme if the vision impairment is not affecting daily life in a significant way. Effects on daily life might include the inability to drive or to read standard print.

However, some people who have vision below these medical thresholds may not require any support, and others with vision above the threshold may have genuine support needs because of a range of circumstances, including:

- Additional disability. For example, a person who has relatively low levels of vision loss combined with high levels of hearing loss (deafblindness) will need access to a range of supports because their vision impairment makes them unable to lip read.

- Non-English Speaking Background. For example, a person who has low levels of vision impairment may need audio description to access a cinema. This support is slowly being rolled out across Australian cinemas, but will not be provided in languages other than English. A person from a Non-English Speaking Background in this situation would still need one-on-one support to go to the movies, even to see a foreign film in their native language.

- Aboriginal and Torres Strait Islander heritage. A person with relatively low levels of vision loss due to diabetic retinopathy living in a remote Aboriginal community may not have access to regular medical checkups to make sure their vision does not get worse.

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[1] Australian Institute of Health and Welfare, 2009, *A Guide to Australian Eye Health Data, 2nd Edition,* -p142, viewed online at: http://www.aihw.gov.au/publications/index.cfm/title/10786

Transport support for someone in this situation is critical, and may prevent other, higher support costs down the track.

- Variability of disability. Some vision conditions become more difficult to manage in certain circumstances because of photophobia (light sensitivity) or night blindness. People with these conditions may be above a visual acuity or field vision threshold, but still need assistance. This is also true of people who may fall just below the visual acuity criteria in one eye and just above it in the other.

- Attitudes to blindness and vision impairment. As with many things in life, people who are blind or vision impaired can have a range of different responses to their disability. Some are proud of their identity, and have high self esteem and good coping skills as a result. Others feel sad or ashamed of their disability, and may spend a long time relying on family and friends because they do not want to admit that they are ‘different’.

Likewise, friends and family can perpetuate dependence because they do not know what supports are available, and because they simply want to help. In rare cases, family support is designed to keep a person dependent so that pension payments will remain in the household. A culture of dependence is especially problematic for young people who are blind or vision impaired, who grow up without basic skills – cooking, washing, travelling independently – and remain dependent as adults.

BCA believes that while it is every person’s right to choose their level of independence and to perceive their disability as they wish, it is important that this is a genuine choice, not the product of lack of information and lack of opportunity. When a person chooses to realise that attitudes of shame and practices of dependence are not working for them, they should not face the barrier of meeting visual acuity criteria to get the support they need.

- Planning for people who have been diagnosed with unpreventable and unpredictable vision loss. Some eye conditions, such as retinitis pigmentosa and macular degeneration cause progressive, unpredictable vision loss. In many instances, these conditions appear slowly and the symptoms of sight loss can creep up on an individual. For these people, planning around their vision loss is impossible.

Once vision loss becomes more apparent, the person will ideally have some coping skills in place to help them as their vision deteriorates. This might include knowing how to use a white cane or how to read Level One Braille. Early intervention for people experiencing vision loss can save money by providing the skills necessary to prevent a gap in their work, recreation and social lives, keeping them productive throughout their changes in vision.

However, it is important to remember that preparing to lose your vision can be difficult and stressful. While there are great benefits to early intervention, it should never be forced on a person for the sake of reducing later costs. To do so might simply bring about other problems, such as a mistrust of the system and greater stress and depression.

A reliance on visual acuity and field vision alone has other problems. Some people find that their optometrists do not fill out forms, such as those required for Disability Support Pension, properly, and they are left unable to access the financial support they need on a day to day basis.

Language is also important. In Australia, three terms are usually used to self-describe vision related disability:

- (Legally) Blind: Usually refers to someone who has less than ten per cent distance vision or less than ten degrees of field vision. This may include people who have some usable sight (light and colour perception, the ability to make out shapes) through to people with no vision whatsoever;

- Vision impaired: Someone with an unspecified level of limited vision;
- Low vision: as above, but often used by people who believe that the term ‘impaired’ is inaccurate and insulting.

However, not everyone uses these terms as just described. A person who is considered legally blind may not call herself ‘blind’ because she has some residual vision and feels that the term is inaccurate. In contrast, someone who could be considered ‘vision impaired’ or ‘low vision’ might prefer to use the term ‘blind’ because it is simpler and more direct.

