

Submission
No 80

**INQUIRY INTO SERVICES PROVIDED OR FUNDED BY
THE DEPARTMENT OF AGEING, DISABILITY AND
HOME CARE**

Organisation: The Shepherd Centre

Date received: 6/08/2010

Partially Confidential

The Shepherd Centre response to the: Inquiry into services provided or funded by the Department of Ageing, Disability and Home Care

The Shepherd Centre (TSC) would like to thank the Standing Committee on Social Issues for the opportunity to respond to the Terms of Reference of the above inquiry.

Background

For the past 40 years, TSC has helped more than 1,500 infants and pre-school and school aged children who are deaf and hearing-impaired to learn to listen and speak through family-centred early intervention programs.

Our ultimate aim is to help every child reach their full potential by developing age-appropriate speech and language to enable them to attend a mainstream school by the time they are school aged.

TSC has an international reputation as a centre for excellence and has one of the largest number of accredited Auditory-Verbal Therapists of any Australian early intervention centre for children who are deaf and hearing impaired.

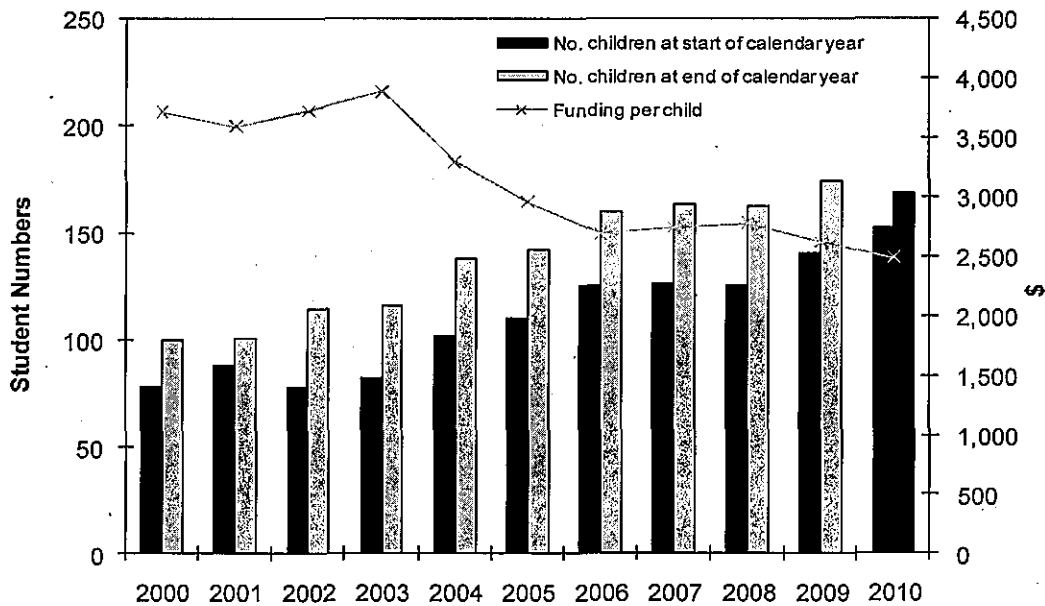
Latest data from our clinical outcomes shows that 90% of our children graduate from TSC and enter mainstream school by the time they are school aged. The vast majority of these children have communication skills on par with their hearing peers.

(Refer to our Outcomes data at **Attachment A**).

For further information on The Shepherd Centre see **Attachment B**. (**Attachment C** shows research-based evidence to support outcomes related to the delivery of early intervention services for permanent childhood hearing impairment).

(a) The historical and current level of funding and extent of unmet need

The Department of Ageing, Disability and Home Care (ADHC) currently provides TSC with \$450,000 for the financial year 2009/10 to support early intervention therapy to children with hearing impairments aged 0-6. TSC has enjoyed a long standing relationship with ADHC (previously DADHC) over the years and the funding calculation is based on the number of services delivered to families. At 16 July 2010, TSC had 168 families across NSW in our early intervention program. This does not include children in our introductory or school aged programs. Government funding has not kept pace with the number of families accessing TSC services. ADHC funding has increased by 32% over the past 10 years, while the number of families has increased by 238% over the same period.



