Senate Inquiry into Options and Services for People Ageing with a Disability – Victorian Deaf Society Submission

Summary

The Victorian Deaf Society welcomes the Senate Inquiry into Planning Options and Services for People Ageing with a Disability and is grateful for the opportunity to present a submission on the many issues of relevance to the inquiry. Given the breadth of the inquiry, we have chosen to limit our submission to areas of direct relevance to our area of expertise, that is issues faced by people who are Deaf or hard of hearing.

For ease of reference, this summary lists all of the recommendations made in this submission – please refer to the relevant section of the report for important contextual information surrounding each recommendation.

Recommendation 1: **That all levels of government work together to achieve greater cooperation in the area of service provision for people ageing with a disability**

Recommendation 2: **That Federal and State governments work together to develop clear guidelines on a person's right to access disability and aged care services simultaneously.**

Recommendation 3: **That a National Disability Insurance Scheme be implemented as a way of financing expanding disability services and streamlining service provision and responsibilities.**

Recommendation 4: **That disability support services be funded to collaborate with aged care service providers to provide accessible information for clients on services to support ageing in place and support to access these services.**

Recommendation 5: **That disability agencies be funded and supported to provide specialized HACC workers to cater to the needs of HACC clients with lifelong disabilities that impact on behavior or communication.**

Recommendation 6: **That the Federal Government implement funding incentives to encourage aged care facilities in selected areas to become specialists in caring for clients with a particular disability**

Recommendation 7: **That the need to provide advocacy and support services for clients living in aged care facilities be factored into government funding formula for disability support agencies.**

Recommendation 8: **That aged care accreditation standards include standards and expected outcomes specifically addressing the communication, activity and support needs of residents with disabilities.**

Recommendation 9: **That all arms of government work together to produce more supported accommodation beds around Australia.**

Recommendation 10: **That new facilities include those designed to enable people who share a disability that impacts on communication to live together even if they have quite different additional disabilities.**

Recommendation 11: **That guidelines surrounding concurrent access to aged care and disability services explicitly consider the needs of people ageing in place in supported accommodation.**

Recommendation 12: **That flexibility be built into funding rules for aged care and supported accommodation places to allow couples to stay together through the ageing process.**

1. Introduction

The Victorian Deaf Society (Vicdeaf) has been the main provider of general and specialized community service support and communication services to Deaf and hard of hearing people throughout Victoria for the past 125 years.

Our services include: audiology, hearing loss management, information and education across a wide range of support services, advocacy, case management, hearing screening, sign language classes (Auslan), interpreting services, clubs and group forums, counseling, support for independent living, research, communication, and employment readiness and support.

Vicdeaf welcomes the Senate Inquiry into Options and Services for People Ageing with a Disability and is grateful for the opportunity to present a submission on the many issues of relevance to the inquiry. Given the breadth of the inquiry, we have chosen to limit our submission to areas of direct relevance to our area of expertise, that is issues faced by people who are Deaf or hard of hearing. In this submission we make a number of recommendations that are of relevance to federal government, some which could be enacted unilaterally by federal government and others that require cooperation with state government or other agencies in order to be enacted.

Vicdeaf is happy to provide further advice or clarification to the inquiry on any of the matters raised in this submission

2. General population trends

Australia is currently experiencing strong growth in both the raw numbers and percentage of the population aged 65 and over. In 2007, people aged 65 and over made up 13% of the Australian population (ABS 2008), however this number is project to rise to 18% by 2021 and reach 25% by 2051 (DHAC 2000:6). These changes are a result of a number of factors, including increased life-expectancy, a falling birthrate and the ageing of the large baby boomer generation.

The factors mentioned above have also led to an increase in the number of people with a lifelong disability who are in their senior years. Particularly among those with an intellectual disability, life-expectancy has increased markedly in the last thirty years (Janicki et al 1999, Patja et al 2000, Yang et al 1999). Increasing numbers of seniors with lifelong disabilities poses a challenge for the aged-care and disability service sectors, and effective service provision will require a higher degree of cooperation between sectors than is being seen currently.

