Australian DeafBlind Council

Australian DeafBlind Council (ADBC)
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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 people, including older people who are deafblind, their families and organisations working in the field.

ADBC seeks to improve conditions and to be an advocate for people who are deafblind across Australia, 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 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 communication and generally leaves them isolated from the community and information and significantly affects their education. With adults, 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 serious efforts to obtain funding, and is the only national information service on and for people with deafblindness, their families and other persons and organisations requiring information on deafblindness. It is supported financially by its members and major suppliers of services to people with deafblindness. It did obtain $15,000 funding from the Commonwealth Government's Department of

Families, Community Services and Indigenous Affairs for a report that was published on deafblindness in 2004-05.

The Extent and Causes of Deafblindness

The 2004-5 report entitled “The Future in our Hands” reviewed the state of services to people with deafblindness in Australia and concluded that, as a general statement, they were not good and the level of provision of services varied significantly from State to State.

Recent research has indicated the numbers of people with deafblindness are significantly higher than had previously been assessed with an unpublished report by Access Economics calculating that there are 288,000 people with deafblindness in Australia. Recent figures from the Bureau of Statistics, which require some clarification and are based on their 2003 Disability, Aging and Carers Survey, indicates a figure of 73,492. While these figures seem dramatically different, on analysis the difference is around at what level of deafness a person can be considered to be deafblind. The difference in the figures is almost totally related to the question of the numbers of person 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.

The current breakdown of numbers of people with deafblindness indicate that there are some 7000 to 9000 people under 65 and 281,000 65 years of age and over if people with a mild hearing loss are included based on the Access Economics Report. This figure will grow with the aging of the population.

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

In terms of numbers by far the greatest numbers are people over 65 years of age. The other significant causes would be Usher Syndrome, a genetic form of deafblindness and, in the population over 30 years of age, congenital Rubella Syndrome. Immunization has dramatically reduced the numbers of people with Congenital Rubella Syndrome in the younger population.

Communication

Most people with deafblindness are not totally blind or totally deaf and this leads to the need to create a method of communication that suits each individual.

Thus People with deafblindness communicate by a wide range of methods. The range and combination of impairments results in a diverse range of different communication methods from speech when using a hearing aid or cochlea implant, sign language including Auslan, signing into the hand (deafblind finger spelling), close range, visual frame, tactile, touch, cues, pictographs, key word sign, print/Braille (including print on palm, computer and email and text). Appropriately qualified interpreters are a continuous problem although this has improved in some States over recent years. Never the less interpreters need to be booked many weeks in advance. There is also a question of who pays for them. For recreational activities volunteers form an important part of the support network. In States that do not have services that provide support to people with deafblindness and where support comes from generic services, there are major problems of finding appropriate interpreters. This can be a major issue when seeing doctors, for hospital appointments, seeing psychologists, seeing audiologists, for financial advice, seeing Centrelink etc. In some cases such as seeing a psychologist or counsellor the psychologist or counsellor needs to communicate in the same language as the one used by the deafblind person. This is not normally the case. In some States interpreter training courses do not include training for methods of communicating with people who are deafblind and many people with deafblindness who need supported accommodation find themselves in services where no one can communicate with them or the level of the person communicating with them is such that it is only very basic so that no true communication takes place. Combined with the deafblindness itself this often leads to depression and other forms of mental illness.

In terms of the elderly the issues are quite different. In most cases the person with deafblindness over 65 has had speech and good sight and lived a normal life in the community. They are too old to learn to sign but may pick up some lip reading skills. This is important to reduce their isolation. Encouragement to use their hearing aids is also important as is use of technologies such as loop systems linked to their television or use in places of entertainment to improve their hearing. Also development of computer skills can be useful and reduces isolation. Visiting support staff also need to have knowledge and communicating skills and an awareness of the technical aids in this area and should encourage older people to use all the options available. If they don't older people, with loss of hearing, become isolated and depressed and can utilise medical facilities excessively simply due to their loneliness and isolation

Awareness campaigns need to be carried out to make people conscious of the need to use their hearing aids and to keep them switched on. Also to make them become involved in what is going on around them or better still to go out to activities. Lessons in lip reading skills, where they have the visual ability to do this, are also most useful.

The Cost of Deafblindness

Although no specific data is kept on the cost of deafblindnes in Australia in the case of the cost of people needing support to live in the community, the cost of education and the cost of supported accommodation the costs are quite high. For people with severe and profound levels of deafblindness who live in supported accommodation it is quite significant and would probably range in the region of $60,000 to over $100,000 per head per annum. In terms of health for such groups of people it would obviously be in excess of typical members of the community.

Other members of the adult deafblind community, especially those with Usher Syndrome which is a progressive, genetic form of deafblindness, frequently suffer from depression as their options in life reduce. Support is available in Victoria and Western Australia for this group of people living in the community from appropriately qualified staff with the ability to

communicate with them although not all people have access to these services.

As is well known the cost of aging is enormous. For people who have developed deafblindness as they have aged there is a cost. It is exaggerated due to lack of support when depression and other forms of mental illness develop especially as community support is usually inadequate as it only tends to deal with the physical requirements, such as rails in bathrooms and may deal with issues such as availability of food, but it does not deal with the issues of hearing loss etc.

