# Senses Foundation Inc's Submission to the

## *Parliament of Australia*

## SENATE INQUIRY INTO HEARING HEALTH IN AUSTRALIA

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### EXPLANATION

Senses Foundation is a non government charitable organisation and the primary service provider and advocate for people who are deafblind in Western Australia. Therefore its submission to this Senate Inquiry relates to Hearing Health as part of the dual sensory loss called deafblindness.

## ADDRESSING THE SPECIFIC QUESTIONS OF THE INQUIRY

### The extent, causes and costs of hearing impairment in Australia:

#### *The extent*

In 2007 Senses Foundation commissioned a study to identify the number, location, age and level of disability of people who are blind with additional disabilities and people who are deafblind throughout Western Australia.

The project, undertaken by Paula Dyke from the Telethon Institute for Child Health in Western Australia, used existing population based statistical data to determine key outcome objectives related to the new target population for Senses Foundation. This approach involved the use of the latest data from the Commonwealth/State Territory Disability Agreement National Minimum Data Set (CSTDA NMDS) and the Australian Bureau of Statistics (ABS) Survey of Disability, Aging and Carers (SDAC). The Australian Institute of Health and Welfare (AIHW) were contracted by Senses Foundation to construct specific tables for the project that would supply more accurate information than could be obtained using previously tried research methodologies aimed at obtaining demographic data for the target groups of interest. The process of defining the target group for the project involved the AIHW using the existing definitions of disability used primarily by the ABS and adjusting these to focus on those with a vision disability and an additional disability and those with both a hearing and vision disability.

The AIHW defined the target group in the following ways:

| **Population** | **SDAC categories included** |
|---|---|
| Deafblind only, and deafblind with additional disabilities | Identified from screening questions, this includes people with a disability who have:<br>A) *at least* partial loss of sight and *total* loss of hearing; and<br>B) *at least* partial loss of hearing and *total* loss of sight; and<br>C) *partial* loss of hearing and *partial* loss of sight. |
| | **CSTDA Categories** |
| Deafblind only, and deafblind with additional disabilities | People identifying as having a deafblind disability (with and without additional disabilities) |

***Project Findings***

In 2003, 8,800 Western Australians indicated they had the dual disability of vision and hearing loss. Of these 8,800 people

- 2,400 were under the age of 60.
- 6,400 were over the age of 60.
- 2,288 live in rural and remote Western Australia.
- Only 181 indicated that they were currently receiving any formal disability services.
- 63%, (n = 5,500) were males and 37%, (n = 3,300) were females.

***Causes***

The causes of deafblindness, classified under the two categories of congenital and acquired deafblindness, are varied and changing in both incidence and prevalence (Admiraal & Huygen 2000; Robaei et al. 2006; Lam et al. 2006;

Lock 2003; Stanley F 2003). The main causes of children being born with deafblindness include:

- Pre and post-natal trauma such as asphyxia and prematurity;
- Maternal alcohol and drug addiction;
- Maternal rubella;
- Cytomegalovirus;
- Toxoplasmosis;
- Chromosomal abnormalities;
- Usher syndrome; and
- CHARGE syndrome.

Acquired deafblindness can result from:

- Illness such as meningitis;
- Infections such as encephalitis;
- Brain tumour;
- Head injury; and
- Ageing.

Usher syndrome can also be described as a form of 'acquired deafblindness'.

The prevalence of the different causes of a vision and hearing disability have been changing over recent years as immunization programs for disorders such as rubella and measles are effectively implemented and increases in technology see the survival of very premature infants and young children with severe chromosomal abnormalities. There is a paucity of literature and well designed research on both the epidemiology of deafblind disabilities and effective assessment, interventions and outcomes. Relevant literature sourced related to the epidemiology and demographics of this dual disability will now be briefly highlighted.

### *Congenital deafblindness*

### *Infections*

Infection with cytomegalovirus (CMV) is reported as being the most common congenital infection in humans (Andriesse et al. 2006). It is more widespread in developing countries and in areas of lower socioeconomic conditions. Cytomegalovirus is a member of the herpes virus family and all share the ability to remain alive, but dormant, in the body for life. Almost all people have been exposed to CMV by the time they are adults, however, in a healthy individual no symptoms will ever develop.