PLEASE NOTE:

1. Data for the years 2000 to 2007 includes ACT numbers.
2. Data for the years 2008 – 2010 excludes ACT numbers.

The current cost per child per year to attend TSC's early intervention program is approximately \$12,000 excluding current government funding. At this stage TSC

receives no federal funding and other States' funding levels of early intervention for hearing impaired children is now well ahead of NSW and ACT.

(b) Variations in service delivery, waiting lists and program quality between:

i. Services provided, or funded, by ADHC

Over the years TSC has provided a multidisciplinary approach and today combines one on one Auditory-Verbal Therapy sessions, Audiology and Family Therapy sessions, weekly playgroups and parent support groups. If TSC is unable to access increased government funding, waiting lists will need to be introduced. Some services in NSW in this field have closed due to funding difficulties and some have had to face rationing or scaling down service provision. This is unsustainable over time.

The former Prime Minister and COAG have determined that every child born in Australia will have access to screening for congenital hearing impairment by the end of 2010. The World Health Organisation's standards require intervention services post screening.

All infants diagnosed with hearing loss at or after birth require access to effective and timely early intervention for early language and communication skills in addition to the services provided by Australian Hearing. Evidence based communication and language intervention needs to start in stages before the child is six months old.

Early Intervention communication skills to develop speech and language together with optimal aiding (hearing aids and/or unilateral or bilateral cochlear implants as medically indicated), must commence by three to six months of age for best results.

Recent researched evidence shows all children who have hearing aids or cochlear implants or both, make better progress if they get early intervention to assist language development. Latest data from TSC clinical outcomes shows that 90% of our children graduate from TSC and enter mainstream school by the time they are school aged. The vast majority of these children have communication skills on par with their hearing peers. (See Attachment A).

This has long term implications of cost savings of an estimated \$117.2M per year will be made in downstream education costs nationally (Access Economics Report, 2006) with NSW taking a large share of those savings.

The social and emotional costs to the individuals and their families are incalculable.

ii. ADHC Regional Areas

TSC provides residential workshops to families from rural and remote areas in NSW. This is an intensive week of therapy, audiology, family support, information and education sessions and provides families with services they can receive in regional areas. ADHC provides no funding to TSC for these workshops. These workshops include intensive sessions of therapy that could be supported by ADHC and relate usually to families from rural and remote locations who could not normally get access to such professional services.

(c) Flexibility in client funding arrangements and client focused service

delivery

TSC currently has a submission into the NSW Government's *Stronger Together Phase 2: A New Direction for disability services in NSW 2006-2016 June 2010*.

This submission proposes an increase in funding to support early intervention language and communication therapy services for children with hearing impairment aged 0-4 following Universal Newborn Screening.

The model proposed is similar to that of the Autism model of \$6,000 per child per year which enables the family to decide what early intervention pathway they wish to take ie spoken language or signing.

The service provided by TSC is family centred. Recognising parents are the primary educators of their child, TSC aims to teach the family the necessary skills to guide and teach their children spoken language

(d) Compliance with Disability Service Standards

TSC has policies for staff and families in place to adhere to the 12 Standards under the Disability Service Standards. These are reviewed annually. We meet all the criteria listed in the national Disability Agreement introduced by the federal government.

(e) Adequacy of complaint handling, grievance mechanisms and ADHC funded advocacy services

TSC has a range of policies for staff and families in place.

(f) Internal and external program evaluation including program auditing and achievement of program performance indicators review, and

TSC has undergone ADHC audits and worked with ADHC to ensure all program performance indicators have been addressed. This is an ongoing process. TSC undertakes ongoing analysis of outcomes (Attachment A), conducts regular parent surveys and evaluates feedback from exit interviews.

