Submission

to the

Inquiry into Hearing Health in Australia

Research Contexts of Cochlear Implantation of Young Deaf Children

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This Submission specifically responds to the claims by some respondents to the Inquiry (e.g., The Shepherd Centre) regarding the need for cochlear implants to become an 'opt out' response for parents of young deaf children identified in newborn hearing screening programs. This would mean that provision of implants should be the automatic response to diagnosis of severe/profound deafness, rather than an 'opt in' response. We argue that such a position is overly simplistic and based on scientifically and linguistically inaccurate perspectives.[1]

In particular, we are most concerned that in the transcript of the Canberra

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[1] We wish to make it clear that we are not opposed to the implantation of children at as early an age as possible after diagnosis of a hearing loss. We believe that many children obtai*n great benefit* from their implant. We do, however, believe that some of the submissions to the Inquiry downplay less than successful outcomes, do not acknowledge the complexity of the personal, social, linguistic and educational factors that determine outcomes, and, in particular, misrepresent the effects of the addition of vision to communication input and misrepresent the demonstrated role that a sign language can play in the development of speaking, listening and cognition in deaf children, including those with implants.

Hearing, the Shepherd Centre CEO Ms Anthea Green, describes the technology of the cochlear implant and the development of implanted deaf children as ‘a miracle’. Such language is neither scientific nor accurate.
Recent and continuing studies show that the outcomes of implantation, while undoubtedly beneficial for many, are by no means consistently beneficial across all individuals and situations.

Research on outcomes of cochlear implantation of young children

There is much research to indicate that many children benefit from early implantation (for example, Simonsen, Kristoffersen, Hyde, & Hjulstad, 2009; Geers, Tobey, Moog, & Brenner, 2008).

However, much research also indicates that results are quite variable and some children do not obtain great benefit (Hyde & Punch, 2009; Hyde, Punch & Komesaroff, in press, a, b).

Spencer (2004), for example, found that language outcomes of implantation ‘ranged from extremely delayed to age appropriate. … [and] varied across [all language] domains’. In her sample, vocabulary outcomes was within the average hearing child range for several children, but for most were average or below. On a syntax test all scores were below the average hearing child range. The younger that children were implanted, the better were their test outcomes. Of particular interest for the ‘opt-in/opt-out’ debate was her finding that ‘*Qualitative analyses indicated higher child language achievement [was] associated with parents’ reports of lengthy, in-depth processes to decide about cochlear implantation’ (our italics).*

A lack of information from early intervention program providers about options for communication, and particularly about the use of Auslan, is reported by Hyde and Punch (2009), who found that ‘many parents expressed a wish to have received information on a broader range of subjects, including social and educational aspects and communication methods, than was readily available to them at the time of making the decision’.

These findings are particularly important in the light of Zaidman-Zait and Ferguson’s (2004) finding that on the Web, where many parents may turn for information,

> Information relating to education, key aspects of habilitation, and choice of communication approaches—all vitally important topics to parents of deaf children—were either barely addressed or neglected altogether. These topics are very relevant to parents in light of the existing debates related to habilitation approaches involving different communication modalities, especially the use of sign language, with deaf children who are cochlear implant recipients. This information is particularly vital because parents

> often make decisions concerning their child’s educational placement and mode of communication concurrent with the decision for cochlear implantation.

They conclude, ‘Overall, then, professionals have a responsibility to guide parents in how to use the Web efficiently, promote parents’ awareness of its disadvantages, discuss the information parents found on the Web, and refer parents to high-quality Web sites’.

Hyde, Komesaroff and Punch (in press, a, b) conducted an Australian Research Council funded research program in partnership with Deaf Children Australia between 2007 and 2009 in the eastern states of Australia. This study, the largest of its kind in the world, has revealed a great deal of the complexity involved in the use of CIs with young children and the differences between what their parents ‘expected’ to happen and what they subsequently ‘experienced’.

This study revealed a number of areas where continuing development and research are critical. These areas include the level of information and ongoing support available for parents in deciding to have their child implanted and the management of their child’s continuing hearing impairment, social and educational development and communication after implantation (see also Hyde & Power, 2006).

Most of the more than 230 parents in Hyde et al.’s Australian study described their child some years after receiving an implant as still ‘deaf’ or ‘socially deaf’ in many situations, especially outside clinics, where most studies reporting implant success have been conducted. For the school years Hyde and Power (2002) demonstrated that many deaf students ‘included’ in regular classrooms were actually quite isolated in social integration terms.

It appears that sometimes children regarded as gaining good benefit from their implant do not cope as well in social situations (e. g., in classrooms) as do children perceived as gaining lesser benefit.