Looking specifically at the Australian Deaf community we see a similar increase in the number of seniors. Here it should be noted that in this submission Deaf (with a capital D) is refers to people who communicate using Auslan (Australian Sign Language) or another sign language and does not include people with a hearing loss who communicate orally. In his 2004 study of the size of the Australian signing population, Johnston notes that a Rubella epidemic in the immediate post-war years saw a sharp rise in the proportion of profoundly deaf babies being born. When coupled with the high birth-rate in the post-war years (the ‘baby boom’) this means the raw number of Deaf Australians in this post-war generation is much higher than seen in previous generations. As the baby boomers are ageing, we are about to see a much higher demand for aged care services for Deaf

Australians than we have seen in past years, and evidence suggests that services are not currently well-positioned to meet the need of this client group.

Reliable statistics on the size of the Australian Deaf community are hard to come by, not least because estimates will vary depending on inclusion and exclusion criteria (e.g. whether the person communicates solely in Auslan or uses Auslan alongside speech and lip-reading). The Australian census provides the best data available and in 2006 recorded 7,150 people 'speaking' a sign language at home, which equates to 3.5 sign language users per 10,000 head of general population. Only a small proportion of sign language users were over 65 at the time of the 2006 census (587), however there is a large cohort of sign language users in late middle age: in 2006 1,527 sign language users were aged 50 or older. No reliable statistics are available on the proportion of the Deaf Australians who have an additional disability. However, extrapolating from figures given for deaf students accessing education support services (Power and Hyde 2002, Richarson 2001) suggests the number is at least 20%.

In addition to the signing Deaf community, a large number of Australians have hearing losses, which impact on their lives to varying degrees. In 2005 The Victorian Deaf Society and the Hearing CRC commissioned Access Economics to write the Listen Hear report, which examines the economic impact and cost of hearing loss in Australia, as well as its extent and causes. The report found that currently, one in six Australians are affected by hearing loss. Hearing loss is highly age-graded, affecting less that 1% of children (0-15 years), but over 75% of people aged over 70 years. As the Australian population ages, rates of hearing loss are projected to increase to one in four Australians by 2050.

Among adults, the incidence of hearing loss is highly age graded. Of those aged 15-50, the overall incidence of hearing loss is estimated at 5%, climbing to 29% for those aged 51-60, 58% for those aged 61-70, and 74% for those aged 71 and over (Access Economics 2006:34). Estimates on the proportion of adults with a mild, moderate or severe-profound within each age group are not available, however for hearing impaired adults as a whole the percentages are thought to be 66% mild, 23% moderate and 11% severe or profound (Access Economics 2006:33). As hearing loss is often a part of the ageing process, services for people with other disabilities need to be alert to the possibility that their clients' hearing may deteriorate as they age. This is particularly so for people who have another disability that impacts on communication, as there is a risk that hearing impairments may be misdiagnosed as a simply progression of the clients' pre-existing disability/condition (this appears to be as common problem for dementia patients in nursing homes, c.f. Burnip and Erber 1996). Service providers also need to be alert to the services and aids/equipment available to support people with a disability and an age-related hearing loss to maximize quality of life for this growing population group.

3. Interface between aged care and disability service

As we are sure many submissions to this inquiry will note, disability and aged care services in Australia are poorly integrated. This in part stems from different funding arrangements: while aged care is a commonwealth responsibility, disability services are largely provided by the states. Such a set-up creates bureaucratic hurdles to cooperation and information sharing, and leads to arguments about who is responsible for funding support services for ageing people with disabilities. In this climate, neither sector has an incentive to take ownership of issues affecting ageing people with a disability, and neither is inclined to develops services for this client group as part of their core activities. How best to maximize cooperation is a contentious and complex area and Vicdeaf with its

specialist expertise in communication would be most happy to consult with government on any proposed reforms.