Some groups of people tend to be at increased risk for active infection and serious complications from CMV, including babies born to women who have a first time CMV infection during pregnancy and those with weakened immune systems due to cancer or HIV infection (The Children's Hospital at Westmead 2006). It is thought that CMV affects one to two per cent of all neonates. However, only 10% show symptoms at birth, varying from slight developmental complaints to serious neurologic, auditory or ophthalmic abnormalities. Although the other 90% of infected neonates are asymptomatic at birth, symptoms of congenital CMV may not be discovered until many years later. Later in childhood, 5% to 17% of these children will develop ocular, audiological, neurological or developmental sequelae (Andriesse et al. 2006).

It is anticipated that there will be increasing numbers of persons who are at risk for CMV infection as the expanding use of child care centres in developed countries is increasing the risk to children and staff working in these centres. In addition, the number of people with weakened immune systems is growing because of increases in organ transplantation and cancer treatments such as chemotherapy and radiotherapy.

Congenital rubella syndrome (CRS) is now a relatively rare cause of deafness and vision disorders in children, primarily as a result of the introduction in the early 1970s of widespread vaccination programs against the disease. It is a viral illness caused by a togavirus of the gene Bubivirus.

When rubella infection occurs during pregnancy, particularly during the first trimester, foetal infection is likely and often causes miscarriages, stillbirths and severe birth defects. The most common congenital effects are cataracts, heart disease, sensorineural deafness and intellectual disability.

The number of reported cases of CRS in the United States has declined from 77 cases in 1970 to a total of 2 cases in 1996. In the United Kingdom, in the 1960s, as many as 300 children per year were born with CRS, and this has dramatically declined with only three cases being reported in 2001. In Australia, in 2002, the national notification rates for rubella were the lowest on record with there being no notified cases of CRS between 1997 and 2002. During the pre-vaccination era in Australia an average of 120 cases of CRS were reported annually.

Given that between 85% and 88% of the population need to be immune to the disease to stop the spread of rubella, some epidemiologists have expressed concerns regarding the maintenance of these low figures in the future as a result of increased global travelling and migration (Gidding et al. 2003). In addition, there are also some concerns that Indigenous women living in remote and rural communities in Australia may not have adequate immunity to the rubella virus. Hunt and Lumley (2004) found that fewer than 75% of Indigenous women from rural and remote communities in the Top End of Australia had adequate levels of immunity. They suggest more specific targeting of public health immunization programs is needed to ensure there is not an increase in cases of CRS in rural and remote Indigenous communities in Australia.

***Chromosomal abnormalities and genetic disorders***

There are a number of chromosomal conditions and syndromes affecting the eye and the ear, and these have recently been described in detail in a comprehensive evidence based overview of vision disorders in deaf children (Nickolopoulos et al. 2006).

It is believed that the incidence of these genetic and chromosomal disorders have been increasing in recent years (Admiraal et al. 2000), with the two attracting most attention in the literature being Usher's syndrome and CHARGE syndrome.

Usher's syndrome is an autosomal recessive disorder and is the most common disease in the category of genetic hearing loss associated with eye disorders. It is characterised by a congenital hearing loss with or without balance disorders and a progressive vision loss resulting from retinitis pigmentosa. Issing and Linthicum (2000) describe three heterogeneous forms of the disorder:

- Type 1: makes up 85% of cases and is characterised by congenital severe to profound hearing loss with the development of retinitis pigmentosa before puberty and absence of vestibular responses.
- Type 2: makes up 10% of cases and is characterised by severe congenital hearing loss and gait disturbances with onset of retinitis pigmentosa after puberty.
- Type 3: makes up 5% of cases and is characterised by progressive sensorineural hearing loss, with onset in childhood or adolescence, and retinitis pigmentosa.

In the United States, the prevalence of Usher syndrome has been estimated to range from 1.8 to 4.4 per 100,000 in the general population; 13-20% in

the retinitis pigmentosa population; and from 1-6% to as high as 30% among individuals who are congenitally deaf (Issing & Linthicum 2000; Hope 1997). The prevalence in the United Kingdom of typical Type 1 and 11 cases is 5.3 per 100,000; higher than in other international population based studies (Hope 1997). In Australia, it is estimated that Type 1 and Type 2 forms of Usher syndrome account for 10% of children who are born deaf, and that one child is born with retinitis pigmentosa in approximately every 3,000 live births in Australia (Better Health Channel 2007).