Kermit, Holm & Mjøen (2005) found, for example

> ‘successfully’ implanted children might face greater difficulties building their identities among speaking peers than ‘less successfully’ implanted children among signing peers. The successful implant user in our study … experiences a lack of recognition in his everyday life on a social level, something that might harm his building of an authentic identity.
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> To implant a deaf child does not necessarily mean securing it [sic] the right to an open future. Our findings show having a cochlear implant might mean loosing important future opportunities. … Our findings point at the different choices made and decisions taken on behalf of the child. If the functional

> use of language in social discourses with peers is a desired outcome, then programs in which clinicians or parents attempt to highly structure the language development of an implanted child may be both too narrowly conceived and ethically problematic.

In the Hyde, Komesaroff and Punch (2009) the large database showed 52% of the students with a CI were in regular classrooms and 51% of these received additional learning support. In terms of school achievement, the class teachers of the children with a CI reported that 69% of these students were below the median levels of achievement of their class peers in key curriculum areas. Clearly these are areas that need to be addressed before anything close to universal benefit for the use of cochlear implants could be claimed (Hyde & Punch, submitted).

Of particular concern in Hyde et al.'s data was the finding that many of the parents said that they believed the implant was 'the only option' for their child. Considering that other options could have included the use of hearing aids, speech and language support programs and access to bilingual programs involving English and Auslan, this finding represents a severe lack of understanding and possibly a restriction of their level of informed consent (Hyde & Power, 2000).

Thus, there are severe deficiencies in the educational and social development of implanted children that remain to be addressed, including delays in literacy and numeracy development.

The role and effects of signing in early language and cognitive development

Another assumption in the Shepherd Centre submission concerns the status of bilingual programs involving the use of spoken English and Auslan or signed English with young deaf children. There is a claim that any signing in early intervention programs leads to poorer speech and English language development.

Most studies conducted internationally point to benefits, and not disadvantages, in the use of bilingual programs for young deaf children (for example, Preisler, Tvingstedt & Ahlstrom, 2002). After all, being bilingual and even multilingual, is common in most nations of the world. The suggestion or implication in the Submission by the Shepherd Centre that exposure to Auslan represents a loss of capacity to acquire and use English is not supported by any credible research and creates an 'either/or' consideration in the minds of parents and the media: that is, either the child speaks and listens, or learns a sign language. Nothing could be further from the truth as common experience shows with other languages acquired simultaneously by Australians in multicultural settings. Why should deaf children be excluded from access to a natural signed language whose design characteristics foster effective acquisition by visual learners, and is not a threat to spoken language acquisition?

Thus, the ‘either/or’ case that is presented is faulty on scientific and linguistic grounds. Indeed, Auslan has been a priority language within Australia’s National Language Policy since its inception (1987). The promotion of an ‘opt out’, rather than an ‘opt in’ situation for implantation of children identified as being deaf in newborn hearing screening programs is a serious misunderstanding of the processes of parental decision making and a misjudgment of the ethics of professional conduct.

The sources of the fear of sign language and the folklore that developed about its imagined capacity to reduce the need to speak or listen are hard to identify. There is perhaps some ‘primitive’ logic that is applied or continued from a 1950’s view of the ways in which a spoken and a signed language might interact negatively.

The advocacy of not signing with deaf children in early intervention programs is often justified by a supposed need for deaf children to function as ‘auditorily’ as possible in order to develop normal speech and listening. In some cases it is advocated that even allowing speechreading by the child to accompany speech from others not be permitted. This is known as a “unisensory” approach[2] and is used by several of the programs that have submitted to the Inquiry. Power and Hyde (1997) have argued that this view is mistaken and may well impede rather than enhance the language and speech development of deaf children. They adduce evidence from normal sensory, linguistic and perceptual development and information processing and early intervention pedagogy theory to demonstrate that multisensory approaches involving ‘traditional oral-aural’: using hearing and vision, provide much better development opportunities for young deaf children, even without the possible benefits of signing.

Parental knowledge of implantation outcomes

Our studies and those of others consistently show that parents make many decisions about their child in terms of the prostheses they use, the languages they use, the schools and programs they choose and the future lives that they envision. To achieve these outcomes parents need comprehensive and ongoing information and support at a time when they are most vulnerable and emotional following the early diagnosis of their child’s hearing loss. An ‘either/or’ presentation, with the faulty assumptions outlined above, limits parental choice. If nothing else, the principle of informed choice dictates a more supportive and comprehensive response from governments, their authorities and early intervention program advisors.

