



# Unseen and Unheard

*The identification of people who are deafblind and people who are vision impaired with additional disabilities in Western Australia*

By Senses Foundation Inc

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## **The Researcher**

Paula Dyke was commissioned by Senses Foundation to undertake this research.

Paula has had over twenty years experience in the disability sector, working as a clinician, manager and researcher. She has led large teams of allied health professionals in delivering services to families with children with disabilities; lectured undergraduate medical and physiotherapy students in disability, paediatrics and research; and, early in her career, worked as a physiotherapist in rural and remote parts of Western Australia.

In 2000, Paula completed a Masters in Public Health degree at the University of Western Australia. Since this time Paula has combined the roles of manager and researcher, facilitating many innovative service improvement initiatives within the disability field.

Paula has undertaken several pieces of qualitative and quantitative research, and has published a number of reports and articles in national and international peer reviewed journals.

Currently Paula is working with the Telethon Institute of Child Health Research on a range of different pieces of research work related to disability and policy development. Paula leads the teaching and research arm of WiZe Therapy and has completed a number of reports and projects for various organisations as a private consultant over the last two years.

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This report has been re-printed to correct an error in the estimate of the total target group for the Senses Foundation: estimate being corrected from 37,900 people to 29,100 people. As a result of the methods by which the data was able to be extracted from the SDAC, the two clients groups (those with a vision impairment and additional disabilities and those with both a hearing and vision disability) were not mutually exclusive with the second group being a subset of the first.

## **Executive Summary**

In 2004 Senses Foundation undertook a major review of its strategic direction and developed a Strategic Plan for the five years 2005 – 2010. In doing this it refined the definition of its clients, their geographic distribution and their age from the very narrow focus which it had held previously, to a considerably larger target population.

The following recommendations were endorsed by the Board of Senses Foundation and include:

- Senses Foundation defines its client group as “people who are blind with additional disability and deafblind”;
- No restrictions in regard to eligibility for services related to the manner in which a person becomes blind or deafblind. A person may be congenitally vision impaired or deafblind, or acquire a vision impairment or deafblindness as a result of disease, injury or ageing;
- Senses Foundation provides services to people from birth to death; and
- Senses Foundation provides services to eligible clients throughout Western Australia.

### **The Project Imperative**

One in every five Western Australians has a disability, that is, 405,500 people. Approximately three quarters of these people report physical disability as their main disabling condition. Findings from the Survey of Disability, Aging and Carers indicated that 9,100 people in Western Australia reported having ‘disease of the eye and adnexa’ as their primary disability and 32,500 reported having ‘diseases of the ear and mastoid process’ as their primary disability (Australian Bureau of Statistics 2004). There is no report of the number of people with deafblindness as a primary disability.

In beginning to implement the new strategic plan, Senses Foundation was unaware of the number of people in Western Australia who were likely to fall within their new broader target population. Therefore, this project aimed 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 used existing population based statistical data to determine key outcome objectives related to the new target population for Senses Foundation. This approach is described in detail in the body of the report, however it essentially 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 two target client groups for Senses Foundation in the following ways:

	<b>Population</b>	<b>SDAC categories included</b>
(1)	Vision impairment with additional disabilities (not deafblind)	People with a disability who have a vision disability (from screening questions or reported long term health condition) PLUS at least one other disability group: intellectual, psychiatric, acquired brain injury, physical/diverse or speech.

(2)	Deafblind only, and deafblind with additional disabilities	Identified from screening questions, this includes people with a disability who have: A) <i>at least</i> partial loss of sight and <i>total</i> loss of hearing; and B) <i>at least</i> partial loss of hearing and <i>total</i> loss of sight; and C) <i>partial</i> loss of hearing and <i>partial</i> loss of sight.
		<b>CSTDA Categories</b>
(1)	Vision impairment with additional disabilities (not deafblind)	People identifying as having a vision disability and at least one other disability group (not including hearing).
(2)	Deafblind only, and deafblind with additional disabilities	People identifying as having a deafblind disability (with and without additional disabilities)

The project resulted in a range of outcomes and findings related to the two key target client groups: those individuals with a vision impairment and additional disabilities and those who have both a vision and hearing disability.

Twelve key findings were determined in relation to demographic variables such as number of people, geographical location, age and gender, level of disability and service usage in the two disability groups. In some of these variables the data was limited in the level to which it could be reported due to small numbers and high standard errors, however baseline data in all of the outcomes of interest were determined.

### ***Key Finding 1***

In 2003, 8,800 Western Australians indicated they had the dual disability of vision and hearing loss. For those individuals who were using CSTDA funded services, 181 indicated they were deafblind.

### ***Key Finding 2***

In 2003, 29,100 people living in Western Australia indicated they had a vision impairment and additional disabilities. Seven hundred and fourteen individuals using CSTDA funded services had a vision impairment and additional disabilities.

### ***Key Finding 3***

In 2003, the population of Western Australia was 1, 947,700; the target population for Senses Foundation making up 1.5 per cent of the total population.