(g) Any other matters

Management at TSC has been made aware of apparent discrepancies between various funding levels across early intervention services. TSC believes that ADHC needs to have greater transparency around what basis funding is allocated as it appears that some organisations have been awarded larger sums than TSC has been granted, yet provide similar (if not lesser) services.

Without funding, TSC's early intervention services are at risk due to financial difficulties where fundraising is not keeping pace with client growth.

Families will demand access to appropriate services for their child following Universal Newborn Hearing Screening. The risk to newly diagnosed infants, their families and COAG policy, is that the sector will be unable to provide infants with access to appropriate early therapy pathways following a hearing loss diagnosis at/following birth. This means the government will not meet their obligations under World Health Organisation standards and the United Nations Convention of the Rights of People with Disabilities.

Attachment A

TSC's Outcomes

High quality outcomes for children have always been the focus for the clinical team at TSC. For over four years the team has been participating in the Language Outcomes for Children with Hearing Impairment (LOCHI) study, run by the National Acoustics Laboratory (NAL). Since beginning participation in the study, TSC has adopted a rigorous assessment procedure so the vocabulary and language outcomes of children in early intervention can be measured.

Clinicians at TSC have presented papers at both national and international conferences highlighting the results in the group of children that have been screened at birth and gone on to school called "From Screening to School". The sample now has 41 children.

Language Outcomes

Within the general population of children with normal intelligence, 84% will have normal language and vocabulary skills. The remaining 16% will have delayed vocabulary or language, even with normal cognitive ability and normal hearing. As a result, we would expect TSC's outcomes to mirror this normal distribution.

The graphs represent the vocabulary and language outcomes of children with a hearing loss at TSC who were diagnosed through the screening at birth and graduated from TSC in 2007, 2008 and 2009. The children represented in the data are those who have hearing loss only, with English as their first language and no known additional needs.

Vocabulary and Language Outcomes: From Screening to School

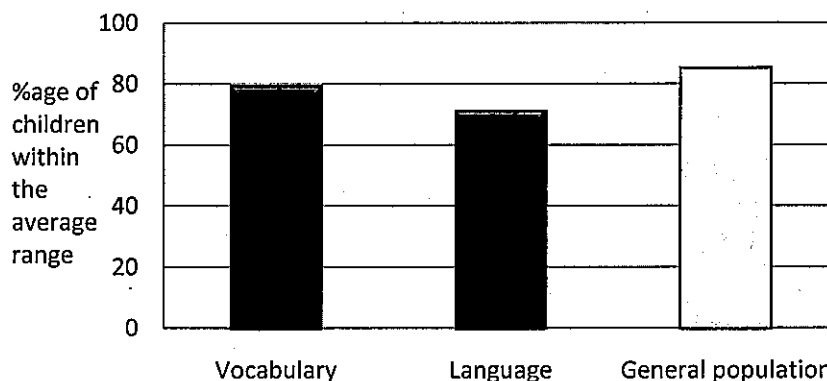


Figure 1: The percentage of children who scored within the average range for vocabulary and language in their graduating assessment, compared with the normal hearing population.

Vocabulary and Language Outcomes: From Screening to School

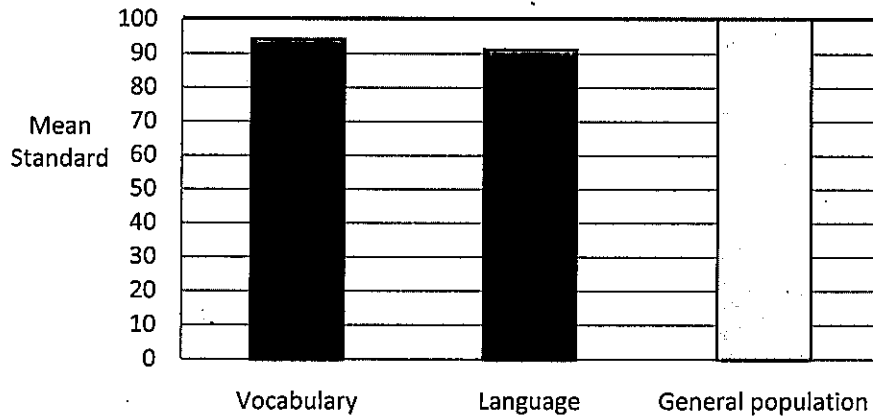


Figure 2: The mean standard score (indicated by the red line) for vocabulary, language and speech in their graduation assessment compared with the standard score for the normal hearing population.