The above examples demonstrate that medical information and medical terms can only go so far in helping to decide whether someone should be eligible for supports. Key to any decision about eligibility should be the person with disability: recognising how they perceive their disability, what is happening in their life and what they would like to be able to do.

RECOMMENDATION ONE:

That all people with a vision related disability who need support should be able to access it under the scheme.

RECOMMENDATION TWO:

While medical information is useful in proving disability and planning for supports, eligibility should never rest on medical details alone. Eligibility and level of support need should be determined through a process which places trust in the person with disability and their supporters to speak honestly about what they need.

A large number of people who become blind or vision impaired acquire their disability after the age of 65, through conditions such as glaucoma and macular degeneration. Although these conditions might be considered to be connected to ‘natural ageing’ rather than ‘disability’, they do not magically appear after a certain age; while it is less likely that a person will lose their sight to macular degeneration before the age of 65, it is not impossible. Separating two people with the same condition on their age alone would be inequitable and in contravention of the UN Convention on the Rights of Persons with Disabilities, which makes no distinctions based on the age of a person. This is especially striking when it comes to adaptive technology:

> *It doesn’t matter if you’re 61 or 81, you’re still going to need things like a CCTV* [to enlarge written material].

The idea of separating ageing and disability also ignores the fact that many people who acquire disability at a much younger age will eventually need ageing related supports. Even if those who acquire their vision impairment before the age of 65 will always be eligible under a disability care and support scheme, they will need to have sensitive, disability appropriate interaction with aged care systems as they become frail.

Furthermore, our social and legal understanding of who is an older person is changing as the makeup of our population changes. Old Age Pension (OAP) eligibility is being shifted to the age of 67, and the age of retirement is steadily rising as older people remain in the workforce part time. That means that some people who are over the age of 65 and losing their vision may still be paying taxes towards a scheme they cannot access.

Blind Citizens Australia is particularly concerned that whatever system is put into place should promote consistency of support for people with disability. For instance, a person who becomes blind after the age of 65 should have the same access to aids and equipment or orientation and mobility training as a person under the age of 65. This is particularly important because access to supports can help older people remain independent for longer.

> *When I was just under 65 I couldn’t get access to Home and Community Care, but once I turned 65 it was available to me. I needed it at both times.*

As the Australian Blindness Forum notes in its submission to the Productivity Commission inquiry into Ageing[2], an older person who is vision impaired may only need help once a week with household tasks like shopping, cleaning and reading mail to remain in their home and out of an aged care facility, which costs significantly more in terms of support. Furthermore, appropriate supports can prevent other problems, such as falls and depression, in people with vision impairment over the age of 65.

RECOMMENDATION THREE:

People who lose their vision after the age of 65 should still receive the same access to services and supports as people under that age. Ideally, this would be done through one scheme because it provides the best chance of preventing discrimination and inequality. If it were to be achieved through two schemes, they should work in tandem on the same rules for access and with resources proportionate to their numbers.

How should assessment work?

As we have seen, people who are blind or vision impaired can have a wide range of conditions. Like everyone else in society, they can also have a wide range of life circumstances: they may or may not have a job, a partner, children at home, retirement savings to live off. Each individual is at a different stage of vision

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[2] Australian Blindness Forum, 2010, *Submission 244 to the Productivity Commission Inquiry into Aged Care*

loss. Some have been born blind or vision impaired, some have acquired their disability; some will be adept at many of the skills needed to function well as a person who is blind or vision impaired and others will not.

Ultimately, each individual will know their own circumstances best. The system should take this into account by offering self assessments of need completed with support, where necessary, from a trained professional with knowledge of blindness and vision impairment. The assessment should take into account formal and informal support, life circumstances and life goals. It should not work from a deficit basis – ‘what can’t you do’ – but should seek to portray all people with disabilities in a proactive, positive light.