Recommendation 1: That all levels of government work together to achieve greater cooperation in the area of service provision for people ageing with a disability

A major concern surrounding this funding split has been the issue of so-called "double dipping", that is the idea that a person who is already receiving funding or support from the aged care sector cannot also receive support from the disability sector (or vice versa). As Bigby (2008) points out, there are no clear guidelines outlining the degree to which people may access services concurrently, however, the *perception* that double dipping is not allowed seems to be inhibiting the degree to which services refer clients who are ageing with a disability on to programs offered by the other sector. In a similar vein the Disability Care and Support Issues paper produced by the Productivity Commission identifies the following problems (among others) stemming from a lack of coordination between service providers:

There is often a lack of coordination, showing up through…:

- *having access to one program restricted inappropriately because of receiving support from another,*
- *concerns about the interaction of the health system with the disability support system*
- *incomplete links between services provided by different governments (2010:11)*

Recommendation 2: That Federal and State governments work together to develop clear guidelines on a person's right to access disability and aged care services simultaneously.

Reform of the aged care and disability sectors will likely need to be extensive and expensive in order to see major improvements in service provision. Here Vicdeaf would like to go on record as supporting the proposed National Disability Insurance Scheme as both a potential source of funding for expanding services and a means of streamlining service provision, responsibilities and budgeting across the three tiers of government. The proposed National Disability Insurance Scheme implies the Commonwealth taking over a number of areas of disability service from the States, and Vicdeaf believes this may lead to better integration of disability and aged care services than what is possible under the current split system.

Recommendation 3: That a National Disability Insurance Scheme be implemented as a way of financing expanding disability services and streamlining service provision and responsibilities.

4. Support to age in place

It is clear that people who have a disability should have the same opportunity to age in place as members of the general population, however, in practice services are not always well equipped to support them. Bigby note that in Australia "no firm policies or services exist to promote ageing in place for people with disability" (2002:237), with the results that the specific needs of this client group are often overlooked.

As in the general population, research on the Australian Deaf community shows older Deaf people have a strong desire to continue living independently for as long as possible as they age (Matairavula 2009, Vicdeaf research in progress). In order to realize this goal, many will need to draw on supports

such as Home and Community Care (HACC) services, however knowledge and uptake of supports seems relatively poor. In a recent Deaf NSW survey of Deaf people aged over 55, only 50% of respondents indicated they knew of Meals on Wheels as a service and only 35% were aware of home care services (Matairavula 2009:31). Currently Vicdeaf is undertaking research with Deaf seniors and findings to date from 50 participants show low levels of service utilization relative to reported need. For example, 9 respondents indicated that they required help cooking for themselves at home, but only 1 was accessing Meals on Wheels, while 11 reported they needed help with cleaning, but only 4 were receiving cleaning assistance through HACC services.

Older Deaf Australians need more information about HACC and other support services, and are not being reached by current brochures and websites targeting the general population. Part of the issue here is that older Deaf Australians often have poor English literacy skills as a result of limited educational opportunities and ineffective pedagogy during their schooling. They thus have a strong preference for accessing information in Auslan rather than in written English, and ideally by a live presenter who can take questions, rather than a DVD or video on the internet. The current fragmentation between aged care and disability service sectors means that aged care services are not always attuned to how to promote their services to clients with disabilities, while services like Vicdeaf have the networks to communicate with clients, but not the detailed knowledge of the aged care sector (or, it must be said, the commonwealth funding) to promote support services.

Recommendation 4: That disability support services be funded to collaborate with aged care service providers to provide accessible information for clients on services to support ageing in place and support to access these services.

Deaf people who do access HACC services face further communication barriers in interactions with service providers. While service providers interviewed as part of Vicdeaf's ongoing research into aged care needs in the Deaf population showed a strong awareness of the need to provide interpreters when performing HACC assessments, they are not in a position to provide interpreters for routine personal care or cleaning visits. The difficulties of communicating with HACC workers was a point raised by numerous seniors in focus groups, with one woman commenting:

> *I was in rehab for three weeks then the council came along and asked me if I wanted some home cleaning help and some personal care help – like shower and bathing. And I just had to accept it so I said yes. I went home and the council person was a hearing person, they couldn't sign so we had to communicate using notes. So they came to clean, they helped me with showering…. But I need a signing person, a person that can sign with me. [The council] gave me a form… asking me if their services were good, and I said yes, but you need better communication, I need a person who can sign.*
> (East Melbourne focus group participant 15/4/10)

