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24 January 2011

Senate Review into Planning Options for People Ageing with a Disability

Comments by Blind Citizens Australia

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

Whilst Blind Citizens Australia recognises that this Inquiry is separate to the Productivity Commission's Inquiry into Disability Care and Support, there are many issues and considerations which overlap. If a person with a disability is unable to access the necessary supports they need prior to the age of 65, the person (and their carer if they have one) is also unable to realistically plan for their future years as an older person. As one of our members commented:

"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."

In our discussions with other disability peak bodies, we are aware that many people with a disability and disability professionals hold the view that a Disability Care and Support Scheme should be extended and made available to people with a disability aged over 65. An extension of age coverage, if adopted, could have a positive effect on the options available to people ageing with a disability.

Some of our members believe that the aged care system may be able to meet the needs of older Australians who are blind or vision impaired. However, for this to occur,

equivalent access to specialist services, equipment and supports would need to be provided at a comparative level to what a person who is blind or vision impaired would receive under the Disability Care and Support Scheme. The Productivity Commission has held a concurrent review into Care for Older Australians which may also have implications for this review.

We draw the Committee's attention to Blind Citizens Australia's submission to the [Disability Care and Support Scheme](#)¹. We would also like to direct the Committee to an excellent submission prepared by the Australian Blindness Forum (ABF) to the Productivity Commission regarding [Care for Older Australians](#)². The ABF submission outlines the key issues affecting older Australians who are blind or vision impaired and key recommendations to ensure that their needs are met. Some of the key points of the ABF submission have been elaborated below, however the ABF submission is essential further reading. The ABF works as a collective body of service providers and with Blind Citizens Australia as the peak body.

Key Statistics

Access Economics estimates that over 575,000 Australians aged over 40 experience vision loss. Within this population, it is estimated that 66,500 meet the criteria of legal blindness. The prevalence of vision impairment increases with age to 70% in individuals who are 70 years of age or older. As the ageing population increases, so will the number of individuals experiencing vision loss. Legal blindness in Australia is defined at 6/60 or a visual field of less than 10° which cannot be corrected by corrective lenses or treatment. Legal blindness prohibits access to a drivers licence. It is projected that the number of people with vision loss aged 40 or over will rise to just over 800,000 by 2020, and people who are blind will rise to 102,750³.

Whilst there is a strong correlation between age and disability, it is important to note that blindness and vision impairment which is acquired later in life is not solely attributable to simply 'getting older'. Investment is necessary to ensure that the needs of older Australians with a vision impairment can be met. This needs to include support and the provision of supports to enable people to live in their own home.

Amongst people who are blind or vision impaired, there are two distinct subgroups

- People who are blind or vision impaired who have acquired their sight loss at birth/early in life and are now ageing
- People who are blind or vision impaired who have acquired their sight loss later in life

This distinction is important. Of the two groups, there is a larger segment of the population who have acquired their sight loss later in life, with our membership compromising both groups.

¹ Blind Citizens Australia, 2010, *Submission to the Productivity Commission Inquiry on Disability Care and Support*

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

³ Access Economics

In speaking with our members and service agency client groups of people with age onset vision impairment, we have made the following observations. People with age onset vision impairment:

- Are likely to be retired or semi retired, most due to age. In some instances, this may be due to the person's own assessment of their functional ability and employability now that they have a vision impairment.
- the person is likely to be supported by family and friends, who they may view as carers. The person is more likely to seek assistance with basic tasks such as daily living and reading mail rather than use aids and equipment to manage this independently.
- are less likely to travel independently (for example using public transport) and are more likely to rely on private transport offered by family and friends, taxis and community transport, where this is available.
- In many instances, people who have acquired their sight loss later in life comment that they are worried about how they will 'cope' after their partner dies. These concerns include whether they will be able to stay in their own home; how they will be able to manage their care independently; and where they will be able to obtain the assistance they need.
- There is a lower take up of adaptive equipment (such as screen reading software, text enlargement software and Braille) and of mobility tools. Whilst a lower take up may be partly explained by a reluctance to embrace new technology, it is also likely due to a greater reliance on assistance by family and friends. As an example, it has been our experience that many older people who are blind or vision impaired are reluctant to self advocate on issues such as accessible materials so that they can read information independently. As one member put it,

"It's just easier to wait until my daughter comes over. I can just get her to read it [the standard print bill] for me."