CHARGE syndrome is a recognisable genetic pattern of birth defects which occurs in about one in every 9 - 10,000 births worldwide. It is caused by a mutation in a single gene, most often CHD7. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. The major clinical features, which are very common in CHARGE and relatively rare in other conditions, include coloboma of the eye causing vision loss, choanal atresia or stenosis, cranial nerve abnormality, ear abnormalities and deafness (The CHARGE Syndrome Foundation 2004).

***Other Conditions***

As highlighted earlier, there appears to have been a significant shift in the aetiology of sensorineural hearing impairment and associated vision impairment due to medical developments such as immunization programs for measles and rubella, better survival rates with neonatal intensive care treatment and improved diagnostic and genetic examination methods. Perhaps the two most relevant emerging 'other conditions' that may result in multiple disability including hearing and vision disabilities are prematurity and Foetal Alcohol Syndrome (FAS).

Foetal Alcohol Syndrome, while often difficult to diagnose, is based on a set of criteria comprised of abnormalities in three main areas: growth retardation,

particular facial features and central nervous system anomalies (which may include sensorineural hearing loss and vision abnormalities). Several studies have demonstrated the difficulties in trying to obtain accurate estimates of the prevalence and incidence of FAS, however the evidence does indicate that there appears to be a strong relationship between poverty and the incidence of FAS (O'Leary 2002).

Foetal Alcohol Syndrome is estimated to occur at a rate of one to two per 1000 live births in Canada and these estimates are reported to be much higher in Indigenous Canadians, 25 – 200 per 1000 live births (Dell & Roberts 2005).

Studies by the Center for Disease Control and Prevention have shown that 0.2 to 1.5 cases of FAS occur for every 1000 live births in the United States (Center for Disease Control and Prevention 2006). In Western Australia the prevalence of FAS is estimated to be 0.02 per 1,000 for non-Aboriginal children and 2.76 per 1000 for Aboriginal children. It is thought these estimates, however, are likely to underestimate the true prevalence due to under diagnosis and under ascertainment (Bower et al. 2000).

Premature birth is a major risk factor for perinatal mortality and disability with key factors contributing to preterm birth including twin and higher order multiple pregnancies and advances in obstetrical technologies and interventions. Although survival rates in very low birth weight infants have improved greatly, there seems to be a risk of severe disabilities such as blindness (2.7-3%) and deafness (1.3-2%) (Davis et al. 1997). In Australia, over the period 1997 – 2001, 7.5% of babies were born preterm (less than 37 weeks gestation) and 1.6% of these babies were very preterm (less than 32 weeks gestation). The proportion of preterm babies ranged from 7.3% in 1997 to 7.7% in 2000 with these proportions being much higher in mothers

identified as Aboriginal or Torres Strait Islander (12.5% in 1997 – 2000) (Australian Institute of Health and Welfare 2004).

### *Acquired Deafblindness*

The most common causes of acquired deafblindness have been described as illnesses such as meningitis, encephalitis and brain tumours; and trauma such as head injuries and aging. Little literature was found that described deafblindness specifically within these conditions with the exception of aging. Most of this literature will be highlighted in the following section focusing on the second key target client group; people with a vision impairment and additional disabilities.

Recent studies in the United States indicate that by the age of 70, 21% of people will have the dual sensory disability of vision and hearing loss (Berry 2004).

Traditionally, older people with vision and hearing disability have not been described as deafblind; however, recent national and international literature confirms that this group fit the functional definitions used by the Australian Deafblind Council and Deafblind International (Prain 2005; Munroe 2004). Improvements in health and decline in mortality rates have continued to increase the life expectancy of Australians.

Population projections suggest that by the year 2026 people aged 65 years and over will constitute over 20% of the Western Australia population, an increase from approximately 11% in 2004. It is evident, then, that as the population continues to age and life expectancy increases the number of people with an acquired deafblind disability is likely to increase significantly.