At present many systems, such as Centrelink, require a person to provide repeated proof that their permanent disability still exists. This is both inefficient and degrading. No matter what the system, if a person has been identified as unlikely to recover their vision, there should only be a one-off medical test. Any further testing should not be to verify over and over again that someone is, in fact, still blind or vision impaired, but to check how their vision has changed and what impact this will have on the supports they need. As one participant in BCA consultations put it:

> *I’ve had my eyes removed and they still want to know whether or not I can see. Do they think they’re &@(#ing well going to grow back?*

Assessment and reassessment should be available at a time and place of a person’s choosing. For example, some people who are blind or vision impaired in rural and remote areas may have no access to transport, and will require assessment through a home visit or at an accessible community location which may not be an ‘office’ associated with the disability care and support scheme. This is particularly important for people who have just acquired vision loss and who may not have the skills or the emotional stability to go to a new place to go through a new process.

Re-assessment should be done on a regular basis, perhaps once every eighteen months to two years for people with stable eye conditions and stable lives. Longer or shorter periods of assessment should be available if a person’s circumstances are particularly stable (such as an older person with no plans to move house who has a younger family member providing informal support), or changeable (a young parent in rental housing who is losing their vision rapidly). If a person’s circumstances change between assessments they should be able to request a new assessment and a re-evaluation of allocated funding.

Standards for assessments and assessors should be national, with consistent training, forms and information sharing across state and local boundaries.

RECOMMENDATION FOUR:

That a standardised, nationalised assessment system be used for the disability care and support scheme. The assessment process should include:

- trained professionals familiar with blindness and vision impairment;
- Suitable self assessment tools;
- Scope for flexibility in when, where and how assessments and reassessments are undertaken.

What should be covered?

People who are blind or vision impaired have very different support needs to most people with disability. Often, supports are short term, and more long term supports tend to be needed on regular intervals rather than on a daily basis, such as home help, peer support or ongoing employment assistance. Daily assistance is only necessary for some supports, such as volunteer drivers and helpers to fill out forms.

For many people who are blind or vision impaired, the provision of income support is crucial to alleviating long-term poverty caused by a lack of employment opportunities. The vast majority of people who are blind or vision impaired use income support for their day-to-day basic needs.

While DSP-Blind is non-means tested, only a small number of recipients receive an above-average income through work. According to the 2007 Vision Australia Employment Survey, just 10% of people earned over what the Australian Bureau of Statistics listed as the average income in 2008[3]. In that year, there were 11,501 DSP-Blind recipients in Australia[4]. This means that just 1,150 people who are legally blind – 0.05% of all pension recipients – earned an above average income and received DSP-Blind.

Of these 1,150 people, many would use the DSP-Blind payment to ensure that their disability related needs are fully or partially met by privately purchasing equipment for their home such as a $2,000 licence for screen reading software like JAWS or paying for regular services such as cleaning and gardening. Indirect costs – such as the cost of living closer to public transport – may also be covered by the DSP-Blind payment.

For many who use DSP-Blind as day to day income the provision of a non-means tested pension should be without question

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[3] Australian Bureau of Statistics, 2008, *Household Income and Income Distribution, Australia 2008* viewed online at: http://www.abs.gov.au/ausstats/abs@.nsf/7d12b0f6763c78caca257061001cc588/5f4bb49c975c64c9ca256d6b00827adb!opendocument

[4] Department of Families, Housing, Community Services and Indigenous Affairs, 2009, *Characteristics of Disability Support Pension Recipients June 2008,* viewed online at: http://www.fahcsia.gov.au/sa/disability/pubs/policy/DSP_rpt_2008/Pages/2_medical.aspx

because it remains separate to their disability specific care and support needs. The small minority with high incomes should be subject to a system of trust: trust that a) the DSP-Blind helps to provide for a range of supports in the context of an individual’s life, and b) trust that the individual will be able to say what supports – such as training, employment assistance and access to transcription services – they need above and beyond DSP-Blind payments. It is important to note the individual’s circumstances as part of assessment because DSP-Blind payments may simply contribute to lowering housing stress for a person who is blind, married with children and living in a large city. A person with the same circumstances in the country may use more on taxi transport costs.