In comparison, our members who have been blind or vision impaired from a young age are often

- less likely to view their significant others as carers. Individuals view their families and partners as just that – families and partners who provide assistance only when assistance is needed.
- May live with a partner or have family members who also have a vision impairment or other disabilities.
- Are more likely to use adaptive equipment and mobility aids (such as a white cane, identity cane or dog guide).
- Are slightly more likely to use public transport and taxis

Individuals who are blind or vision impaired are significantly more likely to be unemployed or underemployed. A survey undertaken by Vision Australia, one of the largest service providers in Australia, indicated that 63% of people who are blind or vision impaired are unemployed or underemployed⁴. The lack of employment opportunities, combined with other social and environmental barriers can create stress and uncertainty about what the future holds and also impact on a person's capacity to acquire wealth across their lifetime. The high cost of services within aged care facilities

⁴ Vision Australia, 2007, *Results and Observations from Research into Employment Levels in Australia* via http://www.visionaustralia.org.au/docs/news_events/Employment_Details.doc

may further limit the choices a person has as to where they can live and how they may be supported in the future.

Key considerations for ageing Australians with a disability

(a) Inadequacies in the choice and funding of planning options currently available to people ageing with a disability and their carers;

First and foremost, disability and aged care should be part of a seamless system which is consistent across Australia and meets the needs of the people accessing it.

“Welfare...health and well being is important. There is often only support for blindness but a lot of agencies need to be more holistic. People have multiple disabilities that need to be met, not just blindness”. Member, Melbourne.

Access Economics has estimated that 730,000 people experience dual sensory loss (both a hearing and vision impairment), with 97% of this population aged over 65 years of age. The research, conducted in 2005, estimated that the cost of unpaid care for people with dual disability was \$4.6 billion⁵.

People who are blind, vision impaired and those with multiple disabilities have reason to be concerned about what their future will look like. We have heard of many instances where individuals have saved parts of their pension over an extended period of time to purchase a much needed piece of equipment or have put aside savings that have been quickly eroded by the rising costs of living. These issues are further exacerbated for individuals living in regional and rural areas and individuals who are solely reliant on the Disability Support Pension to survive. People should be able to access the supports that they need, regardless of whether that need is acquired pre or post 65 years of age and irrespective of where the person lives. This is a principle upheld by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD)⁶.

The inadequacies in the choice and funding of planning options are outlined in the following sections, with strategies included to improve the wellbeing of older Australians with a disability.

(b) Ways to ensure the continued quality of life for people with a disability as they and their carers age;

People need access to services that are responsive to their needs. There are a number of areas where improvements are necessary to ensure not only a continued, but higher, quality of care.

Better access to home and community care

Often, individuals who are blind or vision impaired only require basic assistance to live independently. As the ABF notes in its submission⁷, an older person who is vision

⁵ Taylor, Penny, *Making Sense: The economic impact of dual sensory impairment and multiple disabilities*, Powerpoint presentation delivered April 10, 2010. Available at www.ableaustralia.org.au/content-files/Penny%20Taylor%20Presentation.pdf

⁶ <http://www.un.org/disabilities/default.asp?id=259>

⁷ Australian Blindness Forum, 2010, *Submission 244 to the Productivity Commission Inquiry into Aged Care*

impaired may only need help once a week with household tasks like shopping, cleaning and reading mail to continue to live in their home. This is often preferable to the individual and less costly than supporting an individual within an aged care facility. Appropriate supports can prevent other problems, such as accidents, falls and depression which are significant risks for people who are blind or vision impaired. Social involvement and regular activity also reduce functional decline and can increase independence.

At present, access to home and community care (HACC) services are dependent on a person's age, where they live, whether their council has a funded program and an arbitrary assessment of the person's disability, rather than an assessment of their needs as an individual. Many of our members in regional areas have told us that home and community care "does not exist if you are under the age of 65", and can still be restrictive above the age of 65. For some, occupational health and safety restrictions on the work of HACC staff can also mean that there are still gaps in day-to-day housework which need to be filled. We share ABF's concern that "HACC funding specifically excludes 'rehabilitative services specifically directed solely towards increasing a person's level of independent functioning' when access to orientation and mobility and independent living can delay entry to residential care."

Nationally, there is a need to improve consistency in the application and eligibility of the scheme to ensure that people across Australia can receive access based on the extent of their needs. It is also imperative that the scheme aligns with the principles of the UN CRPD.

A need for increased awareness and understanding of disability

As the population ages, there will be increasing numbers of older Australians with a vision impairment who will be unable to continue to live independently in their own homes.

One of our major concerns is the level of preparedness of aged care facilities and the sector as a whole in meeting the needs of current and future residents who are blind or vision impaired. A common view is that aged care facilities and retirement homes 'just don't understand blindness'. People are concerned (in many instances rightly so) that they will simply be forgotten.

"[The] aged care system does not kick in with the services people need or want".
Member, Canberra

A member Joe*, who speaks English as a second language, told one of our advocates that he looked forward to her calls because he had 'no one to speak to'. Joe also spent most of his days confined to his room because he could not see the communal TV and was unable to participate in the activities his hostel offered.

