Hearing Health in Australia

Submission to the Community Affairs Reference Committee

Alliance for Deaf Children

October 2009

Contents

Background

Alliance for Deaf Children

The Alliance for Deaf Children has been operating since 2002/03 and is represented by six not-for-profit organisations across Australia and New Zealand.

They are:

- Taralye in Melbourne - covering Victoria;
- Telethon Speech and Hearing in Perth - covering Western Australia;
- Cora Barclay in Adelaide - covering South Australia;
- Shepherd Centre in Sydney - covering New South Wales;
- Hear and Say in Brisbane - covering Queensland
- The Hearing House in Auckland - covering New Zealand

Each of these organisations provides auditory-based oral language services for deaf and hearing impaired children, has a service focus on early intervention, is parent founded (or has significant involvement of parents) and provides sole geographical representation from each Australian state and New Zealand.

A Extent, causes and costs of Permanent Childhood Hearing Impairment (PCHI) in Australia

Extent

Deafness is the most common disability in neonates *(Cole & Flexer, 2007)*.

Research literature suggests that the number of children in Australia born with a permanent hearing impairment greater than 35 decibels in one or both ears is 0.6 and 1.3 per 1000 live births respectively.

"Using this estimate for Australia it is calculated that 481 children may be born with bilateral or unilateral PCHI each year. The predicted yield of unilateral and bilateral PCHI from an Australian UNHS (universal newborn hearing screening) program...was modelled and estimated...to be 607 infants."
(Medical Services Advisory Committee Universal Neonatal Hearing Screening MSAC Reference 17 Assessment report, Nov 2007)

Causes

Approximately 60% of congenital deafness is due to genetics with the remaining 40% due to environmental factors or complications (such as high serum bilirubin level, birth weight < 1500 grams, low APGAR scores, oxygen deprivation at birth, viral infections) at the time of pregnancy and/or birth.

The most common form of genetic hearing loss is due to recessive inheritance caused by a range of gene mutations but most commonly involving the connexin 26 gene. Recessive inheritance of deafness means that parents are unaffected (ie do not have congential hearing loss).

Approximately 95% of children who are born deaf have parents with hearing.

Approximately 40% of children who are deaf have an additional special need.

Costs

A comprehensive report on the cost of hearing loss in Australia is detailed in a report by Access Economics: Listen Hear! The economic impact and cost of hearing loss in Australia, February 2006.

In relation to costs associated with early childhood intervention service for PCHI, the estimated cost per hearing impaired child per annum in any effective early intervention program (regardless of therapy model or communication modality) is approximately $15,000 - $17,000. Based on the estimated incidence and prevalence rates reported above, approximately 2,400 young children from birth up to 4 years of age (ie approximately 600 in each of the four years) are eligible for early intervention. Nationally, this equates to funding in the order of $36-41M to provide an effective national early intervention service for children in this age group.

Centres within the Alliance for Deaf Children receive 25-60% of recurrent operating costs from State Government sources. State funding is derived from a single source in some states and multiple sources in other states. For example, Government funding in Victoria is received from the Department of Education and Early Childhood Development and in NSW funding is received from Ageing, Disability and Home Care Department, Department of

Community Services, Department of Education and Training – YCWD and Department of Education and Training - NGO.

Recommendation

- ***It is suggested that the Commonwealth consider providing annual funding, for up to four years, of $6,000 per annum to the family of each eligible child under a proposed PCHI funding program.***

  Funding for 4 years would cover the critical period of intensive early intervention. Later diagnosed children – aged over 1 year - may already have significant language delays which take time to recover. This model proposes funding from the date of diagnosis up to the end of the calendar year in which the child has their fourth birthday. The Commonwealth may wish to consider making funding support available up to the fifth birthday in order to assist children and families to navigate a successful transition to universal pre-school placement.

  Commonwealth Government funding at a suggested level of $6,000 per child per annum would be in the order of $14M-$15M each year. Funding the extra year would increase numbers to 3,000 eligible children and the program cost to around $18M per annum.

  Commonwealth funding would complement existing State Government subsidies and assist in meeting the significant funding gap which is currently met through fundraising on a recurrent basis in order to provide essential early support.

B Implications of PCHI for individuals and the community

Individuals

Language acquisition for children occurs most naturally and prolifically between the ages 0-4 years, hence the need for early detection, diagnosis and intervention. Strong research exists to support these needs:

- 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".

- Early brain development is critical to future life prospects . . . *(Hart, B., & Risley, T. R. (1999).* A number of social, economic, environmental and physical factors that put brain development at risk have been identified. It is axiomatic that any factor that retards or diminishes brain development will adversely affect future life prospects and the ability of an individual to manage his or her life effectively.

- 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 retard 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). A sensitive period for the development of the central auditory system in children with cochlear implants: Implications for age of implantation. Ear and Hearing. 23,p.5)*

Community

Long term capacity building and savings for our community exist if investments are made in early detection, and diagnosis of PCHI and professional early intervention support for families. This has been identified by the Medical Services Advisory Committee as follows:

- The Medical Services Advisory Committee investigation into a national Universal Newborn Hearing Screening Program took a long term societal perspective in concluding that "identifying a larger proportion of hearing-impaired infants at an early stage (ie< 6 months of age) would result in a cost saving overall".

