

blindness and low vision services

March 2011

Inquiry into Caring for Older Australians Productivity Commission, GPO Box 1428 Canberra City ACT 2601

Email: agedcare@pc.gov.au

Submission to: The Productivity Commission

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Advocacy

About Vision Australia

Vision Australia is Australia's largest provider of services to people who are blind, have low vision, are deafblind or have a print disability. It has been formed over the past six years through the merger of several of Australia's oldest, most respected and experienced blindness and low vision agencies. These include Royal Blind Society (NSW), the Royal Victorian Institute for the Blind, Vision Australia Foundation, Royal Blind Foundation of Queensland, and Seeing Eye Dogs Australia.

Our vision is that people who are blind or have low vision will increasingly be able to choose to participate fully in every facet of community life. To help realise this goal, we provide high-quality services to the community of people who are blind, have low vision, are deafblind or have a print disability, and their families. The service delivery areas include:

- early childhood
- orientation and mobility
- employment
- accessible information
- recreation
- independent living
- · Advocacy, and

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 working collaboratively with Government, business and the community to eliminate the barriers our clients face in making life choices and fully exercising rights as Australian citizens.

Our knowledge and experience gained through interaction with clients and their families, and also by the involvement of people who are blind or have low vision at all levels of the Organisation, means that Vision Australia is well placed to provide advice to governments, business and the community on the challenges faced by people who are blind or have low vision fully participating in community life.

We have a vibrant client consultative framework, with people who are blind or have low vision representing the voice and needs of clients of the Organisation to the Board and Management through Local Client Groups, Regional Client Committees and a peak internal Client Representative Council. The involvement of people who are blind or have low vision and who are users of Vision Australia's services representing the views of clients is enshrined in Vision Australia's Constitution.

Vision Australia is also a significant employer of people who are blind or have low vision. We employ 192 people with vision impairment, or more than 18% of our total staff.

Given that Vision Australia is a national disability services organisation, that we provide services at a local level through 67 service centres and outreach clinics, and given that we work with over 47,000 people who are blind, have low vision, who are deafblind, or have a print disability each year, we understand the impact of blindness on individuals and their families.

Of those we work with from July 2009 to June 2010, just over 20,000 were adults over the age of 65 years. Over a three year rolling period the number of clients over 65 years of age is 34,000.

Vision Australia believes that it is important for us, as Australia's largest blindness organisation, to submit comment on the direction and recommendations as set out in the Caring for Older Australian's Report (January 2011).

In general we support the direction and recommendations set out in the report however, given the incidence of vision loss, and sensory impairment generally, in older age groups, we believe that it is essential that there be a stronger focus on the needs of older Australians with a disability built into the final model. We also believe, given the intersection between the Productivity Commission's work on the disability care and support scheme, and that the focus of the direction of the recommendations coming out of that work is primarily targeted to people who acquire a disability under the age of 65, that the Caring for Older Australians inquiry must be clear about supports for older Australians with a disability.

Defining blindness and low vision

Generally, blindness is regarded as total loss of sight or a degree of sight loss such that it results in a person having no more than light perception, or is defined as "legally blind". Legal blindness means that someone is not able to see at 6 metres what a person with normal vision could see at 60 metres (6/60). It could also be that they have a field of vision which is less than 10 degrees compared to a visual field of 100 to 135 degrees for someone with a normal visual field.

Blindness, particularly total blindness, is relatively well understood by the broader community but the definition of legally blind, particularly where individuals seem to have some sight but are referred to as "blind", is not well understood within the broader community.

Low vision and vision impairment are often used interchangeably. While there are some definitions around these terms it is generally agreed that the World Health Organisation (WHO) definition of 6/18 vision is widely used. This would mean that a person defined as having low vision or vision impairment could only see at 6 metres what a person with normal vision could see at 18 metres.

Some argue that a lower level of loss, resulting in a visual acuity of 6/12 vision should be used to define low vision. In Australia, under the Australian Road Rules, a person must have 6/12 or better vision to be eligible for an unconditional drivers license.

The ABS, Australian Bureau of Statistics, has indicated that in 2007/08 there were at least 412,700 people aged 65 or less living with blindness or vision impairment in Australia. Of these, it was estimated that approximately 61,000 are blind.