Note the sample in Figures 1 and 2 is 19 as we have removed data for children for whom English is not the first language and children who have other disabilities.

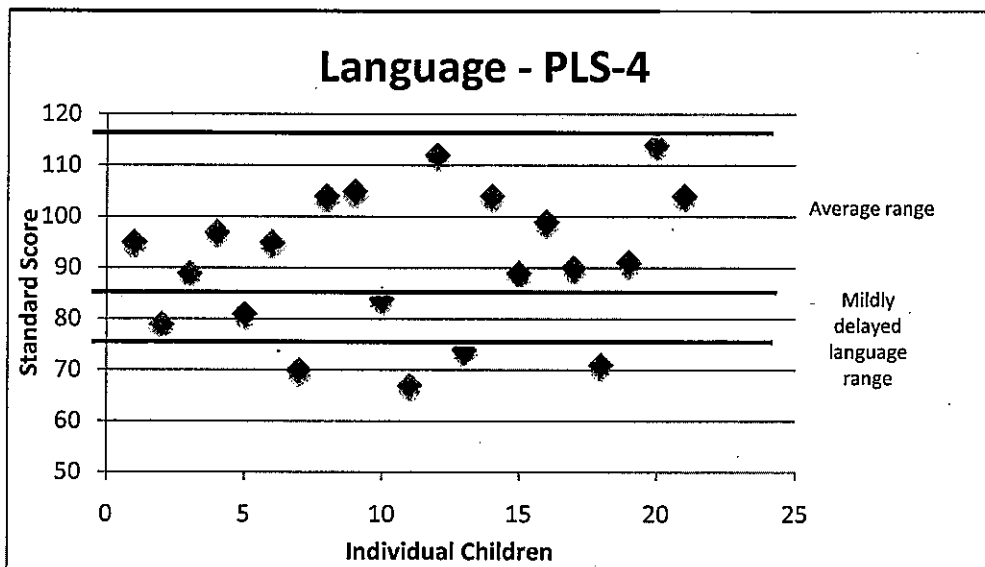


Figure 3: Graph representing the distribution of individual scores of children for language in their graduating assessment.

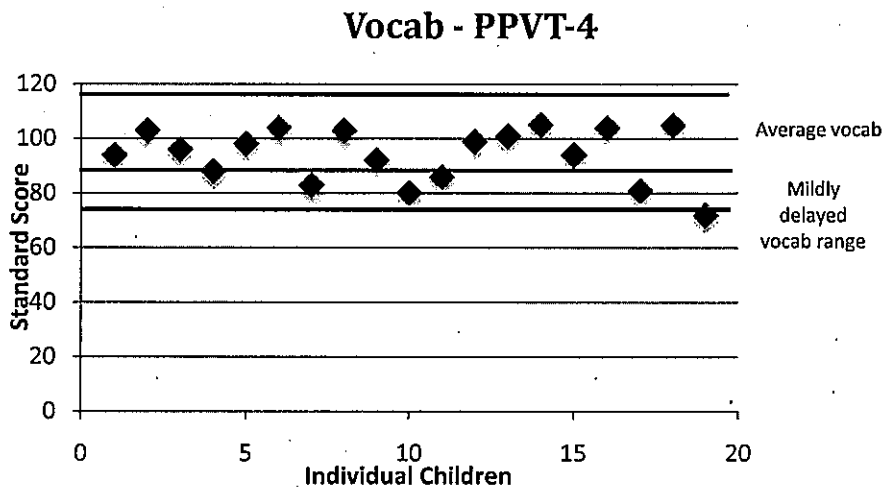


Figure 4: Graph representing the distribution of individual scores of children for vocabulary in their graduating assessment.