- "Children identified with PCHI through UNHS appear to have improved communicative abilities compared those (sic) identified without UNHS, according to the small study with the most sensitive form of measurement – direct and blinded observation of children."

- "The long term direct cost savings from the reduced need for special education and rehabilitation and the possibility of indirect savings from enhanced productivity in adulthood outweigh by an order of magnitude the cost of the actual screening and diagnosis."

(Medical Services Advisory Committee Universal Neonatal Hearing Screening MSAC Reference 17 Assessment report, p. 151 Nov 2007)

Further importance of investing in the early years has been identified through the Commonwealth Government's partnership with State Governments in the National Reform Agenda for Early Childhood as follows:

- "The Australian Government's agenda for early childhood education and child care focuses on providing Australian families with high-quality, accessible and affordable integrated early childhood education and child care........Investing in the health, education, development and care of our children benefits children, their families, our communities and the economy, and is critical to lifting workforce participation and delivering the Government's productivity agenda."

(Department of Education, Employment and Workplace Relations, 2009)

C Adequacy of access to hearing services, including assessment and support services and hearing technologies

Assessment

Australian State Governments recognise the importance of ensuring that infants born with PCHI are identified and treated as soon as possible. In July 2009, the Council of Australian Government (COAG) agreed to ensure that by the end of 2010 every child born in Australia will have access to screening for congenital deafness.

The current status of State-based hearing screening programs in Australia is as follows:

- State Wide programs: ACT (>98%), NSW (>98%), QLD (>98%), TAS (>95%), SA (>97%)
- Partial roll out: VIC (57%), WA (65%), NT (55%)
- National aggregated coverage: 84%

The aim of newborn screening is to detect a suspected PCHI in the first month of life, diagnose a confirmed hearing loss within 3 months of birth and have a child enter an effective early intervention program before 6 months of age. All State programs are based on this 1-3-6 principle.

Support Services

UNHS is not an end in itself. The aim of UNHS should be to facilitate the entry of children with PCHI into effective early intervention programs in order to maximise life and learning outcomes and realise their full human potential. 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). These programs are essential services and should be funded as such to enable timely and equitable access for all children regardless of demographics, residential location or other barriers.

Hearing Technologies

Early access to hearing technologies, consistent use of, and maintenance of devices are important in order to achieve the best outcomes for children.

Through Australian Hearing and established cochlear implant clinics, Australia is in a unique position to deliver state-of-the art hearing technologies to deaf individuals. Ideally, infants diagnosed with PCHI would be fitted with hearing aids by 3 months of age and eligible infants offered cochlear implantation within 12 months of diagnosis. Currently there is reported variability in infant's equitable and timely access to cochlear implants across Australia due to funding limitations. Adequate funding should be available to meet the supply of cochlear implants on demand.

Recommendation

- **Refer to Appendix 1 for a summary of recommendations for a national best practice policy for deaf and hearing impaired children using spoken language.**

D Adequacy of current hearing health and research programs, including education and awareness programs

The Cooperative Research Centre, NAL and Australian university researchers have all made significant contributions to research in the childhood deafness field. It's important that research into outcomes for PCHI is given ongoing priority as this will continue to inform models of early intervention service delivery, and assist in developing quality assurance standards which can be used to measure accountability of service providers.

Promoting collaborative work between early intervention agencies (such as adopting a common assessment protocol for children), is another way of developing benchmarks, setting goals and generally raising awareness of the outcomes which can be achieved.

Contact
If you have any queries about information in this submission, please do not hesitate to contact:

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Appendix 1: Summary recommendation for a best practice policy for deaf and hearing impaired children using spoken language

Key elements of a national best practice policy for deaf and hearing impaired children using spoken language

National Policy

1. All children to have equitable and timely access to newborn hearing screening (NBS)
2. All children to have equitable and timely access to diagnostic referral and testing
3. All children to have equitable and timely access to accredited service provision for early intervention (EI) regardless of family demographics, cost, location or other barriers
4. All children to have on-going support to achieve their innate potential in all areas of early childhood development – language, speech, cognitive development, social/emotional well being, physical development

National Strategic Goals

1. All children with Permanent Childhood Hearing Impairment (PCHI) detected within 1 month of birth
2. All children with PCHI diagnosed as early as possible within 3 months of birth and fitted with hearing aids
3. All children with PCHI enrolled (and family actively participating) in an accredited locally-available early intervention program by no later than 6 months of age
4. Spoken language skills for children with PCHI in line with national expectations for children with normal hearing at school entry
5. Age appropriate levels for all children with PCHI at national benchmark testing points under NAPLAN (Years 3, 5, 7 & 9)
6. All children identified as suitable for cochlear implantation to have access to appropriate technology within 12 months of initial identification and diagnosis
7. Training and support for professionals in the workforce to ensure an adequate labour supply and professional skill levels to meet quality standards within a world's best practice framework

Identified Outcomes

1. Measurable improvements in literacy and numeracy for all children with PCHI
2. 95% minimum coverage for NBS
3. 99% entry of children screened through NBS into EI before 6 months of age
4. Reduced welfare dependency over time of adolescents and adults with PCHI
5. Higher levels of entry into university and TAFE
6. Improved mental health measures for children with PCHI
7. Family engagement with service provision

Appendix 2: Key Contacts
Alliance for Deaf Children

Person	Position	Organisation	Contact
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