ADBC

Australian DeafBlind Council

Australian DeafBlind Council (ADBC)
Submission: Productivity Commission Inquiry into Long Term Disability Care and Support Scheme

Date: 4th June 2010

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INTRODUCTION

The Australian DeafBlind Council (ADBC) was initiated following the National Deafblind Conference in Melbourne in 1993. It was established to meet the need for a national deafblindness network and representative council working with and for people who are deafblind and their support networks, including professional organisations. At present, ADBC represents the estimated 288,000[1] people, including older people who are deafblind and supports their families, professionals and organisations working in the field.

ADBC seeks to improve conditions and to be an advocate for people who are deafblind across Australia, as well as their families and encourages their self organisation and self determination by:

- Disseminating and being a source of information on deafblindness
- Providing a forum for collaboration and debate, and
- Co-operating with government bodies and organisations
- Taking up issues of concern to people with deafblindness, their families and support networks and organisations

ADBC also seeks to be the hub of a national deafblindness network.

ADBC is committed to educating members of the public about deafblindness since this unique dual sensory disability affects an individual’s mobility, their ability to communicate and generally leaves them isolated from the community and information, and significantly affects their education. With adults and children, the dual disability affects an individual’s ability to function independently, as well as causing difficulties in developing social networks and independent travel.

ADBC is an unfunded body, despite strenuous efforts to obtain funding, and is Australia’s only national information service on and for people with deafblindness, their families and other persons, professionals and organisations requiring information on deafblindness. It is supported financially by its members and major suppliers of services to people with deafblindness. It obtained $15,000 funding from the Commonwealth Government’s Department of Families, Community Services and Indigenous Affairs for a report on deafblindness that was published in 2004-5.

THE EXTENT AND CAUSES OF DEAFBLINDNESS

Recent research has indicated the numbers of people with deafblindness are significantly higher than had previously been assessed, with a report by Access Economics calculating that there are 288,000 people with deafblindness in Australia. Recent data from the Bureau of Statistics, that require further clarification and are based on their 2003 Disability, Aging and Carers Survey, and indicate a figure of 73,492. While these totals appear dramatically different from one another, on analysis the difference relates at the level of deafness at which a person can be considered to be deafblind. The difference in the numbers is related to the question of the number of persons having a mild hearing loss (ie someone whose hearing loss is between 25 and 45 decibels). In both reports the majority of people with deafblindness, are people over 65 years of age. It is estimated that by 2050 there will be one million people in Australia who are deafblind.

The current numeric breakdown of people with deafblindness indicates that there are some 7000 to 9000 people under 65 years and 281,000 aged 65 years and over if people with a mild hearing loss are included, based on information in the Access Economics Report. This figure will increase with the aging of the Australian population.

Apart from aging, the major causes of deafblindness are CHARGE Syndrome, Congenital Rubella Syndrome (mainly in people over 30), premature birth (historically often due to use of excess oxygen shortly after birth), Usher Syndrome, Cytomegalovirus, other viruses and diseases such as Meningitis, Down Syndrome, Refsum’s Syndrome, someone who has a hearing impairment and acquires a vision impairment and vice versa. However there are many other causes.

Deafblindness and aging start in some people before the age of 65. However, in terms of numbers, by far the greatest number are people over 65 years of age. The other significant causes is Usher Syndrome, a genetic form of deafblindness and, in the population over 30 years of age, congenital Rubella Syndrome. Immunisation has dramatically reduced the number of people with Congenital Rubella Syndrome in Australia’s younger population.

THE COST OF DEAFBLINDNESS

Although no specific data have been kept on the cost of deafblindness in Australia; costs arise from:

- people needing support to live in the community;
- education; and
- supported accommodation.

For people with severe and profound levels of deafblindness who live in supported accommodation, costs are significant and will probably range from about $60,000 to over $100,000 per head per annum. In terms of health costs for such groups of people, these would obviously be in excess of those for typical community members.

Other members of the adult deafblind community, especially those with Usher Syndrome (a progressive, genetic form of deafblindness), frequently suffer from depression, as their life-style choices reduce. Researchers must continue to explore the additional mental health experiences and issues faced by people who are deafblind.

A study undertaken by Mary Tass, a psychologist at Melbourne-based Able Australia Services in 2009 has concluded the following:

“The results of depression and anxiety in people in the deafblind sample are a reflection of the challenges and difficulties faced by people with a dual sensory loss. Many deafblind people have had a life (or large segments of life) of isolation, loneliness, boredom, frustration, communication difficulties and breakdowns, unemployment, and the frustration of relying on support workers for simple tasks and chores. They also had to make the continual adjustments that are necessary as sight or hearing (or both) deteriorate over time. The loss and grief is ongoing, not only because of the deafblindness itself, but the changes and deterioration of the senses that often take place. As changes occur, deafblind people experience fear and worrying about the future. They worry about accommodation, support, safety, and more years of loneliness and isolation. Distractions in the deafblind person’s life are limited and often difficult to sustain. The high percentage of depression and anxiety in the current sample is understandable, given the issues and challenges that arise.”

