

Submission: Inquiry into Hearing Health in Australia

Please accept this submission which addresses issues relating to early intervention services for hearing impaired infants and has been prepared in relation to the third term of reference for this inquiry – *“the adequacy of access to hearing services, including assessment and support services, and hearing technologies”*.

This submission is being made by “Hear the Mum’s”, a group of parents with children enrolled in the St Gabriel’s Auditory-Verbal Early Intervention Program and with the support of the Early Intervention Therapists from the St Gabriel’s Auditory-Verbal Early Intervention Centre.

The submission focuses on three main issues:

1. The accumulating evidence on the efficacy of newborn screening/early identification and subsequent early intervention for hearing impaired infants.
2. The inadequacy of government funding provided to early intervention service providers, and the recent implications of this on one particular centre in the Hills District of Sydney, NSW.
3. The importance of families being able to both choose and access a variety of different early intervention services – dependent on their own personal needs and goals.

1. The accumulating evidence on the efficacy of newborn screening/early identification and subsequent early intervention for hearing impaired infants

New Born Screening

“International research suggests that early diagnosis and intervention such as amplification (hearing aids or cochlear implants) and special education helps most children with a hearing loss. Usually, children who are diagnosed and receive intervention before the age of 6 months demonstrate better speech and language development and learning skills than those who are diagnosed at a later age. (Yoshinaga-Itano *et al.* 1998 *Pediatrics* 102:1161-1171)

Without a screening program, babies often aren't identified or diagnosed until at least one year of age, and often as late as 2 or 3 years, after language delays become clear. These babies are at higher risk of having poorer long-term outcomes in language and learning.

Infant hearing screening programs are currently being trialed or established in all states and territories except Tasmania. These are at different stages of implementation.”

(http://www.rch.org.au/vihsp/info.cfm?doc_id=7684#4)

In December 2002, the NSW State Government introduced universal Statewide Infant Screening for hearing impairment (SWISH) to detect hearing losses in babies. Since this time, the Government has been able to boast an impressive 98% screening rate for all newborns within NSW of which 1.68 babies per 1000 born are identified with some type of significant hearing impairment.

(www.premier.nsw.gov.au/Newsroom/Articles/2009_Articles/090914_NSW_leads_the_country_in_infant_hearing_screening.html)

"The New South Wales Statewide Infant Screening-Hearing (SWIS-H) program has been operating across New South Wales since December 2002. In the first year, 73,000 babies were screened, 145 babies received refer results in both ears and were referred to diagnostic audiology, and 64 of these were diagnosed with a significant hearing loss (permanent bilateral impairment).

Prior to implementation of the SWIS-H program, the average age of detection of permanent hearing impairment in NSW was 18 months and the average age of hearing aid fitting was 22 months. SWIS-H now aims to ensure that intervention commences before 6 months of age."
(http://www.rch.org.au/vihsp/info.cfm?doc_id=7684#4)

Earlier this year, Kevin Rudd announced that every newborn child in Australia will be tested for hearing impairments under universal newborn hearing screening. From a national perspective with the increase in screening services there will be an increased demand for Early Intervention Services, it is therefore essential that the Government(s) provide the necessary funding to support existing and new early intervention services and infrastructure.

Early Intervention Programs

Families of newly diagnosed hearing impaired infants in NSW are provided with information, generally through the 'Choices' booklet given to parents by Australian Hearing. The 'Choices' booklet outlines the choices that parents have in terms of communication options and the various organisations that provide Early Intervention for children with hearing impairments. The majority of these services are provided free of charge by charitable organisations.

Parents initially need to decide the mode of communication they believe is the most appropriate for their family and their child. The choices that are generally made are Auditory-Verbal, Auditory-Oral, Auslan, Total Communication or Bilingual – sign/spoken language. The mode of communication chosen will then often determine the early intervention program that the family will enrol in as most organisations specialise in providing a specific type of intervention.