Often, people who are blind or vision impaired have one-off or short term requirements for support, such as:

- Access to adaptive equipment, including screen enlargement or screen reading software, Braille displays, talking GPS navigators or speech enabled mobile phones. Training to use adaptive equipment is also critical, and often unavailable to people in rural and remote areas, or is only available in group settings which may not suit everyone. For some, the highly personal decisions about what to use can be taken out of their hands. Many people with small amounts of remaining vision will still use screen magnification software, no matter how much strain it causes, because they are visual learners, yet service providers may decide that they ‘don’t need’ visual aids.

  Although aids and equipment are vital to the social inclusion and employment participation of people who are blind or vision impaired, there is a lack of training, especially in one-on-one settings for people not comfortable learning in groups. Access to maintenance and ongoing advice can also be difficult, especially from a qualified source rather than a ‘friend of a friend’.

Progress in universal design may make some adaptive technology obsolete in the long run for some people, but this is a long way off. For example, Apple has installed screen reading and screen enlargement software in its computers and mobile phones, meaning that people who buy their products don’t have to pay up to $1,000 extra for appropriate software. At present, this doesn’t provide a ‘catch-all’ fix because Apple products are more expensive than most computers or mobile phones, making them too expensive for many people on low incomes. There are very limited other choices in in-built speech on mobile phones and computers at the moment. Free screen reading software is available, but there is limited funding for further development of the program, which has been undertaken by Australians who are blind volunteering their time and computer programming expertise.

Even when universal technology design reaches a point where there is a range of affordable or free choices, expensive adaptive technology may still need to be used by some people with disability. While screen reading software works well for most people who cannot see the screen to read, it does not work well for those who have severe to profound hearing impairments. They will need Braille displays for these devices.

Often, adaptive technology cannot be bought through aids and equipment programs, which tend to focus on mobility and communication aids. In South Australia, the Royal Society for the Blind has developed a system of long-term loans (for people unable to afford payment) and short term loans (for people who need, for instance, a large and difficult to transport closed circuit television to read print materials while they are in hospital), part payment and full payment for aids and equipment. However, consumers expressed concern that the scheme only pays a flat rate for part-payments, not the half amount advertised.

Anecdotally, there have been some concerns that service providers have made ‘exclusive’ deals with certain aids and equipment providers, so that a smaller range of choice is available to people who are blind or vision impaired.

Those who are working have generally found the JobAccess system a good way to get work-related aids and equipment. In many cases, it is simply a matter of applying for what you need, a short wait for an assessment and then approval of the equipment.

For people who are not in work, however, getting access to aids and equipment can be very difficult. There is no support for people who need aids and equipment for community participation as volunteers and the support provided to young people before, during and after school is ad-hoc in quality and quantity.

Underlying the need for aids and equipment is the need to have access to a computer connected to the internet. For many people who are blind or vision impaired, access to the internet via their chosen technology can be critical to participation in a range of areas of life which might otherwise be off limits: reading the paper, looking for work, finding and filling out forms, and shopping independently if an online shopping option is available to them.

Many people who are blind or vision impaired find the cost of buying a computer and maintaining an internet plan to be prohibitive. For these people, knowledge of, and access to, low cost computer provision services such as Technical Aid for the Disabled is paramount. Offering cheap phone and internet plans as well as access to low-cost computers helps close a large gap in participation.

- Employment services are used by many people who are blind or vision impaired. According to the 2007 Employment Report issued by Vision Australia, 63% of people who are blind or vision impaired are either unemployed or underemployed. Theoretically, the need for employment services should be short lived; a person with qualifications and a disability should be able to find a job relatively quickly. Sadly, this is not the experience of many people who are blind or vision impaired:

  I've got qualifications and I've applied for jobs. I even offered to work somewhere for free for four weeks, but they turned me down. Over the past fifteen years I've gotten nowhere.

  For many people who are blind or vision impaired, this is the critical issue with regards to employment: not access to services, but the opportunity to find an employer with the right attitude to hiring someone with their disability. Work needs to continue to improve employer attitudes and to make sure that the public service remains a leader in providing employment opportunities.

  Lack of other supports listed in this document – such as computer equipment compatible with screen reading software – can prevent otherwise qualified and competent people who are blind or vision impaired from getting and keeping jobs.