As for any linguistic minority group, the easiest solution to this problem is for HACC services to actively recruit personal care workers, cleaners and other staff who are proficient in Auslan. The City of Whitehorse has done just that for its client body of around 8 Auslan users but other councils may struggle to find care workers with Auslan skills or feel that the number of Deaf people requiring HACC services does not warrant the employment of specialist workers. In Victoria, councils have some discretionary funding to purchase HACC services from certain state-wide CALD (culturally and Linguistically diverse) service providers in order to ensure that the linguistic and cultural needs of CALD clients are appropriately catered for. Unlike other HACC services in Victoria, the CALD providers are not tied to servicing a particular municipality, but can work for any council that requires their services. Vicdeaf argues that this model could productively be extended to include disability service providers. This would see organizations such as Vicdeaf provide HACC workers

fluent in Auslan where needed and other disability organizations provide workers who understand the clients' special needs, behaviors and communication styles.

Recommendation 5: That disability agencies be funded and supported to provide specialized HACC workers to cater to the needs of HACC clients with lifelong disabilities that impact on behavior or communication.

5. Moving to residential care

While it is the strong opinion of this submission that people with a disability should be supported to age in place if they wish to, some will inevitably want or need to move into residential care. Like other linguistic minority groups, Deaf people are at high risk of loneliness and isolation in residential care and may also have difficulty effectively communicating their health needs to staff. These are problems faced by other disability groups. Bigby notes, for example, that the families of people with intellectual disabilities who had entered aged care facilities had a number of concerns about the care their loved one was receiving, including "the quality and appropriateness of aged care accommodation, staff not adequately attuned to needs and environments that foster dependence and provided insufficient stimulation" (2002:238). Some of the problems that can arise from isolation and unstimulating environments are illustrated in the following anecdote from a Vicdeaf focus group:

> *I had one brother who was blind [and Deaf] – he was on a farm. And he was – he went to a home. And they were all, there were no Deaf people or vision impaired people around him. He was the only one there, he became more and more alone. He got so frustrated. And what he did was go out, and there was a whole range of cars parked on the road. He went out and flattened all of the tyres on all of them, he was so annoyed. And finally someone listened to him. He loved gardening, he loved carpentry work and now he's been moved to XXX. He has company, he loves it there.*
> (Geelong focus group participant 13/4/10)

One possible solution that has been tried in a number of Australian states is to run dedicated aged care facilities for members of the Deaf community. Deaf societies in New South Wales, Victoria and Tasmania have all run aged care facilities in the past, but have all divested themselves of these facilities because of their high overheads, which could not be offset by the small number of Deaf people making use of the facility. In both Victoria and New South Wales, the former Deaf aged care facilities still maintain a small number (circa 15) of dedicated beds for Deaf people, while Queensland has also negotiated a suite of seven beds at one Brisbane aged care provider. Staff at the facilities have basic Auslan and Deafness Awareness Training and the facilities also maintain adaptive technology, such as visual smoke alarms and TTYs, that meet the safety and social needs of Deaf residents. In Victoria we have also seen a private aged care facility with no previous connection to the Deaf community develop a small Deaf wing after several Deaf people showed interest in moving to the facility.

The model of having a 'Deaf wing' within a larger aged care facility seems to work well in practice and provides a financially viable compromise in meeting the needs of this client group[1]. However, it is not enough to simply have one such facility in each state. As a Vicdeaf focus group in Geelong forcefully noted, people in regional areas do not want to have to move to a capital city to access an

---

[1] Bigby et al (2008) also provides tentative evidence that aged care facilities with a small cluster of residents with intellectual disabilities were better able to meet the needs of these residents than facilities with only one or two residents with intellectual disabilities.

aged care facility that caters to their disability – they want to be able to stay in their community, close to their family and friends and still receive appropriate care (a similar sentiment was also expressed in Matairavula 2009:25-7). Within large cities like Melbourne or Sydney it is also unrealistic to expect people to move from one side of the city to the other. There is thus a strong need for multiple aged care providers in each city (in different locations and mixing high-care and low-care facilities) to develop small wings for clients with particular disabilities.

Recommendation 6: That the Federal Government implement funding incentives to encourage aged care facilities in selected areas to become specialists in caring for clients with a particular disability

Disability-specific clusters go a long way to ensuring that staff and facilities are able to meet the needs of residents ageing with a lifelong disability. However, it should also be expected that these residents will continue to need support and advocacy services from disability specific organizations in areas such as communicating needs/ requests/ desires to the age care facility management, managing disability-related health conditions and participating in disability-specific social groups. It is thus imperative that disability agencies receive targeted funding to allow them to continue to meet the needs of this potentially quite vulnerable client group.

