DISABILITY CARE AND SUPPORT, DRAFT INQUIRY REPORT
RESPONSE FROM SENSES FOUNDATION,
WESTERN AUSTRALIA

Senses Foundation wishes to congratulate the Federal Government for its commitment to developing a National Disability Strategy to "enhance the quality of life and increase the economic and social participation for people with disability and their carers". Senses Foundation is absolutely supportive of this initiative.

Senses Foundation also recognises the considerable work undertaken by the Productivity Commission in its deliberations and in developing the Draft Report and congratulates the Commission for taking such bold steps rather than dealing with the many issues associated with the funding and provision of services for people with disability in a piecemeal fashion.

While supporting many of the Commission's major recommendations, Senses Foundation is keen to ensure that the needs of people who are deafblind in Western Australia are understood and met in the final strategy. Senses Foundation has some comments and concerns relating to the proposed NDIS as a whole and relating to the specific services required by people who are deafblind. These are provided below.

The proposed NDIS as a whole

The Disadvantage of Equity between States

While many States may have had limited services development for people with disability, Western Australia has had significant annual growth in disability funding over many years. This has led to a number of excellent services being available for people with disability. Senses Foundation is keen to see the NDIS ***build on*** rather than replace what is available for people with disability in Western Australia, particularly enabling an increase in the amount of service available and an increase in the choice of service available.

Senses Foundation is concerned that the proposed NDIS could provide an equitable service to people with a disability across Australia and inadvertently reduce the current amount and choice of service for the person with disability in Western Australia.

A Federal System vs a State System

There is a perception that West Australians "do better" under a State system than they do under a Federal system. There is also a perception that there is more flexibility under a State system than a Federal system. There is a perception that a State system can be better designed with local knowledge to meet the needs of West Australians than a Federal system. Finally, there is the reality that addressing issues with any system is easier if you can do this at a State level than having to travel to Canberra for policy discussion.

For all of these reasons, Senses Foundation is keen to see a strategy that generates its funding federally, set national benchmarks, and develops assessments and outcome measures nationally, but is administered through State disability bodies for example the Disability Services Commission.

Senses Foundation is concerned that the proposed NDIS may not have the flexibility and accessibility to meet the needs of the person with disability in Western Australia.

Understanding Deafblindness

Senses Foundation is concerned that, while the Commission may have a good understanding of the needs of many people with disability, the Commission may not have a good understanding of deafblindness and its impact and may inadvertently limit their access to appropriate assessments and services.

The Australian Deafblind Council defines deafblindness in the following way:

'deafblindness is a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialization, mobility and daily living'

The population of people with deafblindness has received little research attention from either a national or international perspective. In developed countries the incidence of deafblindness is described as being 20 per 100,000 people. Theoretically then, this means that currently in Australia 4,087 people (0.02% of the total population) are deafblind.

However, in a 2007 study in Western Australia which was commissioned by Senses Foundation and undertaken by Paula Dyke of the Telethon Institute for Child Health Research quite a different incidence was identified. Given the suggested incidence in developed countries the researcher expected to identify 386 individuals with deafblindness. However, the study identified 8,800 people. (Unseen and Unheard, 2007)

Of these people,

- 2288 live in rural and remote Western Australia
- Only 181 indicated that they are currently receiving any formal disability services
- Approximately half have a profound or severe disability
- Half reported that they needed help with more than one core activity, of self-care, mobility or communication, and that this help was required on a daily basis.

People with deafblindness require services which are different from those designed specifically for people who are either blind or deaf.

Although deafblindness is a low incidence disability, many people have high support needs across many areas. People with deafblindness are frequently described as being far from homogeneous with many of the needs of the people who have congenital deafblindness being quite different from those who have acquired deafblindness. While it is thought that the latter group are greater in terms of numbers, those born with a vision and hearing disability tend to have more associated significant disability such as physical and intellectual disabilities.

The causes of deafblindness, classified under the two categories of congenital and acquired deafblindness, are varied and changing in both incidence and prevalence.

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
- CHARGE syndrome.

Acquired deafblindness can result from:

- Illness such as meningitis
- Infections such as encephalitis
- Brain tumour
- Head injury
- Ageing
- Usher syndrome can also be described as a form of ‘acquired deafblindness’.

Deafblindness also significantly increases morbidity and mortality.

- Deafblind babies and children are at risk of not receiving sensory and other stimulation vital to their normal development which increases the risk of intellectual disabilities and limits their normal development
- Adults with deafblindness have decreased mobility, and increased amount of falls, hip fractures, Osteoporosis, stroke, heart disease and arthritis
- Deafblindness causes reduced cognitive processes such as memory, and increased states of confusion and depression
- Older people with deafblindness report poorer health than older people with solely a hearing impairment or solely a vision impairment
- Functional problems increase, eg. difficulties getting out in the community is increased by 4.7 times in older people with deafblindness compared to the normal older population; difficulties getting out of bed

increases by 3.8 times; difficulties with cooking increases by 4.7 times and difficulties with the administration of medicine increases by 4 times
- Mortality rates for people who are deafblind are increased between 1.6 to more than 3 times.