  Access to specialist employment support from staff who understand blindness and vision impairment is a particular problem, especially in rural and regional areas. Often, people who are blind or vision impaired find that they have to educate their employment consultant about their abilities and the equipment they need when they go to a disability employment agency with more generalist staff.

Those who would like to start their own businesses have no financial support, even though some of the attitudinal and access barriers could be overcome best in a small business setting. Members of BCA suggested that seed grants for small businesses run by people with disability would be useful.

- Life skills training: People who are blind or vision impaired may need specialist training in life skills (cooking, cleaning), reading (learning Braille) and getting around safely (learning a new route or how to use public transport through an orientation and mobility instructor). The time it takes to teach these skills and the intensiveness of support varies from person to person.

  Learning these skills can prevent a person from requiring other supports later on. The obvious example is that learning to cook and clean independently will mean that a person who is blind or vision impaired needs less help from Home and Community Care services.

  Less obvious are the benefits of learning to read Braille. Without Braille skills, many people who are blind or vision impaired rely heavily on audio information and their literacy skills suffer. They do not remember how to spell words or use punctuation and grammar because these things are not reinforced through audio communication in the way that they are through seeing or feeling a sentence laid out. This is a particularly pervasive problem for children raised to rely on speech translations of text, who may leave school with a great deal of knowledge but no functional literacy. Without good literacy skills, people who are blind or vision impaired will experience lower levels of employment, a more limited ability to advocate for themselves and a lack of freedom of expression.

In many instances, training is provided by qualified professionals, such as staff with a postgraduate qualification in orientation and mobility who have been through a structured training program with a service provider. There is some concern among the blind and vision impaired community that a move to individualised funding would allow less qualified staff into the marketplace. This concern has to be balanced with the need for timely service provision, especially for people in rural and remote areas who may not have access to a qualified orientation and mobility or Braille instructor for a long time. In these instances, there should be genuine choice between hiring a professional or hiring someone to do informal training, or possibly combining the two.

People who are blind or vision impaired also use ongoing supports, such as:

- Home and Community Care (HACC) services. Even with appropriate life skills training, there are some activities that a person who is blind or vision impaired will not be able to do if they are living alone or with another person with disability. These things include household maintenance, shopping and reading mail. While the current HACC system provides excellent services for those who can access it, many people under the age of 65 find that services are limited or completely unavailable. The same is true of people in rural and remote areas. For some, occupational health and safety restrictions on the work of HACC staff can mean that there are still gaps in their day-to-day housework which need to be filled.

Access to HACC services and other care packages can be particularly important for parents who are blind or vision impaired. These services allow families to normalise their lives: parents who cannot drive can make sure their children attend after school activities, those with younger children have a regular way to take them to the park with safe supervision.

- Access to volunteer drivers. Those who live alone, especially in rural and remote areas or outer suburban areas with limited public transport rely heavily on the help of others for day-to-day tasks like shopping. This is especially important because the solutions which might be available in the major cities, such as online shopping delivered at home, are not readily available to people living in other areas.

  I live in an outer suburb and I have a dual disability that makes it hard for me to walk. I got down to just $500 in the bank last year because I had to take so many taxis everywhere.

- Access to information in alternative formats. A large proportion of the world's printed materials are never made accessible to people who are blind or vision impaired. Information can be made accessible through:

  - Large print copies;
  - Transcription into Braille;
  - Audio information, including audio books, information read out on Radio for the Print Handicapped (RPH), and audio description of TV shows and movies;
  - Electronic copies such as Rich Text Format (.rtf) or html versions

  There are a number of programs in Australia which provide information in accessible formats, but they are underfunded and mostly not open to individual choice. For example, accessible formats are offered to students in schools and tertiary education, but transcription is slow and expensive. The National Information Library Service (NILS) can experience long waiting lists for audio and Braille copies of materials. Adults who want Braille or large print materials at work, or from businesses which send them correspondence such as bills, often have to launch disability discrimination claims to get what they need. In the case of ‘hard copy’ materials such as these, the two factors are often time and cost.

Doing a CCIE book conversion is over $2000 for a single book from my last quote. Since there is more than one book to permit you to complete the CCIE, this is quite costly for a professional in the networking profession. My sighted co-workers spend about $100 for the same information. This is just an example and I am sure other professions have similar challenges.