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[2] Also known as an “Auditory-Verbal” approach (http://www.avuk.org/approach.html#crit)

Hyde et al.'s studies show that parents are ill-prepared at the stage of diagnosis to consider the nature of their child's 'future life'. They are neither exposed to nor informed about the potential 'other side' of their child's future life as a person who could be equally at home amongst users of English, spoken and written, and users of Auslan. There is no conflict in this situation. However, most parents are largely unaware of this potential outcome, and they are not encouraged to consider it.

Another feature in the findings of Hyde et al.'s study relates to the unexpectedly high levels of stress experienced by parents following the implantation of their child. Parents were unprepared for the diversity and complexity of possible outcomes and their associated responsibilities and choices over time. This finding relates strongly to the need for a more comprehensive and ongoing level of support for parents, rather than the simplistic presentation of a 'miraculous cure', an 'either/or' choice of language mode, or an automatic 'opt in' situation for the implantation itself. This finding is further emphasised by the significant 27 percent of young deaf children with an additional impairment. Intellectual, cognitive, or behavioural impairments mean the outcomes of implantation are even less predictable and more variable.

Outcomes of survey of longitudinal studies of cochlear implant effects

After an exhaustive survey of 57 longitudinal cochlear implant research studies in the USA from 2000-2007, Belzer and Seal (2009) concluded that there were 'supportive outcomes' for many implanted children, but warned 'in some cases [reports of supportive outcomes] may have set inflated expectations for the professionals working with these children and the children's families'.

They found that some samples on which reports were based were not representative of the US demography of childhood deafness ('limited attention has been given to race and ethnicity, socio-economic status, and co-morbid conditions [multiple disabilities]') and that some samples appear to contain 'more privileged' children than others, and even in those, there was considerable variation in developmental outcomes. They state that future research should seek to find truly representative samples and disclose demographic variables, including SES and additional disabilities, that might 'threaten or confound' outcomes evidence '… [and advisors should] temper… conclusive statements that suggest relevance to the population at large'. Belzer and Seal also note that while early reports found a trend towards negative findings associated with children from Total Communication programs (being the use of speech and sign, usually a form of signed English, simultaneously), 'that trend appears to have diminished towards the latter part of the present decade'. As we have noted above, there appears to be no diminution of the benefit of cochlear implants when good oral-aural training is included in TC programs.

Conclusions

Summing up, we have argued that research has demonstrated that under the right conditions, use of signing, Auslan in Australia, if anything facilitates the acquisition of oral/aural skills. As the distinguished American educator of the deaf Dr Donald Moores, after a very large study of early intervention programs in the United States found (Moores, 2008).

> Manual communication had no influence, per se, on the development of oral aural skills, the key factor was the level of speech and auditory training. If a program using sign and/or the manual alphabet had a well developed system for speech and auditory training, the results would be similar to those for auditory or oral aural programs.

Moores concludes

> [My] final concern involves the use or ASL or English based signing with children with implants. There seems to be a common theme among many, but not all, proponents of implants that children, families, and educational programs should not sign. I have heard parents state that they choose to have their children hear and speak and therefore will not sign. If their children want to sign later, fine, but not while they are acquiring spoken language. Whatever their decision, I wish them, and their child, success, but I am afraid that they have been faced with an unnecessary either/or decision when a both/and option might be more feasible. A judicious mix of sign and speech communication may be effective in enhancing communication and learning and will pose no threat to oral development. Withholding sign may have a deleterious effect for some children. There is a danger that to the old philosophy that children should be allowed to succeed or fail orally before assigning the losers to some kind of manual communication is being resurrected for children with implants. This is unnecessary and self-defeating. First, signs can be integral to a child's development. … Waiting for a child to show a certain level of progress orally represents a regression in our field. We need an attitude adjustment if we are not to lose another generation of deaf children.

As a final point it is worth noting that Australia has signed and ratified the 2007 UN Convention on the Rights of People With a Disability. Under this commitment we are required to ensure the right to access a sign language, the right to be educated by teachers fluent in sign language, to facilitate the learning of sign language and the promotion of Deaf community. The Convention (Hyde, 2007, 3c) binds its signatories to

> Ensuring that the education of persons, and in particular children, who are blind, deaf, and deaf-blind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in

environments which maximize academic and social development.

To deny, restrict or limit this access though regulation, policy, recommendation, or practice would be a clear breach of our national and international commitment.