Recommendation 7: That the need to provide advocacy and support services for clients living in aged care facilities be factored into government funding formula for disability support agencies.

Finally, in order to protect the rights of people with lifelong disabilities living in aged care facilities, it is important that aged care accreditation standards more explicitly address the care needs of these residents. The current standards[2] list many areas that could potentially pertain to people with lifelong disabilities (such as expected outcomes 3.5 – Independence, 2.10 – Behavior management or 2.3, 3.3 and 4.3 which all refer to education and staff development). However, none of these standards guarantee that facilities will consider the particular communication, activity and support needs of residents with lifelong disabilities (or indeed who speak languages other than English). We feel it is important that explicit standards be developed to measure the quality of service provision, particularly if the Federal government is going to fund some providers to set aside beds for residents with certain disabilities.

Recommendation 8: That aged care accreditation standards include standards and expected outcomes specifically addressing the communication, activity and support needs of residents with disabilities.

6. Issues for clients with high support needs

As we are sure many submissions will mention, there is an urgent need for more supported accommodation beds in Australia. In recent years, inquiries such as the *Senate Inquiry into the Funding and Operations of the CSTDA* (2007), the South Australian 2004 *Inquiry* into *supported accommodation* (2004), and the Victorian *Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness* (2010) have made real progress in identifying what sort of services are required in what areas. While some progress has been made enacting the recommendations of these reports, more work is still needed to address the high level of unmet need for Australians requiring access to supported accommodation.

---

[2] Available at http://www.accreditation.org.au/site/uploads/Accreditation%20standards%20factsheet.pdf last accessed 24/5/10/.

Recommendation 9: That all arms of government work together to produce more supported accommodation beds around Australia

People with multiple disabilities pose a particular challenge for supported accommodation, as services may be set up to cater for a particular primary disability, but lack experience or appropriate supports for clients' secondary disabilities. For Deaf people with additional disabilities supported accommodation can be lonely and isolating if staff and residents are not proficient in Auslan, however there is an extreme shortage of places in residential services dedicated to the needs of Deaf clients. In Victoria, Vicdeaf manages only two 5-bed resident units for Deaf people with additional disabilities, while in Queensland a three-bed training centre is available. Vicdeaf knows of a number of parents who have continued to care for their severely disabled adult children at home because they are deeply concerned about the isolation the Deaf person would face in available supported accommodation. This home care situation comes at great personal and economic costs to families and is often not sustainable in the long term. It also has the effect of masking the need for specialized services in waiting list statistics, as since the parents see no hope of attaining suitable accommodation for their adult child, they do not bother to register them on supported accommodation waiting lists.

In cases where Deaf people are living in residential services with others who are not Deaf, parents and the residents themselves frequently report dissatisfaction with the service providers' ability to communicate with the Deaf resident. Such issues appear to have been at the core of a distressing murder-suicide last year, where a father took the lives of his two sons (who were Deaf and had Cerebral Palsy) amid concerns that the previous operator of the home where the sons lived was not providing staff who were able to communicate with the sons effectively. Cases such as this highlight the pressing need for improved support services for people with disabilities including Deafness that impact on communication.

Recommendation 10: That new facilities include those designed to enable people who share a disability that impacts on communication to live together even if they have quite different additional disabilities.

Currently, many supported accommodation services are set up under the assumption that residents will have similar support needs and will all attend a day program on weekdays. Such a set up limits the opportunity for residents to age in place, as those who retire from day programs or require additional support as they age are forced to seek alternate accommodation. It also seems that the pressure of waiting lists may motivate service providers to move older clients into alternative accommodation (like aged care facilities) before their support needs strictly require the move.