### ***Key Finding 4***

The two key client groups comprising the target group for services for Senses Foundation make up 1.3% (n = 18,000) of the Perth metropolitan population (n = 1,371,700) and 1.9% (n = 11,100) of people living in country areas of Western Australia (n = 576,000). A greater proportion of people with the dual disability of hearing and vision loss live in the Perth metropolitan area (74%) compared to those with a vision impairment and additional disabilities (62%).

### ***Key Finding 5***

Almost 40% (n = 11,100) of those with a vision impairment and additional disabilities live in country areas of Western Australia, 25% of these people living in areas classified as outer regional or remote parts of Western Australia. Six per cent

of those individuals using CSTDA funded services were of Aboriginal or Torres Strait Islander origin.

### ***Key Finding 6***

For the two key client groups of people in Western Australia who have hearing and vision disability and those with a vision impairment and additional disabilities, the greatest numbers were found in the older age groups with 63% (n = 18,300) of individuals being aged sixty years or older. The users of CSTDA funded services in Western Australia who have a vision disability and additional disabilities and who were deafblind were primarily children, adolescents and young adults.

### ***Key Finding 7***

For people in Western Australia with a vision impairment and additional disabilities there was little difference in the numbers of males (54%, n = 15,800) and females (46%, n = 13,300) making up this client group. The distribution was different for people with hearing and vision impairments, with a greater proportion of males (63%, n = 5,500) reporting this type of disability compared to females (37%, n = 3,300), and this was most marked in older adults. This dominance of males was not reflected among the children and young adults who are deafblind using CSTDA funded services, with more females (54%) than males (45%) under the age of 24 years using services.

### ***Key Finding 8***

Overall, approximately half of the people in the target client groups have a profound or severe disability. In addition, half of the people in both disability types reported that they needed help with more than one core activity, and that this help was required on a daily basis.

Forty four per cent of those with a vision impairment and additional disabilities and 48% of those with a dual sensory disability reported having a profound or severe level of disability.

For the client group with a vision impairment and additional disabilities, the proportions of people reporting a profound or severe limitation increased substantially with age. However, it should not be concluded that most of those in the target group reporting a profound disability were in the oldest age groups. For example, among those individuals 60 years and older, half reported a profound or severe disability and half reported a moderate to mild disability.

### ***Key Finding 9***

The high levels of disability among the two target client groups was 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 seven life activities. For those individuals with a vision impairment and additional disabilities, the life areas of education (50%), self care (47%) and community and civic life (48%) were those recording the highest proportions of individuals indicating they always needed help or were unable to do this activity. Higher proportions of those in the younger age groups (0 to 24 years) reported needing greater levels of assistance than those in the 25 to 59 age group, and this was true for all life areas.

For those individuals who are deafblind, the life areas of education (69%), community and civic life (58%), self care (54%) and working (54%) had the highest proportions of individuals indicating they always needed help or were unable to do this activity.

### ***Key Finding 10***

In the two key client groups of interest, for those aged between 15 years and 64 years, at least half reported they had either profound or severe participation restrictions related to employment. There were, however, marked differences in the two groups. For those with a vision impairment and additional disabilities, 28 % reported having no employment restriction compared with approximately one tenth of individuals with the dual sensory disability of vision and hearing loss.

### ***Key Finding 11***

Approximately 70% of individuals making up the two target client groups used more than one type of service group over the 12 month period of interest. The proportions within both groups, relative to the total users of that particular service type, indicate that these two clients groups make up higher proportions of users in accommodation, respite and community access services. However, when looking at the raw numbers actually using services who are deafblind or have a vision impairment and additional disability, community support is by far the greatest service type accessed. Those in the younger age groups were found to make the most use of community support services which include therapy and local area co-ordination services.

### ***Key Finding 12***

When describing the amount or quantity of CSTDA funded services used by the two target client groups, those with a vision disability and additional disabilities reported slightly higher median hours of service in a typical week per outlet (seven hours) than those with a deafblind disability (four hours). Accommodation support service provided the highest mean number of hours of service in a typical week per outlet and community support the lowest mean hours per outlet.

## Conclusion

This project aimed to identify people in Western Australia who may fall within the newly defined parameters of the client group for Senses Foundation. The use of national databases recording data related to individuals with disability within Australia were a successful source of relevant data, particularly when the target populations were specifically defined as they were in this project. Demographic data related to the two disability groups, people with a vision impairment and additional disabilities and those with a vision and hearing disability or deafblind, was obtained. Twelve key findings were determined in relation to demographic variables such as numbers of people, geographical location, age and gender, level of disability and service usage in the two disability groups. In some of these variables the data was limited in the level to which it could be reported due to small numbers and high standard errors, however baseline data in all of the outcomes of interest was determined.

In the project brief, from anecdotal and existing database evidence, Senses Foundation estimated there '*could be* over 5,000 people who are blind with an additional disability or deafblind in Western Australia'. The outcomes of the project have determined that there are substantially more than 5,000 people in Western Australia who fall within the two key target client groups of Senses Foundation: 29,100 people have either a vision impairment and additional disabilities or the dual sensory disability of hearing and vision loss or are deafblind.

Given the projected increase in the number of older Australians in coming years, and the increased incidence and prevalence of a range of conditions contributing to the disability types of Senses Foundation target client groups, these numbers can only be expected to increase in the future.