In relation to the question posed in this Submission as to whether parents should be required to 'opt out' of the potential cochlear implantation of their severely or profoundly deaf infant or young child the answer from the various perspectives of informed consent, research findings, and our international UN obligations is that we should not make any change to current provisions and associated systems in this regard. Australia already has highly effective newborn hearing screening programs *and* one of the highest rates of cochlear implantation of young deaf children in the developed world. This does not mean that we should not do more, particularly in respect to the need for further research examining current research findings of poor performance of children with implants in many of our schools.

Similarly, on the question of whether signing impedes the acquisition of oral/aural skills in implanted children, we have shown that there is little evidence for this claim, and when good oral/aural teaching is part of a program, there are benefits in all areas of development, including listening, speech, and language.

The quality, quantity and period over which we provide information to parents of young deaf children must be increased so that their decisions are more comprehensively informed than is presently the case. Parents need to be able to access this information through more appropriate models of ongoing support for the many decisions, stresses and challenges that they experience not only in the initial decision about implantation, but also in the many future decisions and actions they will need to take. No simplistic 'one size fits all' response for an 'opt-out' option from government or government-sponsored or private agencies, where the use of a CI is seen as essential or associated with universal benefit, is warranted or scientifically justifiable.

To better serve parents and their deaf children, we suggest that there is a need for increased support for further research to examine not only the clinical applications of cochlear implants but also their use in social, cognitive, linguistic and bi-linguistic, educational and future life situations. The current research described in this submission points to many challenges still to be recognized and addressed in these areas to ensure that parents' consent is truly informed.

References

Belzer, K. A., & Seal, B. C. (2009). Children with cochlear implants: A review of demographics and communication outcomes. *American Annals of the Deaf, 154* (3), 311-333.

Geers, A., Tobey, E., Moog, J., & Brenner, C. (2008). Long-term outcomes of cochlear implantation in the preschool years: From elementary grades to high school. *International Journal of Audiology, 47* (S2), S21-S30.

Hyde, M. B. (2007). *Deafness and Human Rights. How the 2007 UN Convention on the Rights of Persons with Disabilities may influence current policies and programs*. Keynote presentation at the Nordic Conference: The dual languages of deaf and hearing-impaired children. Gothenburg, Sweden, September 3rd, 2007.

Hyde, M., & Power, D. (2000). Informed parental consent for cochlear implantation of young deaf children: Social and other considerations in the use of the 'bionic ear'. Australian Journal of Social Issues, 35, 117-128.

Hyde, M., & Power, D. (2006). Some ethical dimensions of cochlear implantation for deaf children and their families. *Journal of Deaf Studies and Deaf Education*, *11*, 102-111.

Hyde, M., & Punch, R. (2009). *A comparison of anticipated benefits and the personal, educational and social outcomes of cochlear implantation in deaf children*. Summary Report of Australian Research Council Project, Griffith University Gold Coast School of Education and Professional Studies.

Hyde, M., Punch, R., & Komesaroff, L. (in press a). A comparison of the anticipated benefits and received outcomes of pediatric cochlear implantation: Parental perspectives. *American Annals of the Deaf.*

Hyde, M., Punch, R., & Komesaroff, L. (in press b). Coming to a decision about cochlear implantation: Parents making choices for their deaf children. *Journal of Deaf Studies and Deaf Education.*

Kermit, P., Holm, A., & Mjøen, O. M. (2005). The ethical debate on cochlear implants and outcome assessments of pediatric cochlear implantation. Paper presented at the Nordic Conference on Education of the Deaf, Olso, June 30th.

Lo Bianco, J. 1987. *National Policy on Languages,* Canberra: Australian Government Publishing Service.

Moores, D. (2008). Editorial: cochlear failures. *American Annals of the Deaf, 153*, 423-424.

Power, D., & Hyde, M. (2002). The characteristics and extent of participation of deaf and hard of hearing students in regular classes in Australian schools. *Journal of Deaf Studies and Deaf Education*, *7*, 302-311.

Power, D. J., & Hyde, M. B. (1997). Multisensory and unisensory approaches to communication with deaf children. *European Journal of Psychology of Education, 12*, 449-464.

Preisler, G., Tvingstedt, A-L., & Ahlstrom, M. (2002). A psychosocial follow-up of deaf preschool children using cochlear implants [electronic version] *Child Care, Health & Development, 28 (*5), 403-418.

Spencer, P. (2004). Individual differences in performance after cochlear implantation at one to three years of age: Child, family, and linguistic factors. *Journal of Deaf Studies and Deaf Education, 9* (4), 395-412.

Zaidman-Zait, A., & Ferguson, J. (2004). Searching for cochlear implant information on the internet maze: Implications for parents and professionals. *Journal of Deaf Studies and Deaf Education, 9* (4), 413-426.