Access to electronic materials is about cost – Braille transcription can be especially expensive – but can also be about attitudes. The Australian government has recently announced that all government websites should comply with international web accessibility standards. While the Disability Discrimination Act (1992) effectively means this should be the case for all Australian websites, many do not comply with the standards, leaving people who are blind or vision impaired to miss out on vital information.

For some people, access to information is achieved through one-on-one help in the form of a volunteer reader or family member. These people can assist with day-to-day correspondence, filling out forms and reading letters aloud. Unfortunately, this kind of support is often very informal and very irregular, meaning that information with a deadline –

such as a bill, or the application form for a course – may not be completed on time.

- Peer support. Much of the information people who are blind or vision impaired get about the service systems and adaptive technologies they use comes from other people who are blind or vision impaired. Not only does it provide emotional support, it offers the chance to have real choice by giving people an understanding of what works well, for instance, on one model of Braille display versus another. If the disability care and support system is to provide individualised funding, this informal way of gathering information and ideas will be especially critical.

  Peer support groups are often run entirely voluntary, or form as part of sport and recreation groups. In many instances, this can mean they are vulnerable to folding if the one or two people 'keeping it together' are not available. Any disability care and support system should provide funding for infrastructure to support local groups and ensure they grow strong and become well connected with each other and their local communities.

- Counselling. For people in the process of adjusting to vision loss, counselling can be critical to making sure that people remain emotionally well. Vision impairment can mean experiencing grief, isolation and depression. It is estimated that people who are blind or vision impaired are between two and five times as likely to experience depression, which can result in less effective use of vision, less contact with blindness and vision impairment service providers, and higher incidences of depression in their partner[5].

  While qualified counsellors are available in some parts of Australia, they are not readily available to people in rural and

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[5] Centre for Eye Research Australia, 2009, *A training manual to aid in the detection and referral of depression in adults with vision impairment*, University of Melbourne, Melbourne.

remote areas of the country. There is limited scope for one-to-one counselling in the services which are available, and staff tend not to have a good knowledge of the range of services which might assist people who are blind or vision impaired.

- Access to health and fitness support. Because many sporting activities are difficult for people who are blind or vision impaired to access, and cooking is a skill which can be difficult to learn, people who are blind or vision impaired often need support to keep healthy and fit. A range of specialised sporting activities exist for people who are already fit, including tandem bike riding and blind cricket, and some service providers offer gym facilities for those seeking fitness. Again, these services are often limited to city locations, and may not meet the needs of all people who are blind or vision impaired.

  Across the board there is limited awareness of the needs of people who are blind or vision impaired in generic health and recreation services such as gyms or local council leisure centres. The same issue can occur with non-blindness specific disability based recreation services.

- Education support. Most students who are blind or vision impaired will need access to information and adaptive technology, but some also need extra one-on-one staff assistance. A vision impaired student studying statistics, for example, may need support from someone to explain the very visual graphs and equations. A child doing physical education will need some adaptations to understand how to dance.

  Many school children who are blind or vision impaired have access to visiting teacher services to help in this regard. However, visiting teachers are not always available for the number of hours needed. At a tertiary level, getting the

> support necessary can mean being a good advocate on your own behalf; while some people who are blind or vision impaired acquire this skill growing up others do not.
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> Like access to information, there are some aspects of educational support which are about appropriate attitudes. School students who are blind or vision impaired can be treated very differently to their sighted peers, with teachers and family ‘coaching’ them through conversations with ‘friends’ who are really assigned buddies. It can be difficult for children who are blind or vision impaired to find and start conversations with other children in a classroom or a playground, and if they do they may be ostracised.

When it comes to attitude, people who are blind or vision impaired feel the negative impact across their attempts to participate in society. From the physically dangerous, such as patting a dog guide while it’s working and thus distracting it, to attitudes which discourage accessing critical services:

> *I called Lifeline the other day. The call started out well. I told them about my parenting skills and they were giving me good feedback about the work I do as a single mum. Then I mentioned partway through the call that I’m blind, and suddenly I was getting all these questions like “Who looks after your kids after school?” and “When do they get to go out?”. It was really inappropriate.*

The blindness and vision impairment service sector has a strong reliance on philanthropic funding to provide services. Consumers worry that changing to a different system of funding will leave service providers underfunded and unable to offer what are currently very good services in critical areas such as recreation, Braille literacy and orientation and mobility.