The results presented in Figures 1 to 4 indicate that children who received TSC's early intervention services are achieving results that are similar to those of their hearing peers. Notably, 80% of TSC children achieved vocabulary scores within the normal range when compared to their hearing peers (only 4% less than the general population). Whilst these children will require ongoing support services within the schooling systems, the level of support they require should be less than if they were entering school with significant language delays.

Speech Outcomes

Data on speech production is currently being collected however we are awaiting normative data based on the Australian population before interpreting and presenting on this information.

TSC will continue to test, analyse and report on its outcomes data.

Attachment B

ABOUT THE SHEPHERD CENTRE

About The Shepherd Centre

- For the past 40 years, The Shepherd Centre has helped more than 1,500 infants and pre-school and school aged children who are deaf and hearing-impaired to learn to listen and speak through family-centred early intervention programs.
- Our ultimate aim is to help every child reach their full potential by developing age-appropriate speech and language to enable them to attend a mainstream school by the time they are school aged.
- The Shepherd Centre has an international reputation as a centre for excellence and has one of the largest number of accredited Auditory-Verbal Therapists of any Australian early intervention centre for children who are deaf and hearing impaired.
- Latest data from our clinical outcomes shows that our 90 per cent of children graduate from The Shepherd Centre and enter mainstream school by the time they are school aged. The vast majority of these children have communication skills on par with their hearing peers.

Growing demand

- The number of families accessing The Shepherd Centre's services across five centres in NSW and ACT has grown from just five in 1970 to more than 250 today. In the last decade, enrolments in our programs have more than doubled.
- Families from remote and rural areas of Australian and overseas are assisted through an **annual residential workshop**, now in its 34th year. The Shepherd Centre has also begun a series of shorter regional workshops to further assist families from outside the Sydney metropolitan area.
- The Shepherd Centre is a registered charity with a Deductible Gift Recipient status. Almost 75 per cent of funding is derived from fundraising and 25 per cent from government funding.

Programs and services

- Children with hearing loss who begin early intervention earlier have significantly better developmental outcomes than similar children who begin intervention later in life.⁵⁻⁷
- The Shepherd Centre **early intervention programs** provides families with 1:1 Auditory-Verbal therapy, audiology, family support sessions, and group sessions including a weekly playgroups and parent support groups.
- Working collaboratively with parents, our therapists guide and coach them to teach their children & to facilitate their child's audition, speech and language development in everyday situations. Children are taught to listen and speak using residual hearing they have the use of optimally fitted appropriate listening device (hearing aids and cochlear implants).
- For children whom hearing aids aren't enough, The Shepherd Centre offers the **First Sounds Cochlear Implant Program**, a joint initiative of The Shepherd Centre and the Sydney Children's Hospital, Randwick. Since 1991, this program has provided medical, audiological and therapy services required to support a child and their family prior to and following cochlear implant surgery. The First Sounds program works with three prominent cochlear implant surgeons in Sydney. Surgeries are performed at the Sydney Children's Hospital, Prince of Wales Private Hospital and Norwest Private Hospital.
- For some of the families attending The Shepherd Centre, deafness may be one of several additional needs for their child. Our teaching staff has a diverse range of specialist skills and is able to confidently work with families to help each child reach their full potential i.e. developing listening and spoken language.

Hearing loss in children

- Each year in Australia, one in 1,000 children (approximately 80 babies in NSW) is born with a hearing impairment. By the time a child reaches school age, the risk increases to three in 1000.¹⁻³

- Early diagnosis and appropriate intervention for children with significant hearing impairment can lead to better outcomes for children and their families in terms of speech, language and social development.⁴
- Since the inception of the NSW SWISH Program (Statewide Infant Screening – Hearing) in 2002, the average age at diagnosis of hearing loss has decreased from 18 months to around four weeks.⁴
- Significant medical advances and improved hearing technology (cochlear implants and hearing aids) over the last decade have helped improve speech and language outcomes for children who are deaf or hearing impaired.

History of The Shepherd Centre

- The story of The Shepherd Centre has its beginnings in 1970. It was a dream realised for Dr Bruce Shepherd and his late wife Annette. Both of their children were born profoundly deaf and at that time there was no suitable program in Australia for teaching deaf children to learn spoken language.
- The Shepherds believed that given the opportunity and with training, children who are born deaf or hearing-impaired should be able to take their place in the hearing world.
- After a long and intensive search, the John Tracy Clinic in Los Angeles and its Auditory-Verbal, family centred approach was used as the model for teaching. The Shepherds believed this method best encompassed the educational and family ethos they wished to emulate.
- With just five families, The Council for Integrated Deaf Education, later becoming The Shepherd Centre for Deaf Children and their Parents, was established.

Our Vision

- To enable children who are deaf and hearing-impaired to develop spoken language so they may fully participate in the hearing world and in so doing reach their full potential.

Our Mission

- To assist children who are deaf and hearing-impaired achieve spoken communication within the family, the educational setting and within the wider community by involving parents and the community in the education and development of the child.
- To develop the skills of the parents and carers, by providing an intensive infant and preschool program, so that children may acquire speech and language, principally using their residual hearing with the use of appropriate listening devices (e.g. hearing aids or cochlear implants).
- To develop language, listening, speech and social skills to facilitate integration of the child with their hearing peers at the earliest possible opportunity and ensure integration continues throughout life.

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Attachment C

Research-based evidence to support outcomes related to the delivery of early intervention services for permanent childhood hearing impairment

- Deafness is the most common disability in neonates (Cole & Flexer, 2007).
- Research evidence on outcomes for children suggests entry into an effective early intervention program before 6 months of age is a key determinant of success in developing communicative competence. Effective early intervention programs for hearing impaired children invariably entail substantial resources, both human (health and education professionals) and technical (hearing aids and cochlear implants).
- Language acquisition for children occurs most naturally and prolifically between the ages 0-4, hence the need for early detection, diagnosis and intervention.
- The key to life chances and success is early childhood development. International research by Dr Fraser Mustard and The Canadian Institute for Advanced Research (CIAR) confirms that the first 12 months of life "... set trajectories that affect health (physical and mental), learning and behavior throughout the life cycle".
- Research confirms that brain development is closely linked with the ability to acquire spoken language. The *inability to hear and listen* impairs brain development and may slow intellectual development (Cole and Flexer, 2007, Kretchmer et al., 2004; Shaywitz & Shaywitz, 2004).
- "Hearing Loss in babies is a neurological emergency because the time window for intervention is very limited. After birth, the brain is at its most plastic for the first 3.5 years and the plasticity decreases sharply after that point (Sharma, et al., 2002). Learning a new language after this point is very difficult. One of the most important skills for developing literacy is phonological processing and the optimal period for this skill is thought to extend from the last 6 months in utero to the first 12 months of life, so early intervention and early listening are pivotal for developing literacy, on which academic achievements are built. (Sharma, A., Dorman, M., & Spahr, A. J. (2002c).

Purchasing outcomes for young deaf children

Early intervention for deaf babies and infants can potentially yield greater returns than any other investment in the field of disability. This is due to a unique confluence of factors.

- Early detection and diagnosis – the ability to detect and diagnose within the first 6 months of life provides the opportunity to have the child meet normal developmental milestones.
- Innovative and effective technology – digital hearing aids and cochlear implants can significantly mitigate the deleterious effects/sequelae of Permanent Childhood Hearing Impairment and provide usable access to sound.
- Effective Early Intervention – research supports the efficacy of early intervention in assisting children to succeed across all developmental domains, thereby effectively "normalizing" outcomes and allowing children to reach their innate human potential.
- Mainstream Placement and Inclusion – allows children to be educated in the mainstream, aspire to meet national literacy and numeracy benchmarks and make successful transitions from education to tertiary education and eventually to gainful employment.
- Pathways to participatory citizenship and independence – obviates reliance on disability pensions, unemployment support and prevents disengagement from the wider community.

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