***Costs***

Please see the following section on Implications

**The implications of hearing impairment for individuals and the community;**

Having an acquired dual sensory loss significantly impacts upon an individuals mobility, socialisation, independence and quality of life.

Research has demonstrated that there are increased health issues as a result of having a dual sensory loss as follows.

- People with a dual sensory impairment generally report considerably poorer health than people with a hearing impairment and poorer than people with a vision impairment (Laforge et al., 1992; Crews et al., 2004);
- Functional problems increase, eg. difficulties getting out in the community is increased by 4.7 times compared to the normal population; difficulties getting out of bed increases by 3.8 times; difficulties cooking increases by 4.7 times and difficulties with the administration of medicine increases by 4 times (Crews et al., 2004);
- People with an acquired dual sensory loss have decreased mobility (affects 48.2% compared to the normal population of 17.8%), increased amount of falls (37.6% compared to 16.5%), increased hip fractures (7.4% compared to 3.8%), increase in Osteoporosis (16.3% compared to 7.7%), increased incidence of stroke (19.7% compared to 6.4%), increased incident of heart disease (32.6% compared to 16.7%) and increased incident of arthritis (77.3% compared to 53.2%). (Crews et al., 2004);

- A combined vision and hearing loss causes reduced cognitive processes such as memory, and increased states of confusion (Brennen et al., 2006; Tay et al. 2006) as well as causing depression (Capella-McDonall, 2005);
- Mortality rates are increased between 1.6 to more than 3 times (Lam et al., 2006; Appollonio et al., 1995; Laforge et al., 1992).
- Mortality rates are increased between 1.6 to more than 3 times (Lam et al., 2006; Appollonio et al., 1995; Laforge et al., 1992).

In the study commissioned by Senses Foundation in 2007 and referred to earlier in this paper, the level of disability for the identified individuals were reported differently from the SDAC and the CSTDA NMDA data, however, both sources of data identified significant levels of disability and participation restriction.

Overall, 48% of the people who were deafblind reported having a profound or severe disability.

In addition, of significance was the finding that approximately half of the people reported that they needed help with more than one core activity, and that this help was required on a daily basis.

The high levels of disability was also confirmed by the CSTDA NMDS data, with anywhere from at least one third to half of the individuals reporting always needing help within each of the described key life activities. For those individuals who are deafblind, the life areas of education (69%), community and economic life (58%), self care (54%), and working (54%) were those recording the highest proportions of individuals indicating they always needed help or were unable to do this activity.

As the CSTDA NMDS data included few elderly individuals, it was interesting to note that higher proportions of those in the younger age groups reported needing greater levels of assistance than those in the 25 to 59 age group, and this was true for all life areas.

An individual's ability to participate in employment provides further information as to the level of disability being experienced by an individual.

For those aged between 15 years and 64 years many reported they had either profound or severe participation restrictions related to employment with only 10% reporting no limitations in participating in the workforce.

These findings related to employment confirm the comments made by Senswide Services who state people who are deafblind are amongst the most disadvantaged in the labour market. Often they are severely isolated in their day to day lives due to the impact of their disability on their ability to communicate and access the community. People who are deafblind have not had sufficient access to open employment services in the past, primarily due to lack of awareness and specialised employment agencies (Senswide Services, Conference Proceedings 2000).

## **The adequacy of access to hearing services, including assessment and support services, and hearing technologies.**

### *Adequacy of access*

In the study commissioned by Senses Foundation in 2007 and referred to throughout this paper it was found that only 181 of the 8,800 deafblind individuals were accessing formal disability services. This was despite 48% reporting a profound or severe level of disability and from at least one third to half of the individuals reporting always needing help within each of the described key life activities.

This finding is reflective of the findings of other research which reports the lower proportions of people with a deafblind disability accessing services than other disability groups is due to a number of barriers to access (Zazove & Doukas 1994). Lock (2003) states that 'it is well documented that the majority of deaf and hearing impaired persons demonstrate difficulties accessing health care and communicating with health care professionals' (p.1230).

Studies have demonstrated the use of services by those who are deafblind differ significantly from those of the general population. Key factors that have been identified as barriers to the deafblind population accessing services include misinformation, miscommunication and lack of basic knowledge about the disability by health professionals (Barnett 2002; Lock 2003).