On the flip side, services for people with multiple disability and those in certain age groups – between 30 and 60, for example, where specialised programs are limited – may come into existence because of demand for tailored solutions.

There is also a broader concern that changes to the system of funding will mean that institutions – such as educational bodies and government agencies – will not fulfil their requirements under the Disability Discrimination Act (1992) to meet the accessibility needs of people who are blind or vision impaired. For example, where a person is choosing to privately learn to read music and play an instrument, they would be expected to pay for their own materials, including the transcription of sheet music into Braille from an individualised funding package or through negotiations with a service provider. A child learning music at school should not have funds diverted from their individualised funding to pay for something the school is legally obliged to provide.

Some of the issues with service provision outlined above are related to the attitudes of the public or specialist service providers. To make sure that individual cases of discrimination and systemic attitudinal issues are addressed, any disability care and support system needs to provide strong support for disability advocacy. This is especially important when it comes to individualised funding because consumer choice can only be fully realised when consumers have access to a full range of information. Information and advocacy needs to be readily accessible through a range of initial supports, including:

- Hospital and medical systems (GPs and eye specialists) for people who lose their vision;

- self help and peer support groups for those not connected to service providers;

- Phone, internet and face to face dedicated information provision for people who may not access either medical assistance or self help.

For those with multiple disability, such as acquired brain injury, physical disability and hearing impairment, sometimes it is difficult to find vision impairment specific services where staff and programs can meet their needs. This group would find flexible service provision especially valuable.

Some supports used by the broader community are also used by people who are blind or vision impaired, such as public housing and public health. People who are blind or vision impaired share the concerns of the broader community about access to these supports. However, the lack of support in health and housing can have a greater impact on someone who is blind or vision impaired: a person in public housing who can drive does not need to wait for a location near public transport and shops to come up. Health services may need to be used more frequently to prevent health problems from occurring because a person is unable to see changing moles or rashes, for example.

People who are blind or vision impaired also rely heavily on concessions and benefits, especially for travel. Without the ability to drive, public transport, community transport and taxis are the only options for independent travel. Those who use free travel passes and taxi concession cards reported that these systems work well, but that access to transport in particular is still difficult because information is not made accessible. Again, it is an issue of attitudes and practice rather than available concessions: staff who are not trained to offer guided assistance or to call out the next stop on a bus or tram; trains where the announcements are wrong.

RECOMMENDATION FIVE:

That all supports required by people who are blind or vision impaired at present should be covered by a disability care and support scheme. Supports in the scheme should include:

- **Aids and equipment supply and training;**
- **Home and Community Care (HACC);**
- **Accessible information transcription;**
- **Life skills training;**
- **Employment support;**
- **Education support;**
- **Peer support;**
- **Counselling; and**
- **Benefits and concessions**

RECOMMENDATION SIX:

That supports should be nationally consistent in availability and accessibility.

RECOMMENDATION SEVEN:

That supports should be distinct from the services that public organisations are legally obliged to provide under the Disability Discrimination Act.

RECOMMENDATION EIGHT:

That strong infrastructure for individual and systemic advocacy needs to be provided to ensure that good supports continue to exist. This should be provided in addition to any support funding given to individuals.

How should supports be delivered?

Blind Citizens Australia believes that choice is a fundamental part of any disability care and support system. For choice to be realised, funding needs to be attached to individuals, with a genuine choice to:

1. Take full control of the funding, choosing supports and acquitting the grant, or
2. Give control of money and administration to an independent broker or agent while still choosing supports independently, or
3. Use a broker for administration and money handling and use a case manager to help make decisions about supports, or
4. Nominate a service provider to offer supports and deal with administration and money.

For those with multiple disabilities which affect their ability to directly make decisions, other forms of decision making – such as circles of supportive family members and friends or micro boards – should be available.

As with all aspects of the scheme, funding should be:

a. National, and thus portable across the country;
b. Administered with a minimum of bureaucracy while still maintaining accountability;
c. Offered alongside appropriate supports such as independent information and advocacy.