A continued quality of life for older Australians who are blind or vision impaired is reliant on

- The adoption of inclusive practices – designing facilities to be accessible to people of all abilities, offering recreation to residents which actively includes all residents irrespective of disability and the provision of accessible information amongst other practices
- Access to a well skilled, trained and resourced workforce which has a good working knowledge of disability and respects the rights and dignity of people with a disability.

This point is particularly pertinent, with many of our members expressing concern that staff are overworked, underpaid and ill equipped to meet their needs. There needs to be additional training opportunities and support, including improved access to ongoing professional development and staff mentoring programs.

We agree with ABF that there should be incentives for employers to invest in training and to retain skilled staff. This should be considered through increased funding allocations and accredited programs aimed to improve and enhance the skill of staff.

Choice – to live in your own home or in supported accommodation

As highlighted earlier, the needs of people who are blind or vision impaired may be different depending on how the person acquired their sight loss. The best quality of care should ultimately allow people to continue to live in their own home, should they choose.

It is important that people who choose to live in aged care facilities remain connected with the community – be it the community where they have raised their family, a community of peers who have the same disability and relate to their needs, or the friendship/interest groups they have made over time. Whilst this might seem simple enough, bureaucracy can burden this process. Concerns of ‘double dipping’ have seen clients of blindness service agencies lose access to blind day programs they may have visited for a long time, simply because they have now moved into an aged care facility. Aged care facilities are funded under the HACC program to provide recreation for residents within their facility. Service providers are funded by HACC to provide recreation for their clients, who may have a specific disability. Unfortunately, there is no recognition that a client may wish to socialise with peers who can relate to their impairment, or that the recreation provided by an aged care facility may not be completely accessible or meet their social needs. This unfairly infringes on the participation of an individual who may already be struggling to adjust to their sight loss.

Some of our members have also expressed concern that there are no specialist facilities that cater exclusively for people who are blind. It is imperative that people are provided with choice. As noted in the ABF submission,

“Whether they [people who are blind or vision impaired] would like to move to a specialised facility (for blindness, for cultural reasons or for religious orientation) or stay at a generic aged care facility within their local community, they need an environment and organisational culture which supports them to maintain an optimum level of independence within that facility”⁸.

Better access to information

Another barrier for people who are blind or vision impaired is access to information. Whilst there is a wealth of information on a range of issues for people who are ageing, much of this information is in printed form only. From pamphlets regarding aged care options, to information relating to health, to forms that need to be completed, information is largely inaccessible to people who are blind or vision impaired. Members have also commented that it is hard to know what services are around.

“People with a disability do not know what services are available and should be able to access a service to point them in the right direction”. Member, Newcastle

⁸ Australian Blindness Forum, 2010, *Submission 244 to the Productivity Commission Inquiry into Aged Care*

A person's experience can be greatly improved if they can access the information that they need, when they need it, in a format which is accessible to them. Accessible formats include large print (sans serif 16 point or larger), Braille, audio, e-text (Word format is preferred over PDF, since PDF documents can be inaccessible to people using screen reading software) and Auslan for people who are deaf or deafblind.

(c)The types of options and services that could be developed to help people with a disability and their carers to plan for the future; and

Better access to supports – aids and equipment and blindness services

People who are blind or vision impaired require specialised assessments and services to meet their needs. Support is required to assist clients to learn how to use adaptive equipment, acquire orientation and mobility skills and to provide strategies to live safely within their own home. These needs do not change at 65 – if a person requires it before 65, they will require this after 65. As sight loss is strongly related to age, it is likely that more individuals over the age of 65 years of age will require these types of services. More so, the ageing population means that more and more people will require access to the rehabilitation services that are often struggling to meet people's needs now.

People in regional and rural areas bear the brunt of poor access to supports. As one member in Toowoomba, aged in her late 40s, put it:

“Toowoomba has only a quarter of an O&M [orientation and mobility] service that they had 6 years ago – service is good when you manage to nail an instructor but there are now queues [to get service]”. Member, Toowoomba.

And another:

“Clients should have more choice in the range of providers they can access – in some places there is only one provider. If the service is crap, the service is crap, you just don't have any choice”. Member, Newcastle

There needs to be a significant investment in regional and rural areas to ensure that people with a disability – and those who are ageing – can access the supports they need now and when they need them. This is important for all Australians regardless of where they live and should include access to health services and allied health care such as counselling (particularly at the time a person is losing their sight or after losing their sight). Better access to specialist services provides a cost effective avenue to address social inclusion, reduce demand for higher care services for some clients and has positive implications for a person's quality of life.

Perceptions of 'double dipping' as outlined earlier (accessing both aged and disability services concurrently) need to change. Put simply, there needs to be greater capacity and flexibility in aged care community support packages to ensure that needs which arise because of age and needs that arise because of disability can be met. There should also be better integration between aged care and specialist service providers.

