

SUBMISSION TO THE SENATE ENQUIRY ON HEARING HEALTH

INTRODUCTION

The Cora Barclay Centre (hereafter CBC) is a South Australian charity that provides a comprehensive range of oral/aural and related services and programs to children who are deaf and hearing impaired and their families. CBC was the first service of its kind in the Southern Hemisphere being founded in 1945 in the early stages of development of hearing aids and oral habilitation programs.

CBC is grateful for the invitation to make a Submission to the Senate Inquiry and would like to invite members of the Inquiry Committee and/or its secretariat to visit our Centre in the course the inquiry should circumstances permit.

Speech, language and the ability to communicate effectively are critical to the intellectual, educational, social and psychological development and well-being of human beings. They are therefore crucial enablers to living a full and rewarding life in modern society.

Over 95 percent of deaf children are born to hearing parents (Mitchell & Karchmer, 2004) who increasingly want their child to learn to speak. Early diagnosis, hearing aid technology, cochlear implants and oral/aural therapy programs combine to make this possible. Full and effective habilitation (or rehabilitation) is now possible and achieved at the highest levels when these services are accessed and maximized.

The results and outcomes are extraordinary – and life changing. It is amazing, and very moving, to hear a profoundly and bilaterally deaf child, adolescent or young man or woman tell their life's journey from diagnosis to school to university, TAFE, an apprenticeship and employment or whatever.

Over the past 20 years, deafness has become a disability that can be entirely overcome if services are planned, coordinated, accessible and appropriately funded. Australia has many of the necessary elements of an effective habilitation system but these are yet to be adequately planned, resourced and coordinated at the Commonwealth or State level. Consequently there are still many deaf babies who are not screened at birth; who have delayed diagnoses; who miss out on, or have to wait for, a cochlear implant or bilateral implant; who are not referred, as they should be, to Australian Hearing or an Early Intervention service following confirmed diagnosis; who are unable to receive the continuing therapy and support they need at school; who are cut off from free government hearing aids and cochlear implant parts when they become adults; who live in rural and remote areas where therapy services aren't available; who are Indigenous Australians with chronic ear infections affecting their hearing and their ability to develop socially, intellectually and academically.

There is much that needs to be done.

Many of the above issues will be addressed in the submissions of others to the Senate Inquiry. Rather than comment on them all, or attempt to address the Inquiry's terms of reference comprehensively, our aim in this Submission is to present ourselves as a kind of case study of the challenges confronting an Early Intervention Service in Australia at the present time. We trust this will be helpful for the Committee in understanding the urgent need for increased funding for services, increased research and the need to build comprehensive coordinated systems of care for deaf and HI children and their families.

OVERVIEW OF SUBMISSION

Terms of Reference for the Senate Inquiry into Hearing Health in Australia

Hearing Health in Australia with particular reference to:

- a) the extent, causes and costs of hearing impairment in Australia;**
- b) the implications of hearing impairment for individuals and the community;**
- c) the adequacy of access to hearing services, including assessment and support services, and hearing technologies;**
- d) the adequacy of current hearing health and research programs, including education and awareness programs; and**
- e) specific issues affecting Indigenous communities.**

THE KEY TO LIFE CHANCES AND SUCCESS IS EARLY CHILDHOOD DEVELOPMENT

A child who is severely or profoundly hearing impaired can hear little or nothing without amplification. Research into deafness and hearing loss has demonstrated that brain development is linked closely with the ability to hear and listen (and to speak and acquire spoken language) and, conversely, that the inability to hear may impair brain development and delay intellectual development (Cole and Flexer, 2007, Kretchmer et al., 2004; Shaywitz & Shaywitz, 2004)

International research by Dr Fraser Mustard and The Canadian Institute for Advanced Research has established that the early years of childhood (starting within the first 12 months) “ . . . set trajectories that effect health (physical and mental), learning and behavior throughout the life cycle”.

Where children are born with, or acquire, severe hearing loss they need to be identified and diagnosed immediately, to receive hearing aids/implants, and to commence intensive therapy to train their parents to teach their child to learn to listen and start language development - otherwise their brain development may be jeopardized. Early diagnosis, aided hearing and intensive auditory-verbal therapy from the first weeks and months of life substantially restore the conditions for achieving normal development. A comprehensive and coordinated response to severe hearing impairment is quite likely the most effective habilitation and rehabilitation known for a human disability.

CBC believes that the most effective habilitation and rehabilitation for babies and children who are deaf or hearing impaired is through a multi-disciplinary approach involving continuing auditory-verbal therapy (AVT), ongoing educational audiology and social and psychological counselling and support for the family.