Support is available in Victoria and Western Australia for this group of people living in the community, although not all people have access to these services. In Victoria this support is provided by appropriately qualified staff with the ability to communicate with people who are deafblind. Additional supports and programs need to be included in the service systems that support people who are deafblind and who are also suffering from depression and anxiety. .

As is well known, the costs associated aging is enormous. For people who have developed deafblindness as they have aged, the financial burden increases. This burden is exaggerated due to lack of support when depression and other forms of mental illness develop. Community support is usually inadequate since it only tends to deal with an individual's physical requirements, for example, support rails in bathrooms or the availability of food, but it does not deal with the issues arising from hearing loss.

The costs associated with interpreter services for Australians who are deafblind are very high. These costs can range upwards of $76 per hour, per interpreter with a 2 hour minimum. This amount also includes booking and agency fees. Due to the complexity of tactile signing, a person who is deafblind generally requires two interpreters. The National Auslan Booking Services ("NABS") provides interpreters for people who are deafblind, however, these services must meet certain criteria and do not include interpreters for day to day living. People who are deafblind cannot meet these high costs and again the follow-on effect results in many individuals experiencing feelings of isolation, depression and high anxiety.

IMPLICATION OF DEAFBLINDNESS FOR INDIVIDUALS AND THE COMMUNITY

A 2004-5 report entitled *The Future in our Hands*[2] reviewed the state of services to people with deafblindness in Australia and concluded that, as a general statement, the services were inadequate, and the level of service provision varied significantly from State to State. Little has changed since the release of this report, and the absence of progress can be attributed to a lack of government and community awareness of deafblindness, lack of funding to support services and lack of available resources.

Unlike people with hearing or visual loss only, most people with deafblindness find themselves totally isolated from the community, including the deafblind community. Isolation from the deafblind community can result from communication difficulty, and the fact that communication needs to be one to one. Many deafblind people can not follow group tasks without individual support, and communication methods can vary considerably. Use of such different communication methods can involve speech, fingerspelling and tactile signing.

The exceptions to the above are technical aids such as hearing aids or where people are trained to use computers where the computers have been converted to meet the specific communication requirements of the deafblind person's method of communication e.g. print to Braille, print to speech etc. The only funded service meeting this need is Ablelink and is in Victoria. It is partially funded by the Victorian Government and by Able Australia Services' general fundraising and from Trusts etc. Some limited services are provided by this organisation into other States.

In Victoria, Able Australia and in Western Australia, Senses Foundation provide services to people with deafblindness. Both organisations are State Government funded and also through general fundraising. There are deafblindness services in NSW that are operated by Vision Australia but this organisation is only able to provide a very limited service of community training and basic support, and is confined to a small area of NSW.

The wide variation in service provision between states and territories in Australia is enormous. Queensland has very limited services while the Northern Territory has none.

Single sensory disability service provider organisations (for example, that serve clients with deafness or with blindness) are not effectively meeting the needs of Australians with the dual sensory disability that is deafblindness. Government funds the larger single sensory organisations perhaps believing that they are able to meet the needs of everyone in this group. The result of the assumption is the lack of properly trained staff within those single disability organisations who are able to assist people who are deafblind.

There needs to be trained staff within all available services who can use sign language or other forms of communication. Without trained staff who can communicate effectively with people with deafblindess, the stresses of daily living can generate feelings of social isolation.

In terms of health, the isolation leads to depression and related illnesses. This factor is a major issue with significant groups of people with deafblindness and generates a substantial cost to the community. The skills required to remediate the situation include, for example, lip reading, proper use of hearing aids, visitors from the wider community who understand their issues and who can encourage them to develop their communication skills. There is also need to support the use of available technology so that service recipients make best use of their remaining sensory faculties. Clients require more than merely someone who advises them to have rails in their shower, and fails to understand their more complex problems.

Such programs as supported accommodation, community support, respite care, day programs, work and recreation together with such computer programs as Ablelink; all come at a cost and avenues for people with deafblindness to be able to access these programs require investigation.

The number of people with deafblindness in Australia’s indigenous population is not known, neither is its affect on this population’s health. Deafblindness must certainly affect health including their mental health, and as well creates a wide range of other health issues. An urgent review of deafblindness in the indigenous population must be undertaken.

The issue of funding upgrades of speech processors in cochlear implants in adults is one of critical importance. The recent Senate Inquiry into Hearing Health in Australia has recommended the following:

Recommendation 12 5.204

"The Committee recommends that the Office of Hearing Services review its policy with regard to the replacement of damaged, lost or obsolete cochlear implant speech processors for eligible clients over 21 years of age, and if possible align it with the replacement policy for eligible clients less than 21 years of age."

The costs associated with deafblindness have a serious impact on the living standards of these Australians in this group, including impacts on their health, it is suggested that ways of reducing these costs be reviewed as a matter of urgency.

THE CASE FOR REFORM

Support

With Australia's inadequate service provision (especially in Queensland) and the current poor co-ordination of state-wide services in NSW leaving gaps in the system, there must be improved equality of services across the nation. There must be service provision equity for all people who are affected by deafblindness.

There is a need for an increase in funding for accommodation for people who require such support, including those with deafblindness and who also have an intellectual disability. Many elderly parents of adult children with deafblindness are forced to make agonising choices when they are no longer able to care for their children.

Consequently there needs to be an increase in support within the community for people with deafblindness, to assist in shopping, recreation and improved social interaction. The greater the community support, the less likely it becomes that someone will have to move into high cost support homes.

Employment

A major concern for people with deafblindness is employment. Many people who are deafblind complete secondary education or university studies but are unable to find suitable employment once they have completed these studies. Particular areas that need to be addressed relate to an employer's lack of understanding of the ways deafblindness affects communication, orientation and mobility training to overcome OH&S issues, accessibility of training in the workplace. There is also a need to help promote career advancement and the need for understanding by employers that it is often necessary to undertake workstation modifications in line with the Workplace Modification Scheme. This government scheme reimburses employers and employment service providers for the costs involved in modifying the workplace or purchasing special or adaptive equipment for eligible employees with disability.

Another area of employment for people who are deafblind is self employment in such areas as computers or IT. However, here again, the need for accessing appropriate employment support services is a must.

Regardless of whether a person who is deafblind is employed or self employed, a great financial commitment is required to cover any adaptive technology and support for the individual. Many people who are deafblind could provide invaluable employment skills if these costs were not so far out of reach of the individual or employer.

Interpreters

NABS provide free interpreting services to people who are deaf and deafblind for any private medical appointments as well as psychologist, orientation and mobility, and some naturopathy appointments. There is no charge for these interpreting services. The biggest drawback for this scheme is that NABS does not provide any transportation support to people who are deafblind. Service providers often have to provide a support worker to pick them up and take them to the appointment so that they meet the interpreter there, and more often than not it is difficult to facilitate these requirements.

However, if the appointment is with a public hospital, the interpreting services are covered by such systems as Oncall or through other funding avenues. The problem with this situation is that the majority of the interpreters used in the scheme have not been trained or have not received professional development on deafblindness-related issues. Many people who are deafblind are frustrated, telling ADBC that their appointments were cancelled or postponed only because the interpreters were not comfortable or trained properly in how to use deafblind tactile interpreting for communication purposes. This situation happens on a regular basis. Again, the issue of transport is a problem. People who are deafblind need to ask service providers for transportation support for medical appointments.

In Victoria, for example, for any Department of Human Services ("DHS") meetings, such as reviews of funding packages, the interpreting services are covered by Oncall and funded by DHS. However, if there is a group meeting, Oncall will not cover any interpreting services. It will only fund one to one interpreting services.

Some examples in Victoria are as follows:

Mental Health Support Group: Received small amount of funding support from philanthropic trusts to cover the interpreting costs for this group. However, when the funds run out at end of June, there are no other funding avenues to ensure the survival of this group. Normally, there is a weekly request for 6 to 8 tactile interpreters and 2 notetakers.

Deafblind Advocacy Group: No funding to cover costs of this group since the grouphas a diverse membership. This group requires 6 interpreters and 2 notetakers at its meetings. This advocacy group is slowly developing better and wider networking contacts, for example with the Self Advocacy Resource Unit (“SARU”).

However, if there are any “informative” or “educational” workshops that are available to the wider community, for example, a workshop on how to prepare a will, funeral information, computer information, financial planning and legal workshops, there are no funding avenues for these events.

Compared to three years ago, the Deaf and Deafblind communities have come a long way and access is slowly improving but there is still a long way to go for a person with deafblindness.

HOW TO DESIGN AND FUND A NATIONAL DISABILITY LONG-TERM CARE AND SUPPORT SCHEME TO MEET LONG TERM NEEDS

The need for individualised funding for people with deafblindness is an idea strongly supported by ADBC. This arrangement would give the person who is deafblind the ability to make his/her own choices about which services s/he wishes to access. It would empower people to make those decisions.

The proposed disability insurance scheme should ensure that people, especially those with deafblindness, have sufficient funding to access the services they require, especially in the areas of employment and accommodation options as they are at a critical stage at the moment.

People must be allowed to do as much for themselves as possible. This means continued training after school that is aimed at keeping them independent and out of high cost accommodation.

An assessment system is needed. One that understands the issues, is associated with individual funding levels and has some responsibility to make certain the person finds a suitable service. Whenever possible, a Deafblind person must be part of this process, or alternatively, advice must be sought from families or equivalent carers.

The number of people in Australia with deafblindness is relatively large, and yet, not adequately catered for. The result of this discrepancy is that many of those in this group of people become depressed and sometimes suicidal. At the moment it is estimated that 9 out of 10 people who are deafblind experience depression and anxiety.

It is important that the staff members of visiting services systems are trained/supplied by organisations that understand this issue, and are able to provide appropriate advice. There are, for example, a great many uncomplicated technical devices that can help people overcome their hearing and vision problems.

While there are, in our communities and neighbourhoods, many activities, often people need to be taken and introduced to these services so that it is necessary for the visiting service to be linked into the community services. Accessible transport is also necessary for people who are deafblind so they can be taken to community events or trained to use the public transport system to get there. Public transport organisations should be required to be more accountable in the ways they distribute information to people with deafblindness.

There is need for better funded employment services where the provider organisation has a higher level of understanding and skill in dealing with people who have significant disabilities, including deafblindness.

There needs to be effective early intervention for a child with deafblindness and their family, to commence upon diagnosis; intervention to be provided by specialist educators/therapists, in collaboration, all of whom have a range of relevant deafblind communication skills.

Training of educators/specialists and education assistants to be included as core component in all Sensory Disability, Teacher Training, Therapy and Special Needs courses. The Auslan interpreting courses need to include modules on a range of deafblind communication methods. Disability courses such as Social Trainers, Cert IV, to include modules on interacting and communicating effectively with people with sensory disabilities, including deafblindness.

Appropriate staff training, particularly in regard to deafblind communication methods, is the key to providing effective life-long support to individuals with deafblindness starting with early intervention as a priority.

All disability service provider agencies should have outside quality control approval including quality of life assessment. Smaller organisations might need outside assistance and funding to set up this process.

SUMMARY

This submission to the Productivity Commission by ADBC, the community agency representing an estimated 288,000 Australians who are deafblind, including older people who are deafblind and their families, professionals and organisations working in the field, makes the following recommendations:

1. The Federal and State governments provide funding for a national information and advocacy service in the same was as other national disability organisations are funded due to the uniqueness of deafblindness.

2. The Commission should investigate the availability of more appropriate services <u>of all types</u>, for example: supported accommodation, community support, respite care, day programs, work and recreation and computer programs such as Ablelink together with adequate support ie. The provision of larger numbers of people who can communicate effectively with people with deafblindness by funding extra resources to consolidate this.

3. The Commission should investigate ways of reviewing and reducing the cost and improving access to <u>interpreter services</u> within Australia.

4. The Commission should recommend that all service personnel working with Australians who are deafblind and who use various forms of sign language to communicate must have appropriate signing abilities and increased access to training to promote their existing skills.

5. That the Commission consider conducting an urgent review of deafblindness in the Australian indigenous population

6. The Commission should consider as a matter of urgency, ways of reducing the cost of upgrades of speech processors for cochlear implants in adults, as per Recommendation 12, 5.204 from the Senate Inquiry into Hearing Health.

7. The Commission should examine ways of ensuring <u>equity in service provision</u> across our nation for all Australians with deafblindness.

8. That the Commission acknowledge in its report, the need for an increase in funding for accommodation for people who require such support, including those with deafblindness and who also have an intellectual disability. Recognise the need for an increase in support within the

community for people with deafblindness, to assist in shopping, recreation and improved social interaction.

9. That the Commission acknowledge in its report the need for an assessment system in Deafblindness service provision. A national referral system or national data base that understands the major issues, and ensures that it clients find a suitable service.

10. That the Commission recommend in its report that public transport organisations should be required to be more accountable in the ways they distribute information to people with deafblindness.

11. That the Commission acknowledge in its report the need for better funded employment services in which the provider organisation has a higher level of understanding and skill in dealing with people who have significant disabilities.

12. That the Commission acknowledge in its report a need for more comprehensive early intervention services for children who are affected by deafblindness.

13. That the Commission acknowledge in its report that all disability service provider agencies should have external independent quality control approval including quality of life assessment.

REFERENCES

[1] Access Economics. (2007). *Making sense, A report into dual sensory loss and multiple disabilities in Australia.* Retrieved 27 May 2010 from http://www.ableaustralia.org.au/content-files/Penny%20Taylor%20Presentation.pdf

[2] Prain, Meredith (2005), *Future in our hands, An update of the 1994 report: Invesigation into the needs of and services for people in Australia who are deafblind*. Melbourne: AbleAustralia.