## Screening

### *Recommendation*

Screening for early identification of Usher Syndrome of children who have been diagnosed as deaf or hard of hearing to ensure they are in receipt of appropriate education and support services as their needs change with progression of the condition.

An Ophthalmolic screening study of 231 deaf students in Oregon, USA to determine the frequency of Usher Syndrome (Brinks et. Al, 2001) found significant ocular pathology in 48%, with 5 students diagnosed with Usher Syndrome. The study concluded that early diagnosis and treatment of eye disease in deaf children would benefit the quality of life of these children.

A study of genetics and the impact impaired vision, hearing and balance as a result of Usher Syndrome on people who are deafblind has been undertaken in the UK in collaboration between Sense UK, the Institute of Child Health and the Institute of Ophthalmology. Research has involved detailed testing of people affected by the syndrome with the findings of the study currently

being evaluated (www.sense.org.uk/usherstudy). An outcome of the study was to set up a Dual Sensory Clinic in London, UK at the National Hospital for Neurology and Neurosurgery. Having health professionals working together rather than in isolation is proving beneficial in increasing their knowledge and understanding of dual sensory loss.

## Specialist Early Intervention Services

### *Recommendation*

The importance of early intervention has been well established. There is no question as to the need for specialist early intervention services to young children who are deafblind. "Young children who are deafblind have unique communication, developmental and emotional needs that require special knowledge, expertise, technology and assistance far beyond that required by other children with disabilities." (Holte, et al., 2006). Children with dual sensory impairments should receive specialised services, such as alternative modes of communication, functional sensory input and orientation to the world around them (Michael & Paul, 1991).

"Providing early intervention service to infants who are deafblind and their families is complicated" (Chen et al., 2000, pp. 5). Chen (1992) recommends that a seamless, comprehensive (multi-disciplinary), coordinated, family oriented system of early intervention is provided to children who are deafblind. Senses Foundation is currently providing such a service to young children, however additional services from the Department of Education and Training to deafblind children under 3 years by teaching staff is resulting in a system that lacks cohesion and direction.

## Adult Services

***Recommendation***

The individual needs of adults who are deafblind will vary considerably dependant on whether they are congenitally deafblind or have acquired deafblindness. Therefore more flexibility in service provision will be required to meet those needs.

For some people who have acquired deafblindness, access to appropriate specialist services will be required to support them to continue to develop new skills and access to equipment that will enable them to regain or maintain independence. This could include adapting communication, activities of daily living, orientation and mobility and accessing appropriate employment and leisure opportunities.

For people who are congenitally deafblind or children transitioning into adult services it is vital that opportunities for stimulation and developing their skills continue to be included in their care plans with support workers who are motivated to enable clients to achieve their potential.

## Communication Guides

***Recommendation***

Senses Foundation is currently undertaking a pilot program to determine the impact of providing a Communication Guide model of service, for people with deafblindness in Western Australia, to reduce isolation by supporting people to access information, increase their ability to undertake a set of activities of daily living; and support access and participation in the community and their sense of well being.

In a number of countries outside Australia, people who have an acquired dual sensory loss are entitled to an assessed level of support to maintain their independence, opportunity for socialisation and community involvement. In some countries this is enshrined in legislation. In Denmark these support workers are called Contact Persons, in the United Kingdom they are Communicator Guides and in Canada they are Interveners. The roles of these people vary between countries, however, they are specifically trained to be aware of the issues related to dual sensory loss and to work with the person to be the link between them and the community, thus minimising isolation. The Canadian model uses Intervenors who undergo training for two years at diploma level. The role of the Intervenor also includes teaching the skills required for ongoing independence. Services described above are not yet available anywhere in Australia.

### Services for Older Adults

Australian Hearing suggest that half of people over the age of 60 have difficulty hearing – for Indigenous people the numbers are much higher, possibly 7 out of 10 people. (How age affects hearing, Information Sheet, Australian Hearing www.hearing.com.au).

Approximately 9.4% of older Australians are vision impaired. Data is limited of people from Indigenous communities who have vision impairment. (Vision problems among older Australians, 2005, Australian Institute of Health and Welfare, Summary - Bulletin No 27, Australian Government). Recognition of the impact to health and wellbeing through deteriorating vision such as increased risk of falls is recognised in the report.