ABOUT THE CORA BARCLAY CENTRE

The Cora Barclay Centre was founded in 1945 in response to a wave of rubella epidemics in South Australia that caused deafness and hearing impairment in a significant number of babies born into hearing families. These families wanted their deaf children to learn to listen and speak just as all the other members of their family spoke. Their response was to establish the South Australian Oral School and Kindergarten with trained teachers specialising teaching deaf children to talk.

With the progressive integration of children with disabilities into mainstream schools in the 1970s and 1980s, CBC evolved from being a special school for deaf children into an organization providing early intervention programs and a kindergarten for deaf and hearing impaired (hereafter HI) babies and continuing therapy and support to deaf students in mainstream schools. In 1988 it de-registered as a school, re-named itself (after its Principal of 40 years) and formalized its role as an oral/auditory therapy centre for HI children and their families.

CBC now provides a comprehensive range of services and programs to deaf and HI children and their families under two broad programs; namely,

- **Early Intervention** (0-5 years) including Auditory-Verbal Therapy (AVT), Cochlear Implant program, a visiting service from Australian Hearing, music and playgroup programs, family counseling, parent advocacy and support, parent mentoring; and
- **Student & School Support** (school-age children) including regular therapy visits as determined by a student's ongoing progress. Junior Primary children may continue to receive weekly or fortnightly visits but later in high school only receive monitoring, review and teacher liaison.

CBC also auspices an exciting youth peer support program called **WHISPA** that develops leadership, self-esteem and mentoring skills in older children who are deaf or HI (the leadership group) who in turn run social and personal development programs and activities for deaf and HI children at school in the age group 13-18 years. Research shows that deaf and HI children are prone to social and psychological problems in their adolescence due to low self-confidence and low self-esteem associated with their disability.

The Centre's clinical and educational team includes auditory-verbal therapists, teachers of the deaf, audiologists, speech pathologists, and a family counselor operating as a family-focused multi-disciplinary team (refer www.corabarclay.com.au for further details of our services and programs).

CBC has an international reputation and pioneering history. It was the first oral centre in Australia (1945); co-founder of the SA Paediatric Cochlear Implant Program (1991); winner of the AG Bell Association Program of the Year Award (1999); and winner of the Australasian Teleconferencing Award for Geographically Isolated Students (2001). The Centre has been a strong advocate for introducing cochlear implantation and universal newborn hearing screening to South Australia. We are also in the forefront of educational audiology, classroom acoustics and sound field systems through our total commitment to ensuring that deaf children receive every support and assistance possible to support their educational and social development.

CBC is a contributor to research and collects its own longitudinal client data for evaluating the positive impact of therapy upon each individual student's progress; comparing an individual student's language progress in relation to their age-matched hearing peers; and providing a body of research that will provide evidence for the effectiveness of CBC's interventions.

INCIDENCE AND PREVALENCE OF HEARING IMPAIRMENT IN SOUTH AUSTRALIA

South Australia has approximately 18,000 live births per annum. The Australian rate of Permanent Childhood Hearing Impairment (PCHI) of greater than 35 decibels in one or both ears is 0.6 and 1.3 per 1000 live births respectively. This translates into new referrals to our service of between 18-25 cases per annum. Approximately 2-5 further cases a year can be expected from late diagnosis, progressive hearing loss or an acute medical condition causing

hearing loss (eg meningitis) although recent international studies have put the rate for diagnosis **post** newborn testing much higher (Cole & Flexer, 2007).

Emerging international opinion also supports hearing aids and language therapy for children with unilateral and mild to moderate hearing losses to ensure optimal development of the brain and associated speech and language (Carol Flexer, 2007)). Since the introduction of universal newborn hearing screening in early 2006 CBC has been receiving an increasing number of enquiries and referrals of children in these categories.

GROWTH IN SERVICE NUMBERS

CBC provides auditory-verbal therapy services to around 180 children including 57 in its Early Intervention (EI) Program (0-5 years) and 120+ in School Support. EI numbers have increased from 21 in 2005 to 57 in 2009 and are forecast to increase to 70+ by 2012. Student & School Support Program numbers have also increased significantly over the past decade with a twenty percent increase since 2000 from 100 to 120 putting significant stress on the Centre's resources.

Increases in new referrals since the introduction in South Australia of universal newborn hearing screening in early 2006 are giving rise to severe service management and funding pressures. Until 2005 the average age of diagnosis was around 18-24 months. With newborn screening, diagnosis occurs much earlier and babies and parents begin Early Intervention services at 6-8 weeks after the first fitting of a hearing aid. They are therefore on service for 18 months to 2 years longer than previously. In addition there are many cases of unilateral and mild-moderate hearing loss that are identified through the screening test and which alert families to the need to find out more about their child's condition and to seek out services. Many of these need assistance in the early stages of coping with the unexpected diagnosis of their child.