A recent Access Economics report, "Clear Focus - The Economic Impact of Vision Loss in Australia", which used the 6/12 benchmark indicates that in 2009 there are over 575,000 Australians aged over 40 who have vision loss with around 70% of these being over the age of 70. The report also estimates that approximately 66,500 people of the above group would be defined as "blind".

While some individuals lose sight as a result of injury, genetic conditions, or illness, the main conditions that lead to significant vision loss, particularly for adults, are:

- macular degeneration
- glaucoma
- Cataract, and
- diabetic/retinal disease

We acknowledge that the Caring for Older Australians inquiry is focused on aged care, however it is important to understand that the eye conditions that lead to vision loss in children are different to those that lead to vision loss in adults.

For children the main conditions that lead to congenital or early onset of blindness are different to the conditions that lead to sight los for adults. The Australian Childhood Vision Impairment Register shows that causes of childhood vision impairment include:

- Cortical Vision Impairment
- Nystagmus
- Myopia
- Optic Nerve Hypoplasia
- Lebers Congenital Amaurosis
- Retinopathy of Prematurity
- Glaucoma
- Retinal Dystrophy and,
- Optic Atrophy.

The prevalence of blindness and vision impairment does increase with age, even though it is not considered to be an inevitable outcome of ageing. It is argued that the increased incidence of blindness and vision loss amongst older Australians is mostly due to the cumulative effects of exposure to risk factors. These risk factors include prolonged exposure to sunlight or smoking, and the long-term impact of other health conditions including obesity and high levels, for prolonged periods, of cholesterol.

Individuals over the age of 70 years currently make up the largest proportion of all people who are blind or have low vision. This group currently makes up 70% of the community of individuals with a significant vision loss which affects daily functioning. All indicators lead us to believe that this group will continue to grow with the ageing of the Australian population.

Based on current incidence rates, by the time a person is aged 60-69 they have a 1 in 20 chance of a level of vision impairment which prevents them holding a driving licence. By the time the person is aged 90, the chance of having vision impairment increases to 2 in 5. Accordingly, 3 out of 5 people at age 90 will have a 'natural' level of vision appropriate to their age, and while they may need glasses, they would not experience a significant functional impact as a result of their minimal vision loss as it is, by and large, corrected by glasses.

Blindness and vision loss affects every aspect of an individual's life. The world is very much geared to function in a visual manner so for those who have little or no vision the functional impact of sight loss is understandable. While people who lose vision can learn to carry out many everyday tasks in other ways, and can compensate for the lack of sight, vision loss is a disability which has a significant impact on the individual and their family and we are of the view that a holistic aged care system must take this into account both for those who are in aged care facilities and those who are remaining at home.

The report notes that there is a widespread view in the community that "fundamental" reform of the aged-care system is needed. Such reform needs to be built and assessed using an appropriate framework, and for those who age with a disability or acquire a disability later in life, the framework must take the disability needs into account. We are also of the view that the aged care framework must also be couched mindful of the intersections with disability policy and programs so that there is no gap, real or perceived, between the aged care framework and disability programs.

We support the principle set out in the report that the system of care and support for older Australians must aim to:

- Promote independence, wellness and continuing contribution.
- Ensure that flexible and person-centred services are available to all older people who need them, and ensure that these services are delivered in ways that promote respect and dignity for recipients.
- Allow consumers to have control and direction over the services they use.
- Be affordable and easy to navigate.

We believe that aged-care services that are developed with these aims in mind should be assessed against the criteria of equity, efficiency, effectiveness, choice, quality, sustainability, but that they are also assessed on how they meet the needs of older Australian's with a disability.

The report indicates that many older Australians find the aged care system difficult to navigate. The Commission recommends that a single Government agency be responsible for providing information, assessments and care coordination. We support that direction but want to reinforce the need for a greater understanding and emphasis on disability, particularly the impact of vision loss for older Australians.

The report notes that aged care should also reflect the increasing diversity of the population by catering for people with special needs. Some groups with special needs are specifically identified in the Aged Care Act 1997, such as people from culturally and linguistically diverse backgrounds. Aged care providers are expected to cater for these groups, and the extent to which they do so is reflected in the grants they receive. People with a disability are not specifically identified in legislation or aged care allocation principles as having special needs and we believe that sensory loss should be included here.