Data on numbers of people with combined dual sensory loss are not available.

***Recommendation***

To develop systems to identify and gather data on the number of people in Australia affected by dual sensory loss or deafblindness.

Local Authorities in the UK are required to identify and keep records of people of all ages who are deafblind and using the statistical data to help with planning for service provision. The guidance goes on to make recommendations on staff training, and ensuring services are tailored to meet the specific needs of people who are deafblind. (Section 7 of the Local Authority and Social Services Act 1970, 2001, Dept of Health, UK)

Many agencies provide Home and Community Care (HACC) services to people who are elderly and have an acquired dual sensory loss. To ensure this group of very isolated people receive adequate support, opportunities for specialised training on how to communicate and assist those with vision and hearing impairment is essential.

**Rural and Remote**

Based on research conducted by the Senses Foundation in 2007, there are a significant number of people in rural and remote areas of WA who are deafblind and who do not receive any formal support services. Only 181 of the 2,288 people who are deafblind and living in rural and remote Western Australia currently receive services from disability agencies.

***Recommendation***

Specialist services for people who are deafblind including education, training and resources to individuals with deafblindness and their families, carers and service providers living in rural and remote Western Australia are required.

## The adequacy of current hearing health and research programs, including education and awareness programs.

### Acceptance of the unique disability of deafblindness

Australia is one of a few countries which does not yet define deafblindness as a unique disability, separate from either deaf or blind. This must be remedied. This results in inadequate and inaccurate data being collected in such surveys as the census and results in inadequate information, education and resources being applied to this disability group.

### Identification of children who are deafblind in the education system

Education and Health professionals need training in understanding the impact of deafblindness and the individual needs of people affected by specialist staff.

## Specific issues affecting Indigenous communities.

The following has been reported previously under Causes of Deafblindness. The following is a summary of the causes of deafblindness which occur at a higher incidence rate in indigenous communities.

***Foetal Alcohol Syndrome*** (FAS) can cause deafblindness. In Western Australia the prevalence of FAS is estimated to be 0.02 per 1,000 for non-Aboriginal children and 2.76 per 1000 for Aboriginal children. It is thought these estimates, however, are likely to underestimate the true prevalence due to under diagnosis and under ascertainment (Bower et al. 2000).

***Prematurity*** can cause deafblindness. In Australia, over the period 1997 – 2001, 7.5% of babies were born preterm (less than 37 weeks gestation) and

1.6% of these babies were very preterm (less than 32 weeks gestation). The proportion of preterm babies ranged from 7.3% in 1997 to 7.7% in 2000 with these proportions being much higher in mothers identified as Aboriginal or Torres Strait Islander (12.5% in 1997 – 2000) (Australian Institute of Health and Welfare 2004).

***Rubella*** can cause deafblindness. Indigenous women living in remote and rural communities in Australia have inadequate immunity to the rubella virus. Hunt and Lumley (2004) found that fewer than 75% of Indigenous women from rural and remote communities had adequate levels of immunity.

Trachoma can cause blindness. It is the leading cause of infectious vision loss resulting in over five million cases of bilateral blindness worldwide. Australia is the only developed country in the world that still has trachoma. It is linked with poverty, poor hygiene and limited access to clean water and health care services. The reported rates in Aboriginal children ranges from 55% in the Pilbara and 40% in Central Australia.

Cataract can cause blindness. For non-Indigenous Australians the prevalence of cataract is estimated to be 0.8%, however for Indigenous Australians the numbers are higher at 3.6% (Australian Institute of Health and Welfare, 2003).

Diabetes Mellitus can cause blindness. Higher rates of diabetes mellitus have been demonstrated in Indigenous populations of Australia compared to non-Indigenous Australians and this has great potential for detrimental vision sequelae (Lamoureux 2004).

### *Indigenous service users*

The rate of Indigenous service users with a deafblind disability was too small to report in the study commissioned by Senses Foundation. A study investigating dual sensory loss in US adults using The National Health Interview Survey 1997-2002 (Caban et al. 2005), reported that Native Americans over the age of 79 had a 3 fold increase, or 48% had a vision and hearing impairment.

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