Senses Foundation Submission to the
Community Development and Justice Standing Committee
INQUIRY INTO THE ADEQUACY OF SERVICES TO MEET THE DEVELOPMENTAL NEEDS OF WESTERN AUSTRALIA'S CHILDREN

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Executive Summary

Currently the services available to children 0- 3 years who are **deafblind** are fragmented. This unsystematic approach results in duplication of services, power struggles between service providers and lack of consistency in intervention strategies, which is detrimental to the developmental outcomes for these very disadvantaged children. This paper recommends that services be amalgamated under Senses Foundation.

Deafblind Service Providers 0-3 years

Senses Foundation

Senses Foundation provides an Early Intervention program to children from birth to 6 years who are deafblind. This program provides a comprehensive therapy service to the children and their families including Speech Pathology, Occupational Therapy, Physiotherapy and Social Work, with Clinical Psychology available.

Senses Foundation also provides a Deafblind Specialist Communication program, which is a state-wide service that uses a consultative model to develop communication with people who are deafblind, their families and

carers. Training is also provided to external organisations and other health professionals working with people who are deafblind.

Department of Education and Training

Within Western Australia, services are also provided to deafblind children from birth by the Deafblind Visiting Teachers from the Western Australian Institute of Deaf Education (WAIDE), a directorate of the Centre of Inclusive Schooling (CIS), under the Department of Education and Training portfolio. The Deafblind Visiting Teachers provide educational and communication support to children who are deafblind.

Developmental Issues for a Deafblind Child

Holte et al., (2006, pp. 214) state that "When both hearing and vision are simultaneously reduced, the net effect dramatically affects the child's overall development of cognition and communication, as well as other vital functions."

A paper by Kirralee Lewis (1998) titled "*Congenital Deafblindness: Etiologies of Deafblindness and Implications for Communication*" outlines the developmental issues associated with a child born deafblind.

The human being is born social. Babies are more attentive to social stimulation. For normal babies, learning opportunities are optimal because 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 have the appearance of inactivity as the expression of high attention level while listening. This is easily mistaken for passivity and lack of attention and interest. 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 are embedded in this.

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, eg smile, give eye contact, be comforted through visual and auditory stimulations. By 6 months of age, a normal child acquires motor skills to assist with exploration of the world and as a result, expand his space of interaction. When the child who is deafblind does not do this, his motor and cognitive development will be delayed. Interference with the baby's development pattern will affect the social, emotional, cognitive and language development. Structuring the child's environment, activities, time and localities can be effective and necessary for their development. It can prevent the development of stereotyped, self-injurious or aggressive behaviour. Structuring is a way by which the person who is deafblind can increase his feeling of security. As the world becomes more ordered, the child who is deafblind can find cues and references to assist with interaction. As a result, the possibilities for communication increase.

In working with people who are deafblind, it is necessary to prevent or solve problems in the areas of communication, access to information and orientation and mobility. It is through communicating with the surrounding, exploring and moving freely that an individual gains understanding of it. A person's relationship or interaction with the world will be dysfunctional and will not be able to increase in understanding if communication, information, orientation and freedom of movement are deprived.

Most mothers of children who are deafblind comment that they lack or have poor contact with their baby. This is apparent through the lack of adult-child interaction, which as a result affects dialogue. Dialogue structure like mutual imitation, turn taking and give and take are very dependant on both vision and hearing. These patterns are the basic prerequisites for social communication. The dialogue between a person with deafblindness and their care giver will typically depend on the care giver. The role of the care giver is to facilitate the discovery of the world on all levels by the person who is deafblind, from basic reflex behaviour through to the most advanced communication with the

environment.

In the development of spoken language, hearing is first and foremost. Hearing can help in establishing contact, increase comprehension of a message and guarantee security for a person who is deafblind when exploring. Normally, hearing is functioning at birth, and is even reported to be functional in utero. Soon after birth, the connection between auditory and visual input can be made and the baby can direct its glance towards the sound source. A baby who is deafblind with some residual hearing will use auditory input to establish contact, eg a slight turning of the head, ceased motor activity, quietness, changes in breathing, movements of the mouth and fingers, etc. Often the signals may be delayed, so the care giver needs to be aware of the adequate reaction that the child displays when he hears a sound. It is important to give the child multiple experiences with sound to establish and use auditory input as other cues. Sound can be used to establish a common focus of attention, if it is made meaningful and distinctive. Verbal communication will never be the only medium, it is important to support communication with other communication methods, eg sign.

Vision is important for many activities which are interpreted as communicative behaviour, eg eye contact, glancing, smiling, grasping, crawling towards a person/object, etc. When a child initiates interaction, vision serves two purposes; as an indicator of interest, and for stimulus perception to trigger child activity. It is estimated that 70-90% of the child's activity is related to vision. Little visual input and few vision related signals make passivity an essential problem when the baby does not see. It is important to use special methods to create spontaneous activity. For the child who is deafblind, hearing and visual aids help use any residual capacity, in additional to this, vibratory stimulation becomes important. The child needs extra cues and more time to process the information.