Draft Recommendations

The report contains 42 Draft Recommendations, spread throughout the report and numbered according to the sections in which they occur (rather than being numbered sequentially). There is only one specific reference to disability in these Draft Recommendations, and that is the need for an evidence base of the dimensions and

capacities of contemporary disability aids (Draft Recommendation 10.2 dealing with adaptable housing).

Many of the Draft Recommendations are relevant to older people with a disability however, and we encourage Government to implement the Draft Recommendations in ways that specifically include a focus on issues affecting people with a disability, particularly those who are blind or have low vision.

Below we have commented on some of the more significant Draft Recommendations that we consider relate, or may relate, to disability.

Draft Recommendation 4.1

Draft Recommendation 4.1 (the first in the report) sets out what the aims of the future aged care system should be. These include the promotion of independence and wellness and the continuing contribution of older people to society, ensuring that all older people who need care and support have access to person-centred services that can change as their needs change, and ensuring that the system is easy to navigate for consumers.

We would like to emphasise that if people who are blind or have low vision are to continue making a contribution to society as they age, there will need to be major commitments to accessibility of government and community services and facilities, and more effective ways must be found to provide access to facilities such as shopping centres, public transport and recreation areas, which are becoming more inhospitable for people who are blind or have low vision generally. Infrastructure such as touchscreen-based queuing technology that is being deployed by government, such as in Medicare Australia offices, is making it more difficult for blind people to be active participants and contributors to society, and as people age, their willingness or capacity to engage with inaccessible technologies and suboptimal undignified solutions diminish.

The services that are needed by a person who is blind or has low vision will depend on a number of factors, including the extent of their vision impairment and the age at which this impairment was acquired. There is a need for a mix of generic and specialist services, and the aged-care system must provide a mechanism to allow this mix to change as a person's needs change.

An aged-care system that is easy to navigate for a person who is blind or has low vision will need to focus much more than at present on making information available in a range of formats to suit individual needs.

Draft Recommendation 8.1

This Draft Recommendation calls on the Australian Government to establish an Australian Seniors Gateway Agency to provide information, assessment, care coordination and carer referral services.

Given that the needs of people who are blind or have low vision are complex and often "fall through the cracks" of government and community agencies (especially the need for information in accessible formats) it is important that such an agency be well-versed in recognising, assessing and responding to the needs of older Australians who have vision loss. A failure to provide needs-appropriate information, assessment and services can have a catastrophic effect on the quality of life of recipients, and without careful attention to detail, needs-appropriateness is unlikely to be achieved for people who are blind or have low vision.

There is likely to be some connection between this Draft Recommendation and recommendations in the report of the inquiry into a disability care and support scheme. If people are required to transfer from one system to another at age 65, then it could mean that there will be a need for substantial duplication of knowledge and resources to ensure that needs continue to be met. Conversely, if people aged over 65 who develop a disability are required to use the aged care system only (through the Gateway) then the Gateway will either have to contract out services or functions back to the disability support system, or duplicate many of that system's functions. In any case, this is an area that should be clarified before the Gateway is established.

Draft Recommendation 9.1

This recommendation is suggesting that the Gateway Agency should cater for diversity and groups with special needs by ensuring that all older people have information and assessment services, by providing interpreter services (for people from NESB, not Auslan interpreters), and by ensuring that diagnostic tools are culturally appropriate.

It is clear that people with a disability are not being considered as a group with special needs, or else that it is not intended that the Gateway agency provide services for them. The report of the inquiry into a disability care and support scheme should clarify this, but, in any case, if a Gateway agency is designed to cater for all older Australians, then it must not ignore the needs of people with a disability. Apart from the obvious need for accessible information, there is an issue with diagnostic assessment tools, some of which can rely on visual tasks without any non-visual alternatives. We suggest that research and evaluation be undertaken into the extent to which such tests are used and their impact on people who are blind or have low vision.

Draft Recommendation 9.2

This recommendation is that the proposed Australian Aged Care Regulation Commission (Draft Recommendation 12.1) should take into account costs associated with diversity, such as the provision of NESB interpreters and professional development activities in the area of cultural awareness.