As noted earlier, older people with a vision impairment often exhibit reluctance to learn new technology or use aids and equipment which could improve their access to information, participation in the community and overall quality of life. This is an area where further work and additional measures are required.

Older people need support and encouragement to learn how to use technology such as screen reading software, magnifying equipment, navigational tools and to develop skills to foster their independence. This needs to be flexible and tailored to the individual to ensure that the person is supported through what can be a difficult time. For many, it is not just about learning new technology, but coming to terms with sight loss which irreversibly changes how things must be done. However, it is our experience that once people learn to use technology, their confidence, participation and independence increases.

“Learning how to use adaptive equipment is important however people must do this in a group which does not suit a lot of people. There is no choice to be able to do this at home at your computer. Doing it in your home has the added benefit that people can be observed in their own setting and other needs can be identified...There needs to be more choice in where and how often training is offered. Really one on one is better”. Member, Newcastle.

The value of independence also needs to be recognised:

“I know a guy on a Veteran’s Affairs payment who was unable to read because he lost his sight. He applied for a CCTV but was denied because it was expected that his wife would just read everything for him. She told me that she could not stand to read the stock report but didn’t want her husband to miss out. She ended up buying the equipment herself, spending \$5000 that she could have used for something else.” Member, Newcastle.

Better access – infrastructure, public transport and health services

The needs of people who are ageing with a disability should not be viewed in a silo. As an example, access to public transport is a key issue affecting people with a disability throughout Australia but also affects people who are transport reliant, those on a low income and other marginalised groups. For people in a regional or rural area, public transport, let alone accessible public transport (such as low floor buses and accessible bus stops) is extremely limited or does not exist. As a member in Toowoomba put it:

“In Toowoomba we do not have public transport on Sunday – this affects everyone. This would make a big difference.”

Good public transport access is reliant on intuitive planning which incorporates universal design and the provision of infrastructure which meets the needs of the community. There are plenty of examples of new housing estates throughout Australia which are built without access to public transport. This is a bigger problem which will have a burgeoning effect on people with a disability who are ageing. This will also impact on their ability to remain in their own homes and to remain independent.

Access to premises is also another major barrier for people who are blind or vision impaired. It is vital that universal design is incorporated in the development of new buildings and when retrofitting existing buildings. Australia recently adopted the Access to Premises Standards⁹ which provides a baseline for building access. Buildings need to be navigable, have legible and accessible signage, good lighting and contrast, a

⁹ Australian Government (2010) *Disability (Access to Premises-Buildings) Standards 2010*, Australia via www.comlaw.gov.au/ComLaw/legislation/LegislativeInstrument1.nsf/0/F1E48F0BD27FFCF4CA2576E2008071DD?OpenDocument

logical layout of facilities and should incorporate wayfinding strategies, such as those proposed by the Cooperative Research Centre¹⁰.

Access to health also needs to be seamless and meet the needs of all patients, family and carers who may or may not have a vision impairment. More information about ways to support and include people who are blind or vision impaired can be obtained from the [Blind Citizens Australia's Hospital Policy](#)¹¹.

Support for carers who have a disability

We are aware of many people who are legally blind who have taken on the responsibility of formally caring for individuals with long term health needs. Whilst this review considers the needs of carers and the needs of people with a disability, this review must also take into account carers who have a disability themselves which can present its own unique issues. As an example, a carer with a vision impairment might only require access to a piece of adaptive equipment to continue to function as a carer for a loved one. Whilst the cost of a piece of equipment might be insubstantial, the benefit of unpaid care to the community is considerable. Further consideration is needed to ensure that carers with disability are able to access basic supports to enable them to continue to provide formal care.

Better data to enable further planning

Finally, good planning is reliant on clear and reliable data about the needs of people who are blind or vision impaired. Whilst there is a wealth of research on eye health, there is far less research on unmet need, how and where people are accessing services, the extent and effects of multiple disabilities and key demographic information. Without this information, agencies and support groups are only scraping the surface in meeting the needs of current and future clients.

(d)Any other matters which would assist carers to find an adequate and appropriate answer to the question: 'What happens when I / we can no longer care?'

We believe that the most important considerations have been highlighted in the previous questions.

For additional information or to discuss the above comments further, please contact Blind Citizens Australia on (03) 9654 1400 or jessica.zammit@bca.org.au.

Yours sincerely,

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This submission is available in large print, audio, Braille and in electronic formats on request for access by people who are blind or vision impaired

¹⁰ Cooperative Research Centre for Construction Innovation (2007) *Wayfinding design guidelines*, Queensland, Australia via www.construction-innovation.info/index.php?id=1097

¹¹ Blind Citizens Australia, 2010, *Blind Citizens Australia Hospital Policy*