It is likely that other Early Intervention Services around Australia are experiencing similar growth patterns.

CBC is one of only a small number of Auditory-Verbal Therapy services that provides continuing intensive therapy to children at school. To an extent this is a product of our history (we started as a kindergarten and school) but our experience over many years, which is confirmed by parents and students, is that it is valuable and effective. Over the past decade there has been a definite trend away from hands-on therapy services to deaf and HI students towards a consultancy model primarily involving teacher liaison and curriculum planning. In the absence of a proper research study it is not possible to determine what is the appropriate level of support for deaf students - and it is likely that needs will differ depending on the age of the student, their speech and language skills, severity of hearing loss, academic ability, and so on. The Cora Barclay Centre recommends that research be undertaken to compare the educational, social and emotional outcomes of children who are receiving continuing therapy and support through school with those that have not.

FINANCIAL CHALLENGES

The CBC expenditure budget in 2009 is around \$1.4M. Of this about 40 percent is government funding (C/wlth and State combined) and 60 percent has to be raised annually by CBC. Government funding levels vary considerably across the Australian States and Territories, as do funding mechanisms.

Raising around \$800K per year is a major challenge for our small administration and fundraising team. It entails active involvement in business enterprises, appeals, events, various other fundraising activities (eg payroll giving), a continuing search for sponsors, and an annual program of grant writing to philanthropic Trusts and Foundations. Small charities such as ours are ill-equipped and resourced for much of this, but it is a necessary fact of life for survival.

Fundraising and events are very time consuming for staff and for families already heavily committed and stressed by their family commitments. Philanthropic Income is unpredictable and one-off, and falls away dramatically in difficult economic times – as it has done this year. This means that with less than half the recurrent expenditure for the year (over 70% of which is staff salaries and wages) covered by government funding, the Centre is under constant pressure throughout the year to raise the \$800K needed to remain viable.

SERVICE COSTS IN EARLY INTERVENTION SERVICES (0-6 YEARS)

The estimated cost per child per annum in Early Intervention is \$12-15K pa for CBC's AVT program (depending on variable factors such as caseloads, home visits, and overhead costs).

In many not-for-profit agencies, such as ours, government recurrent funding is a fixed annual amount and is neither linked to caseload nor indexed. So we have to 'absorb' an ever-increasing caseload through a range of strategies including higher workloads for the clinical team staff, re-assignment of cases, our Program Manager taking an increased caseload, using part-time and casual therapists when they can be found, downgrading service levels for some families – and other such expediciencies that are clearly not sustainable in the longer term. In 2010 CBC will have to appoint an extra EI therapist but do not currently have the funds with which to do this. This is a constant strain on the Board, management, staff and families.

SUMMARY AND CONCLUSIONS

- 1. Modern developments in technology and auditory/oral therapy programs have made it possible for children who are deaf and hearing impaired to learn to listen and speak so well that there is little or no discernible difference with normal hearing children of the same age. This powerfully alters their life prognosis.**
- 2. Over 95 percent of deaf and hearing impaired children are born to hearing parents.**
- 3. Australia has most of the elements for a comprehensive, highly effective habilitation system for deaf and HI children – from newborn hearing screening to school and beyond – but, for optimal outcomes, these need to be better planned, linked and adequately resourced.**
- 4. Excellent service models exist that (1) inform and support parents as the case manager for their deaf or HI child; (2) ensure service quality through accreditation and credentialing; and (3) have in-built research, tracking and monitoring through effective database management. Australia is well placed to develop its service models using local, national and international best practice applicable to our own circumstances.**
- 5. Only a relatively modest increase in funding – perhaps in the order of \$30M per annum - would be necessary to achieve a comprehensive service model that would meet families' needs and provide families with choice of programs and services.**

6. Indigenous ear health is a major problem in both rural and urban settings and needs to be addressed urgently. *If you can't hear, you can't learn.* Chronic ear infections, often leading to permanent hearing loss, are a major impediment to improving educational and social outcomes for Indigenous Australians.
7. More needs to be done to make screening, early diagnosis, and early intervention services more readily available to rural and remote Australians.
8. The Cora Barclay Centre fully supports the submission to the Inquiry of the Alliance for Deaf Children and its recommendations.

Michael Forwood CEO

CORA BARCLAY CENTRE

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