In a recent media release, Carmel Tebbutt (NSW, Minister for Health) claimed that research now exists to support the benefits of Early Intervention on contributing to optimal speech and language development – and she specifically highlighted the importance of SWISH in enabling Early Intervention to happen as early as possible in a hearing-impaired child's life.

(www.premier.nsw.gov.au/Newsroom/Articles/2009_Articles/090914_NSW_leads_the_country_in_infant_hearing_screening.html)

One such centre, St Gabriel's Auditory-Verbal Early Intervention Centre provides individual weekly Auditory-Verbal therapy sessions free of charge (in centre or home visits) for babies and children from birth to six years who have a hearing impairment and are fitted with hearing aids and/or cochlear implant. The program assists children to learn to listen and speak so that upon starting Kindergarten they are able to integrate into a regular school alongside their hearing peers. In Auditory - Verbal Therapy children with hearing impairment are assisted to use hearing as the primary sensory modality in developing spoken language **without** the use of sign language or emphasis on lip-reading. Auditory-Verbal practice recognises the parents as the primary facilitators of their child's speech and language development and therefore parents

are actively involved in therapy sessions and in developing short and long term goals for their child.

St Gabriel's for many years has been at the forefront of early intervention for hearing impaired children having first set up an Early Intervention Centre in 1974 and then by pioneering Auditory-Verbal therapy into Australia in 1984. In 2001 St Gabriel's published the St Gabriel's curriculum and then in 2005 it published a revised curriculum and a software program for creating Individual Education Plans for hearing impaired children. In addition to providing quality therapy St Gabriel's has always had an emphasis on pastoral care where the families along with the child are supported.

Over the last 5 years approximately 90% of the children who have attended the Auditory-Verbal Early Intervention centre at St Gabriel's have begun kindergarten in a mainstream school. This is largely due to the role of SWISH and early intervention.

Due to the historical and ongoing funding deficits affecting early intervention services for hearing impaired children the board of St Gabriel's School for Hearing Impaired Children have taken the very difficult decision to close their Early Intervention Program despite the increasing demand for this service. Currently action is being taken by an independent group - "Hear the Mum's" to obtain emergency funding to support the continuation of these services under a new incorporated association, proposed to be called "Hear the Children Early Intervention Centre" to be located in the Hills district of Sydney. ("Hear the Mums" are currently in process of submitting the formal paperwork to Department of Fair Trading in NSW for the application of a new Incorporated Association, proposed to be called "Hear the Children Early Intervention Centre")

Research

Research supports that the earlier children are identified with a hearing loss and the sooner they begin early intervention, the more effective the therapy can be. Recent studies have shown evidence that infants with a hearing loss who were identified early and received intervention by the age of 6 months fared significantly better in terms of communication development than children identified later (Yoshinaga-Itano, 1995).

The early identification and prompt initiation of intervention services could prevent or greatly reduce the communication and developmental barriers which may occur due to a hearing loss (Moeller, Mary Pat. (September 2000). *Pediatrics*, Vol 106, No 3.)(Yoshinaga-Itano, C. (2004). Levels of evidence: Universal newborn hearing screening (UNHS) and early hearing detection and intervention systems (EHDI). *Journal of Communication Disorders*, 37 (5): 451-461.). Many children diagnosed and attending early intervention by the age of six months can develop language and speech equivalent to that of their normal hearing peers by 36-40 months of age. (www.avli.org/fag)

National Acoustics Laboratories (NAL) is currently engaged in a major research project (LOCHI) that is examining the Longitudinal Outcomes for Children with Hearing Impairment. There are approximately 475 children involved in the study who have been identified with a hearing loss in New South Wales, Victoria and Queensland. The first phase of the project focuses on development up to 5 years of age with children being assessed at 6 and 12 months post hearing aid or cochlear implant fitting and then at 3 and 5 years of age. Funding for this project has recently been extended to allow testing of participants at both 8 and 11 years of age as well. This project is world-first and initial results indicate that SWISH and Early

Intervention are providing positive outcomes in regards to hearing impaired children's speech and language development.

2. The inadequacy of government funding provided to early intervention service providers, and the recent implications of this on one particular centre in the Hills District of Sydney, NSW.

Despite the growing evidence of the critical link between SWISH, Early intervention and subsequent success in speech and language development, the Federal and State Governments are not providing adequate funding for early intervention services for hearing impaired infants (0 - 6 years of age). There are millions of dollars annually being directed to indentifying hearing impaired infants, ensuring children are fitted with the latest technologically advanced hearing aids and/or cochlear implants, ongoing monitoring and testing of children's hearing and funding for research projects to examine and access the positive links between early identification, early intervention and speech and language outcomes. However, there is **not** adequate funding to support the provision of early intervention services. This is obviously an issue that needs to be addressed when there is funding and resources being invested in the diagnostics and provision of hearing aids and cochlear implants and monitoring however there is almost no funding directed to the ongoing provision and sustainability of early intervention services.

Given the volume of recent media coverage and the ongoing inquiries into hearing health it is evident that Government officials continue to support the benefits of early diagnosis and early intervention, however there is a clear disparity between ...the support of early diagnosis and.... the provision of adequate funding to support the early intervention services.

There are a number of facts and issues listed below that we would like to see taken into account when reviewing this submission.

- As a result of SWISH, Nationally children are now being identified up to 18 months earlier than in the past and are therefore accessing early intervention services from an earlier age and are requiring services for between 5 and 6 years. This puts an additional financial strain on programs and the current infrastructure.
- Most early intervention services are being run by charitable organisations which depend upon donations and fundraising to address the shortfall that exists between the funding that the government provides and the actual cost of running a centre.
- In the current economic climate Early Intervention providers are finding it increasing difficult to raise the funds to support the services that they provide. One such centre is St Gabriel's Auditory-Verbal Early Intervention Centre. Despite the fact that this centre has a successful history and its services, Curriculum and Software Program are highly regarded within Australia and internationally, recently a decision has been taken by the board of St Gabriel's School for Hearing Impaired Children to close their Early Intervention Program due to ongoing funding deficits despite the continued demand for this service.

- St Gabriel's for many years has been at the forefront of early intervention for hearing impaired children having first set up an Early Intervention Centre in 1974 and then by pioneering Auditory-Verbal therapy into Australia in 1984. In 2001 St Gabriel's published the St Gabriel's curriculum and then in 2005 it published a revised curriculum and a software program for creating Individual Education Plans for hearing impaired children. In addition to providing quality therapy St Gabriel's has always had an emphasis on pastoral care where the families along with the child are supported.
- Although the St Gabriel's Early Intervention Centre is a small centre with an enrolment of approximately 20 families each year it has always been well respected and been very successful with approximately 90% of the children entering mainstream schools. It is interesting and important to note that of five children (4 current) from the centre who have been engaged in the LOCHI study, being conducted by NAL, all five at each of their age reviews have been assessed as being age appropriate in regards to their receptive and expressive language. (See Appendix 1) This is largely due to the role of attending a quality early intervention program.
- The implications of this centre closing will mean that the children enrolled in this program will need to find Auditory-Verbal Early Intervention services elsewhere and with other services already at capacity there is ongoing concern that appropriate services where the child and family will be happy and able to be enrolled may not be possible. Further to this point, if this service closes at the end of 2009 there will be no centre, West or North West of Strathfield in Sydney's suburbs that offers a strict Auditory-Verbal curriculum which provides a major issue to the ever expanding West and North West Sydney population.
- Since the announcement of the decision by St Gabriel's, "Hear the Mum's" a group of parents and the two St Gabriel's Early Intervention therapists have banded together with the purpose of obtaining the funds to ensure the services are continued. St Gabriel's are supportive of "Hear the Mum's" establishing an independent incorporated association, proposed to be called "Hear the Children Early Intervention Centre" ("Hear the Mums" are currently in process of submitting the formal paperwork to Department of Fair Trading in NSW for the application of a new Incorporated Association, proposed to be called "Hear the Children Early Intervention Centre") to ensure the families requiring early intervention services for hearing impaired infants and children continue to be supported in 2010 and beyond. The services that will be provided by "Hear the Children Early Intervention Centre" will remain focused on offering best practice in Auditory-Verbal early intervention for children with hearing impairment and services for parent education in the Hills district and the expanding West and North West suburbs of Sydney. One small component of the groups action plan includes the development of a book (See Appendix 2, provided as a power point presentation as a separate attachment) to provide real stories from the families to present the current situation to government officials as we lobby for both 'emergency funding' to keep this service operational and 'ongoing funding' to support the future sustainability of the service.
- St Gabriel's Auditory-Verbal Early Intervention Centre has been supported since 1984 by the Christian Brothers and has been able to continue as a result of generous donations and ongoing fundraising. Although it costs in excess of \$200 000 to operate, the centre has not been able to gain access to the DADHC funding that similar Hearing Impairment Early Intervention services of similar size receive which is inequitable and we would encourage further investigation into this. In addition to this point the St

Gabriel's service only receives Intervention Support Funding (ISP) which provides the basic \$1 400 to \$2 200 per child per annum which is not realistic in terms of providing Early Intervention services to hearing impaired children and leaves a deficit of greater than 75% of the total cost to be covered by the service.

- This early intervention service is a critical service in the local hills, western and north western Sydney communities of Sydney, NSW and since the announcement of the closure two families with new born babies who have been recently diagnosed (SWISH) have already been turned away.
- Funding should be at least on par with the funding levels provided to other Early Intervention services in other disability areas. Recently funding for Early Intervention services has been provided for Children with Autism to the level of \$12 000 over two years and \$14 000 in rural areas.
(<http://www.autismpartnership.com.au/WebPage/WebPage.asp?Ref=7977>)
- Funding is provided for diagnosis and medical devices (hearing aids and/or cochlear implants) to children as early in life as possible, however, there is **not** adequate funding to support the early intervention that these children need to have in order to learn to listen and to develop language and speech in order to enter Kindergarten in mainstream schools and ultimately the opportunity to go on to live independent self supporting lives.
- There is a need for Governments to take responsibility for providing appropriate funding to the Early Intervention Services to support children with hearing impairment and prevent Early Intervention services from operating primarily on the back of charitable organisations.

3. The importance of families being able to both choose and access a variety of different early intervention services – dependent on their own personal needs and goals.

As is promoted by the booklet published by Australian Hearing 'Choices', families need to be able to make informed decisions about the people and the services that their family and their child will be associated with throughout their path to learning language and speech. There should always be choice available to parents yet current lack of funding will limit this in the future.

There are a small number of Early Intervention Services for hearing impaired children available. Each service provides therapy based on one or more communication modes; Auditory-Verbal, Auditory-Oral, Bilingual (Auslan/Spoken English) and Total Communication.

There are various reasons why families should be able to choose the Early Intervention service for their child, including;

- Parents need to be able to choose the communication mode for their child. This need may change throughout the development of the child.
- Parents need to be able to choose the service and the people that their child will be intensively working with in order to gain the best outcome for their child.
- While audiological and diagnostic service providers have either a short term or intermittent involvement with the child throughout their life, Early Intervention providers

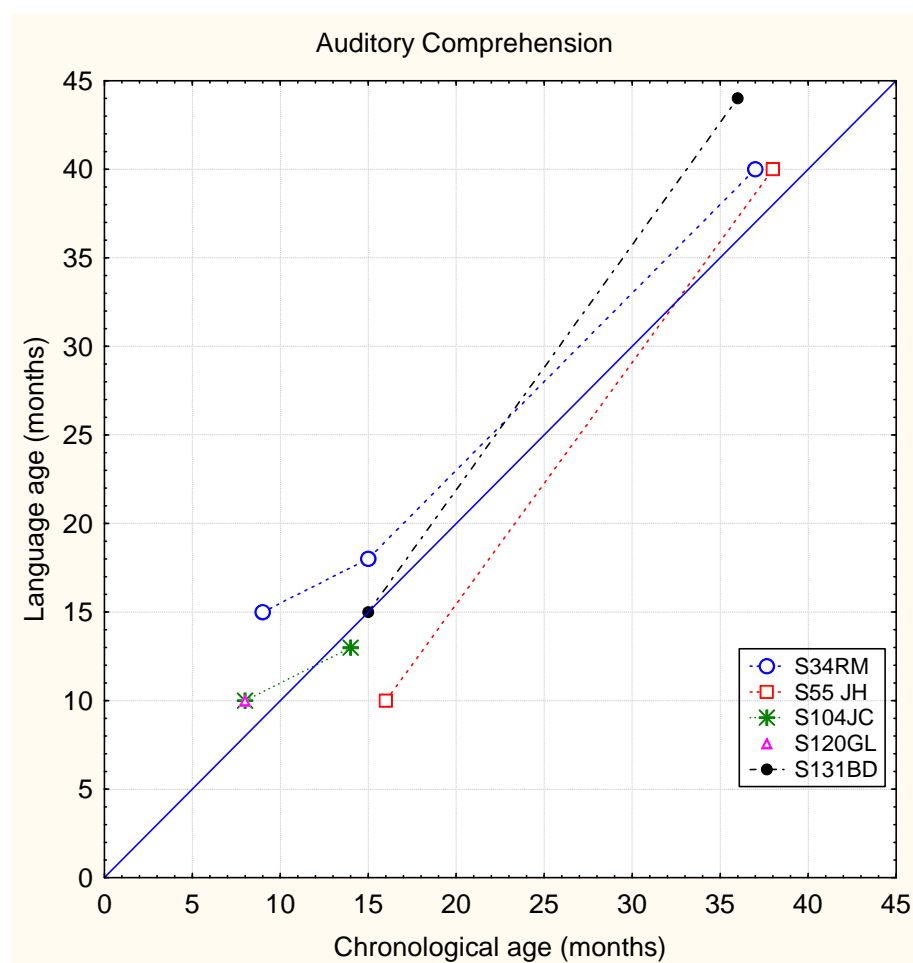
and therapists have a long-term concentrated and dedicated involvement with the child and their family for the first 6 years of the child's life.

- Early Intervention services need to fulfil the ongoing needs and personal objectives of the family participating in the program. Taking into consideration such factors as;
 - the location of the service and where the family lives and how easy it is for them to access the service,
 - the services specialisation in terms of the communication mode and philosophy of the therapy offered,
 - the provision for home visits, where it can be crucial to the ability of some families to access a service,
 - the availability of playgroup services,
 - parent education,
 - parent and family support,
 - size of the centre (large versus small),
 - the history and reputation of the service(s), and,
 - the relationship between the therapist and the child and the family.

Appendix 1 – NAL Outcomes of 5 Children from St Gabriel's Early Intervention Centre

T Ching, NAL, Sept09

Five children from St Gabriel's Early Intervention Centre are enrolled in the Longitudinal Outcomes of Children with Hearing Impairment (LOCHI) study. The Pre-school Language Scale v.4 was administered at several intervals after initial fitting of hearing aids. The subscale scores of Auditory Comprehension and Expressive communication were used to derive equivalent language ages. Results for individual children are depicted by different symbols.



Diagonal line shows complete agreement between chronological age and language age. When a line between 2 assessment points runs in parallel to the diagonal line, it suggests that a child demonstrates age-appropriate development over the first 3 years of life.

Expressive communication