Some people who are blind or vision impaired may choose to administer all of their supports and funding on their own. These people should have access to intermittent information – a place to get answers to questions about tax, occupational health and safety, budgeting and recruitment skills. In planning supports for this group, a need to access information on receipts, through accounting software or law websites should be taken on board both as part of the support plan for each individual and general accessibility planning within the scheme as a whole.

Because of the variety of supports required by people who are blind or vision impaired, it may also be appropriate to have one-off grant schemes for people who only need short-term training or to purchase aids and equipment. Further assistance may be necessary for ‘refresher’ courses or equipment maintenance and repair. It is critical that the system of care and support does not divide up one-off grants from the main scheme, but rather uses them to compliment the operation of the whole program.

Some members have suggested that money for supports could be provided through Medicare, which already has the infrastructure to provide reimbursements to people across the country. More generally speaking, people were concerned about having quick and easy access to funding, with a local point of contact for the scheme. Given the flexible range of supports which will be needed, the support delivery system should be able to offer lump sum payments (in times of crisis or for large purchases), regular payments for regular services, and reimbursement for smaller or ongoing costs as necessary.

It should be noted that the Disability Investment Group bases its costings for a National Disability Insurance Scheme on modelling done by PriceWaterhouseCoopers[6]. In this report, sensory disability costs are capped at $5,000 per year, on the assumption that:

> *… a large proportion of people with severe and profound disabilities require aids and appliances rather than care. Table 23 presents the unit costs applied to the sensory condition group. Essentially, the cost was capped at $5,000 per annum after consideration of the unit costs and lifetime of sensory assistance devices.*

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[6] PriceWaterhouseCoopers, 2009, *National Disability Insurance Scheme – Final Report*, viewed online at: http://www.fahcsia.gov.au/sa/disability/pubs/policy/National_Disability_Insurance_Scheme/Documents/sec4.htm

As outlined above, there are many different types of support required by people who are blind or vision impaired. BCA would be extremely wary of this modelling because it leaves out costly supports such as transcribing books to Braille, training and skills development and home and community care assistance with everyday tasks.

RECOMMENDATION NINE:

That supports should be delivered within a variety of models to offer people who are blind or vision impaired a range of choices, including whether or not to manage money, administration and decision making about supports in detail.

RECOMMENDATION TEN:

That appropriate extra supports should be offered wherever necessary, including extra ongoing support for people who need help making decisions, and intermittent support for those who want to have autonomy. This includes making administration of the system accessible from the start.

RECOMMENDATION ELEVEN:

That supports should be delivered through a system which is localised, and which can offer lump sum payments, regular payments or reimbursement as appropriate.

How should the scheme be funded?

There are many views within the membership of Blind Citizens Australia about how the scheme should be funded. At the core of all of the ideas put forward is a concern that the funding adequately meets current and future levels of need, even in times of economic hardship for the country. Put simply, the right of all people with disability to live dignified lives of choice and participation should be on a par with health and education services for all: we do not stop those services because it becomes more difficult to fund them.

RECOMMENDATION TWELVE:

BCA does not claim to be expert in developing high level government funding schemes. We will offer our support to any form of funding which:

- Supports the dignity of people who are blind or vision impaired, and does not perpetuate a charity model of support;

- Offers society the chance to be aware of, and responsible for, the supports of all people with disability; and

- Remains stable with opportunities for growth.

Closing Remarks

For people who are blind or vision impaired, the change to a long term care and support scheme for people with disability presents a number of opportunities: the opportunity for supports to exist, grow and be more consistent. More importantly, it presents the chance for people who are blind or vision impaired to take their rightful place in the Australian community through meaningful participation in education, employment, recreation and culture. Blind Citizens Australia holds out hope that this system can do a great deal to achieve these goals, but only if it works from an inclusive, rights based angle to lessen bureaucracy and increase trust in the people who know best: people who need the supports.

If the scheme is to be successful, it must be built upon the meaningful participation of people with disability, including those who are blind or vision impaired. To that end, BCA looks forward to providing comment throughout the Productivity Commission process and welcomes any further questions or queries the Commission may have in light of this submission.