Indigenous people are more at risk of having deafblindness:
- Indigenous women in rural and remote communities have inadequate immunity to the rubella virus
- The prevalence of foetal alcohol syndrome is estimated to be 0.02 per 1,000 for non-Aboriginal children and 2.76 per 1,000 for Aboriginal children
- Prematurity is more common in Indigenous babies
- Higher rates of diabetes mellitus have been demonstrated in Indigenous populations
- In Indigenous communities the prevalence of trachoma remains high, with reported rates in children ranging from 55% in the Pilbara and 40% in Central Australia.

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.

However, given the increased incidence and prevalence of a range of conditions contributing to deafblindness, these numbers can only be expected to increase in the future.

Comments regarding Specific Recommendations

Draft Recommendation 3.1

Programs benefiting people who are deafblind but not provided directly to the person who is deafblind

Senses Foundation is very supportive of the Commission’s initiatives of placing the funds in the hands of the individual person with a disability. However Senses Foundation has a program which is valued by the current recipients but which it is not sure could be funded under the proposed NDIS. This program is as follows.

Specialist deafblind communication education, training and resources

Senses Foundation provides specialist communication education, training and resources to benefit children with deafblindness and their families, carers and service providers living in rural and remote Western Australia. It provides education and training to health care workers and educationalists working with indigenous communities. Currently Senses Foundation provides this service in the Wheatbelt, the South West, the Mid West, the Pilbara, the Kimberley, the Great Southern and in the Goldfields Esperance region.

The needs of children who are deafblind are unique and individual and service providers, families and carers require highly specialised training in order to maximise outcomes for these children.

The objectives of this Senses Foundation program are:

- To increase knowledge and skills of service providers working with children who are deafblind or vision impaired with an additional disability in the region;
- To provide resources and training to assist children who are deafblind or have a vision impairment with additional disabilities and their families and carers that maximises their life outcomes;
- To train and educate key health care workers in the Indigenous communities of the region in the causes of deafblindness and vision impairment with additional disabilities; and
- To develop key links with local stakeholders in the region, including key personnel within the local Indigenous communities.

Feedback received suggests that this is a highly valued service.

Senses Foundation is concerned that education, training and resources programs such as this, which do not have the person with a disability directly involved, will have no means to be funded under the proposed NDIS.

Draft Recommendation 3.2

Early Intervention for People who are Deafblind

Senses Foundation would imagine that children born with deafblindness would fall easily into the group described in Recommendation 3.2

- *“be in an early intervention group, comprising*
    - *those for whom there was a reasonable potential for cost effective early therapeutic interventions”*

However we are concerned that people with Usher’s Syndrome should also fall into this early intervention group but they would not easily do so given the current definitions.

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. There are 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. The prevalence in the United Kingdom of typical Type 1 and Type 2 cases is 5.3 per 100,000; higher than in other international population based studies. 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.

The diagnosis of Usher Syndrome is devastating. As their field of vision deteriorates, the person with Usher has difficulty with their communication as it becomes increasingly difficult to see sign language or lip read. They also have increasing difficulty with all their activities of daily living including personal care, home management, shopping, mobility and transport, and continuing with their employment. They can feel isolated, not just from the hearing, sighted world but also from their family and friends.

Senses Foundation currently provides a range of services to people who have Usher syndrome including mobility training, training with home management activities, employment support and social and emotional support.

Senses Foundation trusts that people with Usher‘s syndrome would be considered eligible for early intervention services.

Senses Foundation is keen to ensure that people with Usher Syndrome are considered eligible for early intervention services under the proposed NDIS.

Draft Recommendation 4.1

Reasonable and Necessary Services for People Who are Deafblind

Senses Foundation is concerned by the words “reasonable and necessary” in this recommendation and seeks to ensure that the Commission understands the support services needed by the person with deafblindness which would not necessarily appear obvious to a person not working in this specialist area.

As stated earlier, deafblindness is described as a unique and isolating sensory disability resulting from a combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living.

In this definition deafblindness is described, not in terms of sensory impairment, but as the functional impact a combined hearing and vision loss has on an individual's life. The interaction of both a hearing and vision loss can have considerable consequences in the areas identified and it is these functional limitations that require the involvement of speech pathology, physiotherapy, occupational therapy, social work and clinical psychology. These services are important for the individual throughout their childhood and into adulthood.

A paper by Kirralee Lewis (1998) titled "*Congenital Deafblindness: Aetiologies of Deafblindness and Implications for Communication*" outlines the developmental issues associated with a child born deafblind. She comments that the human being is born social. Babies are more attentive to social stimulation. For babies without sensory disabilities, learning opportunities are ideal as the learning is based on the child's own activities and the responses are instant. Babies with deafblindness show little activity which can be interpreted, and any activity which does occur, can be unusual and unexpected. Babies who are deafblind are less awake because they are less stimulated by visual input, they cry less and move their limbs less. When babies who are deafblind cry less than other children, they are deprived of the attention from the care givers and the learning opportunities which go hand in hand with this interaction. The child who is deafblind is at risk of not being able to initiate social interaction and give rewarding feedback due to the sensory impairments. For example smiling, giving eye contact, being comforted through visual and sound stimulations such as seeing and hearing their mother's face and voice.