If we are serious about the idea that supported accommodation should be home-like rather than institutional, then Vicdeaf argues more should be done to support residents to age in place if they wish to do so. This may include reforms to allow people living in supported accommodation to access HACC services like personal care and respite services, flexibility in funding to cater for those who have retired from supported employment or the creation of retirement-village style cluster housing which allows people to live independently but with specialized support service close to hand. These points link back to Recommendation 2 that there needs to be greater clarity and cooperation in allowing people concurrent access to disability and aged care services when their needs require it. Vicdeaf also notes that these recommendations have much in common with recommendations 7.10-7.14 of the Victorian government *Inquiry into Supported Accommodation for Victorians with a Disability and/or Mental Illness* (FCDC 2009:xxii) and would like to lend its support to the recommendations of that inquiry more generally.

Recommendation 11: **That guidelines surrounding concurrent access to aged care and disability services explicitly consider the needs of people ageing in place in supported accommodation.**

Greater flexibility is also required to cater to issues surrounding ageing couples living in group homes. Current philosophy guiding disability services strongly supports the rights of all people to form intimate relationships, however, issues can arise in designing services that allow couples living in supported accommodation to stay together if one of them develops additional support needs as part of the ageing process. Of course, couples in the general population are also sometimes separated because one partner develops high support needs, however our point here is that residents of supported accommodation are much more vulnerable to this because services generally have strict rules about the level of independence required in order to live in the facility. Vicdeaf is currently trying to assist a man living in supported accommodation to be reunited with his wife (who is living in a nursing home in the absence of a suitable supported accommodation place), however the aforementioned rigidities in the supported accommodation system mean there is not the funding available for her to move in with him, and he is too young, fit and healthy to gain (or want) a nursing home bed. Examples such as this demonstrate that while policy firmly espouses the rights of people with disabilities to live normal and fulfilling lives, in practice much more needs to be done to facilitate this and cater for changing support needs as clients age.

Recommendation 12: **That flexibility be built into funding rules for aged care and supported accommodation places to allow couples to stay together through the ageing process.**

References

ABS (Australian Bureau of statistics) 2008. *Population Projections, Australia, 2006 to 2101.* Available at http://abs.gov.au/ausstats/abs@.nsf/mf/3222.0 Last accessed 30/4/10.

Access Economics.2006. *Listen Hear! The economic impact and cost of hearing loss in Australia. A Report commissioned by Vicdeaf and the Hearing CRC*. Melbourne: Access Economics.

Bigby. C. 2002. Ageing with a life long disability: Challenges for the aged care and disability sectors. Journal of Intellectual and Developmental Disabilities, 24,4: 231-241

Bigby, C., R. Webber, B. McKenzie-Green & B. Bowes. 2008. A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *Journal of Intellectual Disability Research*. 52: 404-414.

Burnip L.G. & N.P. Erber. 1996. Staff knowledge regarding hearing loss and communication among nursing home residents. *Australian Journal on Aging* 16,1: 40-3.

DHAC (Department of Health and Aged Care). 2000. *Ageing gracefully: An overview of the economic implications of Australia's ageing population profile*. Canberra: Department of Health and Aged Care, Portfolio Strategies Division.

FCDC (Family and Community Development Committee). 2009. *Inquiry into supported accommodation for Victorians with a disabilityand/or mental illness*. Melbourne: Victorian Governement Printer.

Janicki, M., A Dalton, C.M. Henderson & P. Davidson. 2001. Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability & Rehabilitation*, 21,5:284-294.

Matairavula, K. 2009. *Deaf Seniors : a profile of deaf seniors in New South Wales 2009 (full report)*. Sydney: The Deaf Society of New South Wales.

Patja, K., M. Iivanainen, H. Vesala, H. Oksanen & I. Ruoppila 2000. Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research* 44,5: 591-9.

Power, D, & M. Hyde. 2002. The characteristics and extent of participation of deaf and hard of hearing students in regular classes in Australian schools. *Journal of Deaf Studies and Deaf Education*. 7: 302-311.

Productivity Commission. 2010. Disability Care and Support Issues Paper. Canberra: Productivity Commission

Richardson, J. 2001 The representation and attainment of students with a hearing loss in higher education. *Studies in Higher Education.* 26: 183-204

Yang Q., S.A. Rasmussen & J.M. Friedman. 2002. Mortality associated with Down's syndrome in the USA from 1983 to 1997: A population-based study. *Lancet* 359(9311):1019-25.