Communication is often delayed in a child who is congenitally deafblind. Some may develop a level of competency with functional sign language and supplement it with other symbolic systems (eg objects of reference). Those

with additional physical and intellectual disabilities may rely totally on non-symbolic communication methods, or a combination of both.

Deafblind Children and Specialist Early Intervention Services

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).

Amalgamation of Deafblind Early Intervention Services under Senses Foundation

"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 be 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.

Senses Foundation is the primary services provider and advocate for people who are deafblind. Senses Foundation has its origins 111 years ago as the Royal W.A. Institute for the Blind. In 2001, the Royal W.A. Institute for the Blind amalgamated with the W.A. Deafblind Association to form Senses Foundation. Senses Foundation has proven itself to be an important organisation providing valuable services to West Australians. Senses

Foundation has a budget of $4,500,000 per annum and generates almost 20% of this through its own fundraising.

Senses Foundation has strong links internationally with other providers of service to people who are deafblind. Senses Foundation was recently successful in obtaining the Secretariat for Deafblind International, the global organisation that promotes services and advocacy for people with deafblindness. Through this role and the links that have been established, Senses Foundation is able to determine world's best practice in terms of intervention, assistive technology and service delivery to people with deafblindness. Senses Foundation also hosted the National Deafblind Conference in 2002, and the 14th Deafblind International World Conference in Perth in 2007.

Senses Foundation's Early Intervention and Specialist Communication programs are family-centred services that are staffed by therapists and other staff who have specialist knowledge in deafblindness. They are able to provide interventions to assist in all aspects of the development of a child who is deafblind, including their communication needs.

Senses Foundation is also able to support the entire family of a child with deafblindness. A respite service is available to allow parents to take a break from their caring role. This service strengthens and maintains the capacity of families to provide ongoing support and care for their family member with deafblindness. A Sibling Support program is also offered to brothers and sisters of child with deafblindness, and provides strategies for coping, a chance to discuss their issues with other children in a similar situation, all in a fun and activity based environment. Additionally Senses Foundation is able to access equipment that children with deafblindness require, such as wheelchairs, voice output devices, potty chairs, hoists and standing frames, through various Government schemes,.

The 1.7 FTE Deafblind Visiting Teachers from the Department of Education and Training state that they have a very narrow focus with the deafblind

child, their communication. The Deafblind Visiting Teachers have training in either Deafblind Education, Deaf Education, Vision Education, Special Education, Early Childhood Education or Secondary Education. As their qualifications indicate, they are trained in education practices and theories. Here in Western Australia and in most other developed countries, education does not commence for the child until 4 years of age. These teachers do not possess the relevant skills, even in the area of communication, to provide effective, evidence-based assistance to children 0-3 years.

With a small cohort of children 0-3 years with deafblindness in Western Australia and limited resources available to support these children, a centralisation of funding and services with Senses Foundation would ensure better developmental outcomes for these children.

Deafblind Definition and Causes

There are a range of disabilities present in the Australian population, including sensory, physical, mental and intellectual from a range of conditions. Deafblindness is one of the most isolating disabilities for our population.

Deafblindness can be described as “a unique and isolating sensory disability resulting from the combination of both a hearing and vision loss or impairment which significantly affects communication, socialisation, mobility and daily living” Australian Deafblind Council (ADBC) 2004.

Deafblindness does not mean having no vision and no hearing, rather degrees of vision and hearing impairment. The main causes for a combined hearing and vision loss or deafblindness in children 0-3 years of age are:

- CHARGE Syndrome
- Prematurity
- Congenital Rubella Syndrome
- Fetal Alcohol Syndrome
- Down syndrome
- Leber's Congenital Amaurosis
- Turner syndrome
- Leigh's Disease

- Maternal Drug Use
- Meningitis
- Cytomegalovirus
- Severe Head/Brain Injury
- Goldenhar Syndrome
- Batten Disease
- Hunter Syndrome
- Pallister Killian Mosaic Syndrome
- Prader-Willi
- Sturge-Weber syndrome
- Congenital Syphilis
- Plus others

Senses Foundation is committed to people who have deafblindness and would welcome the opportunity to provide additional information should the Committee require it.

References

Chen, D. (1992), *Early Intervention*. National (USA) Symposium on Children and Youth Who Are Deaf-Blind.

Chen, D., Alsop, L. & Minor, L. (2000), L*essons from Project PLAI in California and Utah: Implications for Early Intervention Services to Infants who are Deaf-Blind and Their Families*. Deaf-Blind Perspectives, 7(3), pp. 1-5.

Holte, L., Prickett, J.G., Van Dyke, D.C., Olson, R.J., Lubrica, P., Knutson, C.L., Knutson, J.,F., & Brennan, S. (2006), *Issues in the Evaluation of Infants and Young Children who are Suspected of or who are Deaf-Blind*. Infants and Young Children, 19(3), pp. 213 – 227.

Lewis, K. (1998), *Congenital Deafblindness: Etiologies of Deafblindness and Implications for Communication*. Renwick College Winter School on Deafblindness paper.

Michael, M.G. & Paul, P.V. (1991), *Early Intervention for Infants with Deaf-Blindness*. Exceptional Children, 57(3), pp. 200-210.