The importance of early intervention has been well established but providing early intervention service to infants who are deafblind and their families is complicated. 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. Children with deafblindness require specialised services, including alternative modes of communication, functional sensory input and orientation to the world around them. Senses Foundation recommends that a seamless, comprehensive, multi-disciplinary, coordinated, family oriented system of early intervention be provided to children who are deafblind.

As the child with congenital deafblindness becomes older, these therapy supports need to continue, due to the complex nature of this unique disability. At times of transition from lower to upper school and from education to vocational or alternatives to employment services, the need for therapy support is even greater.

For older children, young adults and middle-aged adults, who acquire deafblindness as a result of injury or disease, support from the speech pathologist, physiotherapist, occupational therapist and social worker is essential. Without support from these services, individuals who have acquired deafblindness lose their independence and ability to participate in vocational, social and recreational activities, due to impaired ability to communicate, move around in their environment and receive information they can understand. As there is a strongly association with depression in people who have acquired deafblindness, clinical psychology is also an important service that should be available to older children and adults who are deafblind.

Senses Foundation seeks to ensure that the Commission understands the "reasonable and necessary" services needed by the person with deafblindness.

The Opportunity to Introduce New and Innovative Services

Senses Foundation is very supportive of the Commission's initiative to support the development of "innovative support measures" and is keen to ensure that the proposed NDIS has the ability to accommodate new support measures which are identified through this recommendation where their effectiveness can be empirically substantiated.

Senses Foundation is currently engaged in a pilot project to explore the impact of specialised support in the form of Communication Guides. Currently there are a number of countries providing this specialised support to people who are deafblind however no program has yet been established in Australia.

International programs have demonstrated that this specialised intervention, even at limited levels each week, can reduce isolation, increase independence and reduce the likelihood of premature admission to institutional care for people who are deafblind. In a number of countries outside Australia, people who are deafblind 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, in Canada they are Interveners and in Western Australia we are calling them Communication Guides. These people are specifically trained to be aware of the issues related to deafblindness and to work with the person to be the link between them and the community, thus minimising isolation, and teaching the skills required for ongoing independence. This role is not to develop independence with an aim to then remove support, but to support this ongoing need.

If Senses Foundation can substantiate the effectiveness of Communication Guides in improving the wellbeing of people with deafblindness, Senses Foundation wishes the proposed NDIS to have the flexibility to accept the introduction of Communication Guides as a reasonable and necessary service for the person with deafblindness.

Senses Foundation is keen to ensure that the proposed NDIS has the flexibility to accommodate and fund new support measures where their effectiveness can be empirically substantiated.

Draft Recommendation 4.4

Many of the interventions in the disability sector are not substantiated by clinical evidence. Most would be based on historical precedence. In the area of deafblindness, there is a paucity of literature and well-designed research on both the epidemiology of deafblind disabilities and effective assessment, interventions and outcomes.

Senses Foundation has funded its own study identifying the number, location, age and level of disability of people who are deafblind throughout Western Australia. Senses Foundation is also undertaking research into the impact of Communication Guides on a number of wellness measures for the person with deafblindness.

Senses Foundation is keen to see an opportunity for further funding of research on both the epidemiology of deafblind disabilities and effective assessment, interventions and outcomes under the proposed NDIS.

Draft Recommendation 13.3

Senses Foundation acknowledges that the Commission seeks to support carers with this recommendation and welcomes this. However Senses Foundation is concerned that sibling support programs such as the following, are not covered in this recommendation.

<u>Sibling Support</u>

The longest lasting relationship in a family is a sibling relationship. Senses Foundation believes that if typically developing siblings are supported as they grow up, the chances they will elect to remain lovingly involved with their sibling as adults, is increased.

Throughout their lives, the brothers and sisters of children with disabilities will share many of the same concerns their parents will experience for their sibling with a disability, as well as issues that are uniquely theirs. Among the concerns mentioned by parents, and siblings themselves include feelings of isolation, guilt, resentment, jealousy, anger, embarrassment, worry about their sibling, perceived pressure to achieve, increased care giving demands and concerns about their role in their sibling's future.

Senses Foundation currently provides a program, directed by professionals with expertise in the specialist area of deafblindness, to address the special needs and concerns of siblings who have a brother or sister with such a unique disability.

The outcomes of such a programs are positive and multifaceted, ensuring:

- support for the well being of the sibling;
- better life and future for the child with a disability – having sibling needs addressed, bonds between siblings and the child with the disability are

enhanced due to a greater understanding of siblings, having less resentment and less cause to compete for parental attention; and

- parental reassurance, regarding enhancement of lifelong relationships between brothers and sisters including the child with the disability, to achieve and safeguard a good life for their sons and daughters with disabilities and to facilitate the capacity of siblings to support each other.

Feedback received suggests that this is a highly valued service.

Senses Foundation is concerned that sibling support programs, which do not have the person with a disability directly involved, will have no means to be funded under the proposed NDIS or that the family will be required to choose between services for the child with a disability or support for their siblings, if they wish to participate in program such as this.

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