As with the previous Draft Recommendation, there is no mention of disability here, and this is certainly an issue that should be examined in the light of the proposed disability care and support scheme recommendations.

We acknowledge that the Commission may respond that at this stage its focus is on the establishment of a framework rather than the fine details of how the framework will be operationalised, but the complete absence of references to disability does give us cause for concern. We believe that the Productivity Commission inquiry into caring for older Australians must acknowledge and respond to how the framework will address disability needs and how the aged care system will intersect with broader disability policy and programs.

Draft Recommendation 10.1

This recommendation is that the Australian governments should develop a national approach to the provision of home maintenance and modification services, including uniform terms of eligibility and services to be provided.

Vision Australia believes this is a positive recommendation. We would like to see it implemented and we strongly believe that it should include services that might be needed by people who are blind or have low vision but which may not be needed by other groups. There is no reason that the onset of blindness or vision impairment for someone who is older should be a factor that, in itself, determines that they cannot live independently in their own home. Modifications to the home environment, many of which are simple and not costly, may mean that a person will stay in their own home for years prior to accessing an aged care facility.

This is another area where the Productivity Commission's inquiry into the feasibility of a disability care and support scheme potentially intersects with the aged care framework. If a home maintenance and modification scheme is to be established we would strongly recommend that it be done in the light of recommendations coming out of the disability care and support scheme.

Draft Recommendation 11.3

This recommendation is that the Australian Government should promote skills development through an expansion of courses to provide aged care workers at all levels with appropriate skills.

Vision Australia constantly sees evidence that the needs of people who are blind or have low vision are not well-understood by aged care workers or volunteers, whether they be in residential aged care facilities or providing in-home services. We support this recommendation however we strongly believe that any such expansion in skills development must include modules focusing on disability in general, and the needs of people who are blind or have low vision in particular (especially in view of the projected increase in this group as the population ages).

Draft Recommendations 12.1 and 12.2

These recommendations call for the establishment of the Australian Aged Care Regulation Commission (AACRC) which would be responsible for regulatory oversight of the aged care system, standards and accreditation, and dealing with complaints from providers and consumers.

This AACRC is likely to have relevance for older people with a disability, and the Draft Recommendations relating to it should be considered in light of the report of the inquiry into a disability care and support scheme.

Draft Recommendation 12.3

This is recommending that the Council of Australian Governments (COAG) should agree to publish the results of quality assessments using the Community Care Common Standards.

Vision Australia believes that these Standards should be reviewed to ensure that they include reference to the experiences and expectations of people with a disability. There is certainly a significant amount of anecdotal evidence that people who are blind or have low vision often struggle to have their needs recognised and addressed in the aged care system, especially in residential care facilities.

Draft Recommendation 13.1

This is recommending that the AACRC should be a national clearing-house for aged care data.

We support this recommendation as we believe that there should be better capture of data around many aspects of aged care including elements related to disability. It would be essential however that work be undertaken to ensure that common definitions of disabilities and collection tools be developed to capture meaningful information.

Draft Recommendation 14.1

This recommendation relates to the implementation of reform, and calls on the Australian Government to announce a timetable for change, undertake consultation with providers and consumers, embed feedback processes, grandfather existing care users and some existing financial arrangements, sequence reforms carefully to facilitate adjustment to the new system, and establish an Aged Care Implementation Taskforce.

It is evident from the report and the Draft Recommendations that disability is not seen as a discrete strand of the aged care system. Vision Australia has now had an opportunity to consider this in light of the proposed disability care and support scheme and we are strongly of the view that implementation must include an engagement with the disability sector including organisations such as Vision Australia that have such significant interaction with older Australians who have vision loss.

We would also suggest that the proposed Aged Care Implementation Taskforce include a representative with specific experience in the disability sector.

While we are generally supportive of the direction set out in the Caring for Older Australians report, it is hard to see how beneficial long-term changes to the aged care system can occur if there is a failure to recognise and respond to the reality that there are older people who do not have a disability, older people who acquire a disability (which may or may not be aged-related), and people with a disability who age. These groups have distinct characteristics and needs, and those needs cannot simply be addressed by assuming that a person-centred approach in and of itself is sufficient. We believe that there must be a stronger and more deliberate emphasis on disability and that this emphasis must be clear to the aged care sector.

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