Implication of Deafblindness for Individuals and the Community

Unlike people with straight hearing loss most people with deafblindness find themselves totally isolated from the community, including the deafblind community. The exceptions to this are those with technical aids such as hearing aids or 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 eg print to Braille, print to speech etc etc. The only funded service meeting this need is in Victoria and is 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 terms of health this isolation leads to depression and related illnesses and is a major issue with significant groups of people with deafblindness and is a cost to the community.

For people over 65 who become deafblind, deafblindness generally means isolation often coupled with depression and an inability to communicate with anyone. Lip reading, proper use of hearing aids, visitors who understand their issues and who can encourage them to develop their communication skills and use the technology available to make best use of their remaining sensory faculties and not just someone who advises them to have rails in their shower etc and doesn't understand their wider problems, is essential.

The Adequacy of Access to Hearing Services, including Assessment and Support Services and Hearing Technologies

Except for children's hearing, services generally cater for people with straight hearing loss with staff either totally untrained or not having the expertise to deal with the issues met by people with multiple disabilities, especially those with deafblindness. In many States this means interpreters who cannot sign or communicate in the mode of communication used by the person fronting for testing, tests that rely on the person being able to see, follow a series of instructions and cues that are not appropriate for a person who is deafblind or has other disabilities as well as a hearing impairment. Frequently adaptive technology is designed for a person with a hearing loss and is not able to meet the needs of someone with multiple disabilities

Whilst they have a long way to go, for many individuals the advent of emails, mobile phones with the ability to text and vibrate and computers have been a boon to people with deafblindness. As well as being able convert the message to a format they can use it also gives the person time to take in the message and then reply. This is not usually possible for a person with a combined vision and hearing impairment.

Access to services is also limited in many States because of the lack of interpreters other than those who are straight Auslan interpreters. Signing into the hand, co active signing and other specialist techniques are not available

With most people who are deafblind finding employment is difficult and if they are not in some form of supported accommodation or living with their parents they generally live off the pension so any cost is important. So the $35-$40 cost of Australian Hearing Services is significant as is the cost of batteries. A free service would be of assistance to this group of people coupled with the opportunity to have more regular check ups

The Adequacy of Current Deafblindness Health and Research Programs, Including Education and Awareness Programs

There is a total lack of research into the late onset issues related to adults whose deafblindness is due to Congenital Rubella Syndrome (CRS). There is empirical evidence that glaucoma, heart attacks, problems of the spleen and liver develop in adults whose deafblindness is due to CRS. This might also be true of people with a hearing loss due to CRS. Some data is being collected in the USA but its relevance to the Australian situation is uncertain. Deafblind people living in the community and especially those living in Supported Accommodation should be tested for potential issues such as glaucoma regularly

Likewise, a person with deafblindness can learn through the whole of their life and, particularly, continue to develop into their mid 20's. Once they have left the education system, in most cases, education stops completely.

There is very little awareness of deafblindness in the community. This is especially important when considering the aged. Research is needed on the needs aged

There are two major areas of research related to deafblindness that need urgent attention. They are:

1. the issues related to people over 65 years of age both living in the community, in the wide range of supported communities and those in hostel accommodation
2. the issue of the incidence of deafblindness in the indigenous community. At present no one is aware of the numbers of people with deafblindneass in this community, their circumstances and issues. Base on the numbers with hearing impairments and vision impairment the numbers must be significant.

Summary and Suggestions

The lack of support, lack of appropriately qualified interpreters, staff with the ability communicate when providing health and related services, community services and other services including to the aged and lack of staff with the ability to communicate with them at audiological services etc is leading to depression and mental illness and a range of health issues. **It is suggested the inquiry reviews the issue of the lack of staff with the ability to communicate with people with deafblindness and general communication difficulties in health services, providing community support including community and hostel support to the aged**

Late onset issues for the population of adults who are deaf or deafblind due to Congenital Rubella Syndrome is believed to be a major hidden issue in this population. **It is recommended a 4 to 5 year longitudinal research project is needed to establish the depth of this problem and to make recommendations on what action is necessary**

Better qualified and more knowledgeable staff are needed to support the rapidly growing population of older people in their homes who are becoming vision and hearing impaired to make certain they utilise all the facilities available to them. Not only hearing aids but technology including appropriately adapted computers. This also includes staff in hostels etc. This should reduce the level of depression, mental illness and suicides in this community**. It is recommended that the issue of staff with an understanding of the communication issues relating to supporting to older people in the community be investigated**.

It is also suggested that an awareness campaign aimed at older with a hearing impairment be considered to encourage them to use their hearing aids and other technical facilities

The rapidly growing population of older people with a vision and hearing impairment (deafblindness) is a major long term issue for society. If the issue is not faced there will not only be a significant growth in costs to society but a growth in depression and other types of mental health. **It is suggested an in depth review of deafblindness in the growing**

older population be undertaken with recommendations on future action.

Because the costs associated with deafblindness have a serious impact on the living standards of people of this group of people, including health, **It is suggested ways of reducing these costs be reviewed.**

The number of people with deafblindness in Australia's indigenous population is not known as is its affect on this population's health. It must affect their health including their mental health plus create a wide range of other health issues. **It is recommended to the inquiry that a review of deafblindness in the indigenous population be undertaken.**