Severe to profound hearing loss—are we really managing it in New Zealand?

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It is 24 years since the first cochlear implant surgery was performed in New Zealand and 22 years since the first child was a recipient of a cochlear implant. This is clearly not new technology, but one which still has the ability to transform the life of a child or an adult. Hearing loss has serious consequences for development of oral language, emotional and social development, educational attainment and employment.¹,²

Not only is cochlear implant technology the recognised standard of care for most children and adults with severe to profound hearing loss, it is also a cost-effective medical intervention with potential for indirect cost savings in education and community support.³⁻⁵ The factors influencing outcomes in an individual child or adult are myriad, and expectations for children with multiple disabilities or meningitis are lower than when the aetiology is “non syndromic recessive deafness” which is the most common cause of deafness in newborns and young children in New Zealand.

For many children born with a severe to profound hearing loss, a cochlear implant may give them an opportunity to develop normal speech and language, attend mainstream school and engage in a nearly full range of employment opportunities. Long-term studies of children who have received cochlear implants also demonstrate that many are able to use the telephone and some learn musical instruments and other languages.⁶,⁷

Early diagnosis and treatment is one of the most important factors positively influencing successful outcomes (and cost-effectiveness) in cochlear implant use, hence the concern of Bird et al⁸ who demonstrate significant delays in referral to the New Zealand Southern Cochlear Implant Programme for some children, some of whom were turned down as candidates because of their age. Included were children with known risk factors for hearing loss. This is a failure of the medical, audiological and nursing community.

Delivery of cochlear implant services in New Zealand is administered by the Northern and Southern Cochlear Implant Trusts, funded principally through the Ministry of Health (based on a fixed number of children and a fixed number of adults receiving an implant each year) supplemented by piecemeal fund raising. Even though children receive funding priority, on occasions this fixed approach has proved inadequate.

When Waikato District Health Board (DHB) commenced neonatal hearing screening (prior to the development of a National Programme), some children diagnosed at birth with severe to profound hearing loss were unable to receive timely treatment as no allowance had been made for the downstream resultant need for cochlear implants.

Additional fixed funds have since been made available for cochlear implants in anticipation of increased numbers of neonates referred from the National Newborn
Hearing Screening programme, but in the last 2 years most of these funds have been fully utilised even prior to screening “roll out.”

Cochlear implants, while demonstrably cost-effective, require a significant up-front investment of approximately NZ$ 50,000 for the initial assessment, hardware, surgery and rehabilitation. Demand for implantation in adults has increased. Performance with cochlear implants has continued to improve with improving technology, and thus people with lesser degrees of hearing loss (but still struggling to hear with hearing aids) are now able to benefit. New hybrid devices (which combine hearing aid and cochlear implant technology) designed for people with mainly high-frequency hearing loss are now also available.

At the present time there are 127 adults on waiting lists for cochlear implant surgery. The term “waiting list” is clearly a misnomer. Sixty to 70 people are added to the “waiting list” each year while only 25 are funded to receive an implant. That is, the waiting list for cochlear implant surgery for adults is growing by approximately 40 per year. Most of the adults on the Southern and Northern Cochlear Implant Programme “waiting lists” will never receive one.

New Zealand insurance companies are not obliged to fund cochlear implants (and therefore specifically exclude them), as they are required to do in Australia where 70% of the implants are funded through private insurance. This is very clearly an important factor contributing to the numbers of New Zealanders on waiting lists who are medically and audiologically appropriate for a cochlear implant, that can neither get one publicly nor through medical insurance. This situation could be changed by an alteration in health policy direction.

It is important to remember, however, that hearing with current implant technology is still not normal and even the best implant users struggle to hear in some situations, particularly in background noise.

In recent years bilateral implantation has resulted in improvements in ability to hear better in these “acoustically hostile” situations. In the UK the National Institute for Health and Clinical Excellence (NICE) guidelines released in January 2009 may oblige UK health boards to fund bilateral implants for children for this reason, and bilateral implants in adults who are additionally visually impaired. In New Zealand, some children with families who can afford a second implant have received them. Few adults have done so.

The long-awaited New Zealand National Newborn Hearing Screening Programme is now in the third and final year of its roll-out across the district health boards. The intention is that all neonates will be screened for hearing loss by 1 month of age and babies identified as at risk of hearing loss will receive full diagnostic audiology by 3 months, with intervention if required, by 6 months of age. Intervention may include the use of hearing aids or cochlear implants in addition to education habilitation services.

Estimates that 120–170 newborn children with permanent bilateral hearing loss were likely to be detected through the National Neonatal Hearing Screening Programme were based on historic data collected by the National Audiology Centre (functionally no longer in existence) from voluntary reporting by audiologists. Data also indicate a substantially disproportionate ratio of Māori and Pacific children diagnosed with
hearing loss, who may be more at risk of non attendance for follow-up audiologic assessment.

Data have not been collected since 2005 and this situation is not expected to improve until funding is available for a more comprehensive database incorporating other aspects of child health. The National Screening Programme is therefore compromised in its mission of vigilant follow-up of “missed” babies without a national database, which was recommended by the Advisory Group to the National Screening Unit in 2005.12

Enthusiast members of the New Zealand Society of Audiology have recently reinstituted an independent deafness database based on voluntary reporting of new diagnoses, and more meaningful data about the frequency and severity of hearing loss occurrence is expected by the end of the year.

Bird et al point out that the neonatal hearing screening programme will reduce the number of delayed referrals for cochlear implantation. However, stumbling blocks may persist for unscreened children and also for those with a gradual onset of deafness who have normal or nearly normal hearing at birth. As a rule of thumb, we may expect, by age 5 years, approximately double the number children diagnosed with hearing loss that were diagnosed at birth.

The main aetiologies are: (non-syndromic) genetic, congenital cytomegalovirus and meningitis. This means that despite the existence of a newborn hearing screening programme, professional vigilance must be maintained. The days of finger clicking, hand clapping and bell ringing by family practitioners and Plunket nurses to “diagnose” hearing loss should be long gone and all children suspected of hearing loss should be referred to an audiologist. A regular programme of audiologic monitoring of children with identified risk factors, combined with the before school check should help supplement parental and health worker awareness.

In their paper, Bird et al indicate that paediatric electro-physiologic audiology expertise is always available. In fact, there is only a small handful of audiologists with the requisite skill and experience in interpreting diagnostic ABR tests, which are a form of EEG. The National Screening Unit is attempting to address this partly through up skilling courses, but it is simply not realistic to have an expert paediatric audiologist/auditory electro physiologist on each doorstep of 20 DHBs. Diagnostic and management inaccuracies can expect to continue, consequent on small paediatric audiologic caseloads in small DHBs.

Awareness of deafness in the medical community needs to increase/improve. Greater leadership from the Ministry of Health needs to be reflected through: completion of a National Hearing Loss Database; reshaping expert paediatric audiologic support of the Newborn Hearing Screening Programme, and; redirecting policy on cochlear implant and insurance funding if we are to see acceptable outcomes for deaf children, adults and society. The sooner the better.

**Competing interests:** Dr Brown is a cochlear implant surgeon, a member of the current and previous advisory groups on Newborn Hearing screening to the National Screening Unit and is Chairman of (and a shareholder in) Dilworth Hearing Ltd.

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References: