



## A comparison of Anticipated Benefits and the Personal, Educational and Social Outcomes of Cochlear Implantation in Deaf Children

This research project, commenced in 2006 and funded by the Australian Research Council with support from Deaf Children Australia as industry partner, has now completed its data collection and analysis stages and the results are being compiled for publication. The original investigators were Dr Linda Komesaroff, Faculty of Education, Deakin University, Professor Merv Hyde, School of Education and Professional Studies, Griffith University, and Professor Mirko Bagaric, School of Law, Deakin University. In August 2007 Dr. Renée Punch joined the project as a Senior Research Fellow. This report was prepared by Professor Merv Hyde and Dr Renée Punch.

Ethics approval and support for the conduct of the study were provided by a number of education departments, cochlear implant programs, and other organisations that participated in the study; these are indicated in the Appendix. Significant interest in the study is already appearing in national and international forums. To date, one paper has been presented at a conference in Norway and another is scheduled for presentation at the Mental Health and Deafness conference in Brisbane in October 2009. Currently, seven individual papers are in preparation for publication in international journals.

The following summarises the focus of the study and its findings.

### **Description of the study**

The study investigated three major aspects of childhood cochlear implantation: 1) the expected outcomes of implantation; 2) families' decision-making process; and 3) the personal, social, and educational outcomes of cochlear implantation for deaf children and their families. It examined these areas with a relatively large sample of parents, teachers, and young cochlear implant recipients across a range of locations in Queensland, New South Wales, and Victoria. It included children with varying lengths of time since their implantation and thus gained the perspectives of the parents, teachers, and children about the lived experience and functional outcomes for implanted children and their families over time.

The parent survey contained three sections. The first collected demographic data about the children and their families. The second contained questions about the parents' experiences of making the decision to implant their child. The third contained five

subscales asking parents to indicate their pre-implantation expectations and post-implantation experiences of their children's outcomes. These subscales were 1) Communication Abilities, which reflected abilities in spoken language in functional, everyday situations; 2) Social Skills and Participation, which was concerned with children's acceptance by hearing peers, social participation with children in general, and having improved social skills; 3) Wellbeing and Happiness, with items about children's happiness, frustration, and safety with the implant; 4) Academic Achievements, including children's ability to participate in regular classes and items concerning levels of achievement in numeracy and literacy; and 5) Future Life, with items about children's general functioning and independence as well as their identity as deaf or hearing persons.

The teacher survey asked teachers to report on outcomes in the same domains as on the parent survey, with the exclusion of the Wellbeing and Happiness subscale, which contained items specific to parents' knowledge of their children. An additional section of the teacher survey assessed the level of participation of children in their school and classroom activities in four areas: academic, social, independence, and physical presence in the regular classroom.

The study utilised a mixed methods approach that allowed the quantitative survey findings to be extended and elaborated by qualitative findings from in-depth interviews and open-ended written responses. This combination of methods proved to be efficacious in not only revealing the specific quantitative details in answer to the research questions, but also increasing the relevance of the quantitative findings by enabling a deeper understanding of parents' and children's implant experiences through the analysis of the qualitative data.

### **Participants**

Surveys were distributed to parents of children who had received cochlear implants before the age of 18 and to teachers working with deaf children in early intervention programs, primary schools and high schools. Each teacher and early intervention specialist supporting children with cochlear implants was asked to complete a survey based on one randomly selected child whom they supported. Completed surveys used in the analysis numbered 247 for parents and 151 for teachers. The children reported on in the surveys had a range of ages, age at implantation, and duration of implant use. Almost 90% of the parent survey respondents were mothers. Despite sustained efforts to include parents who were Deaf, only one survey respondent was a Deaf parent.

Approximately 10% of the respondents in these two groups were interviewed: 27 parents and 15 teachers. In addition, 12 implant users, aged between 10 and 17 years, have been interviewed.

### **Making the decision for cochlear implantation**

The quantitative findings indicate that, in making the decision for their children to have cochlear implants, parents used a range of sources of information, most especially cochlear implant programs, audiologists, and doctors, with these sources being followed in importance for parents by families of children with cochlear implants. Relatively few parents used deaf organisations or deaf adults, with or without cochlear implants, as information sources. In the interviews, 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.

The majority of the parents reported that making the decision to have their child implanted was stressful and difficult. However, a sizeable group of parents reported otherwise. These parents tended to decide quickly, usually because they felt that an implant was the “only way” their child would gain communication through speech and hearing, and so was the only option for their child. Overall, the decision-making period was quite short, with 60% of parents taking less than three months to make their decision.

Parents generally found making decisions about having a second, bilateral implant for their children more difficult than the first, being concerned that possibly marginal gains might be outweighed by disadvantages.

### **Parents’ expectations and experiences of children’s outcomes**

The study compared parents’ reports of their pre-implant expectations with their experiences of post-implant outcomes on a large number of items related to the five outcome domains. The quantitative findings indicate that this group of parents as a whole had held relatively high expectations of their children’s communication, social, academic, wellbeing and future life outcomes from cochlear implantation. They also indicate that the parents’ experiences of their children’s outcomes with their cochlear implants were relatively high. There was quite a close match between expectations and experiences, and where there were high levels of uncertainty in expectations, these were informed by experiences, usually in a positive direction. There were particular outliers from this general conclusion in the academic achievements domain, particularly in the case of achievements in literacy and numeracy, where parents’ uncertainty about possible outcomes moved in both directions with experience, but with more parents indicating a move in a negative direction than was found in the other domains. This is obviously of concern.

Of responses to questions about overall satisfaction, four fifths of the parents indicated that their expectations had been met. These findings suggest that the majority of parents had high levels of satisfaction with their children’s outcomes with their cochlear implants. Nevertheless, a proportion of the parent group did not indicate satisfaction. For example, a tenth of parents reported that their overall expectations had not been met. Further, a tenth of parents were not currently satisfied with their children’s communication abilities, social skills, and academic abilities. These findings are consistent with those of other studies in which between 5% and 20% of parents have reported unmet expectations.

From the qualitative findings, it is clear that parental expectations were closely intertwined with parental hopes. The findings suggest that parents’ expectations, hopes and beliefs about cochlear implantation may more accurately reflect the love they have for their child, the determination they have to do the best for their child, and their conviction that a cochlear implant is the only way for their child to most fully participate in a hearing world, than arise from the range of outcomes explained to them by professionals. Parents tended to interpret such explanations in the most positive context.

### **Comparison of parents’ and teachers’ experiences of children’s outcomes**

There were statistically significant differences between teachers’ and parents’ reports of children’s outcomes on the four domains common to both the parent and the teacher surveys, (communication abilities, social skills and participation, academic achievements, and future life) with teachers reporting lower levels on all four subscales. As noted above, the strength of parents’ hopes for their children and their emotional investment in their children’s implantation could have led to generally more positive perspectives of the outcomes than those held by teachers. However, although parents and teachers were

reporting on children drawn from the same population (i.e., children who had been implanted in NSW, Victoria and Queensland), these two groups of respondents were not necessarily reporting on the same children in each case.

### **Communication outcomes**

Spoken language communication abilities were reported to be relatively high by parents and somewhat lower by teachers. Some children were developing, or had developed over a period of years, near normal speech and language outcomes, but these tended to be in specific situations involving familiar communication partners, such as family members, and in familiar contexts and optimal listening environments. In broader contexts, such as in regular classrooms and in social groups and gatherings, the picture is not as positive, with parents and teachers reporting difficulties for children in these environments.

### **Social outcomes**

In the survey subscale of social skills and participation, parents indicated relatively positive outcomes for their children. However, the qualitative findings reveal that the area of their children's social skills and participation remained a concern for many parents, who were aware of their children's difficulties in groups and how those difficulties affected their social inclusion. For many parents, worries about social participation increased as their children reached adolescence and appeared to struggle with issues around being deaf and fitting in with hearing peers. In addition, findings from both the quantitative and qualitative teacher data indicate less than optimal social outcomes. It appears that even children with excellent outcomes in spoken language development and communication experience the phenomenon of "social deafness."

Overall, it seems that issues around friendship and fitting in with hearing peers were as real for these children with cochlear implants as for other deaf or hard of hearing children for whom these social problems have been reported in the literature.

### **Academic outcomes**

More than two thirds of parents reported that their children were able to participate easily in a regular class, and slightly more than one third of teachers reported this. Between 50 and 60% of teachers disagreed that children were achieving high standards in reading, writing, and maths, or were achieving at the expected level for their age, whereas between 18 and 23% of parents indicated disagreement on these items.

### **Wellbeing and future life outcomes**

In areas of children's general functioning, independence and identity as deaf or hearing persons, the large majority of parents believed their children were happier, less frustrated, and safer than they would have been without the implant. Almost 60% of parents believed their child functioned like a child with normal hearing, whereas only 30% of teachers reported this. Close to 30% of parents and teachers believed the child had developed an identity as a deaf person, while two thirds of parents, and slightly more than one third of teachers, reported that the child comfortably shared both deaf and hearing identities.

### **Impact on the family, parental stress and rehabilitation demands**

A statistically significant difference was found between parents' expectations and experiences on the rehabilitation stress subscale of the survey, with parents experiencing more stress than they had expected pre-implantation. In addition, living in an outer

regional or remote location was found to predict higher levels of parental stress. A major theme in the qualitative findings concerned the amount of work and time parents dedicated to their deaf child in the areas of early intervention and speech training as well as in terms of frequent appointments for mapping and other ongoing requirements related to the use of the cochlear implant. They reported feeling stressed by the time needed to travel to and attend appointments, and by the difficulties this imposed on their other children and on the family's financial situation.

The extent and quality of support in practical, functional ways was an issue for many parents. Parents described frequent problems with implant equipment breaking and parts needing replacing. When these could not be replaced quickly, it was worrying for parents and difficult and frustrating for their children to be unable to use their implant and thus be without their means of hearing, sometimes for several days in the case of families living long distances from appropriate services. It was clear in our interview findings that parents greatly appreciated when replacement parts, loaner speech processors, or repairs were delivered expeditiously.

Parents whose children did not do well with the implant and whose speech and language development was poor clearly went through particularly stressful periods. In cases where auditory-oral approaches were not proving effective and parents moved towards using sign, they often lost a valuable support base if they were unable to continue attending the same early intervention centre.

#### **“Still deaf” and the role of sign language in the children’s lives**

The quantitative findings indicated that parents overwhelmingly chose cochlear implantation for their children as a means to develop communication through hearing and speaking, and that parents' expectations in the main were that their children would not need to use a sign language or sign support. However, experience would seem to have tempered this perspective to some extent and a substantial proportion (between 20% and 30%) of children were reported by both teachers and parents to be using some form of sign communication.

The qualitative findings elaborated on these findings, providing details of ways in which children were using sign and of parents' views about sign communication. The interview findings showed that many parents, despite facing, at times, strong discouragement from early intervention centres and cochlear implant clinics, had become convinced of the benefits of sign language for their children. These parents saw the value of developing communication with their children through sign language so that they could communicate whenever the children were not wearing their implants' external device, whether because of equipment breakdown, or when the children were in situations where it could not be worn, such as swimming. Some parents also valued Auslan as a way for their children to establish a connection to other deaf people and a sense of Deaf identity, or of a dual, Deaf/hearing, identity. However, the issue remained relatively unclear for the majority, and is a worthy topic for future study.

Parents often used the term “still deaf” to describe their children. They, and some of the teachers interviewed, asserted that many people, including regular class teachers and school authorities, had misconceptions about the nature of cochlear implantation and did not understand that the children still experienced limitations to their hearing, difficulties managing in many auditory environments, and delays in aspects of their development that necessitated ongoing support and accommodations in the school setting.

### **Factors predicting outcomes**

Through multiple regression analysis of the parent and teacher survey data, a number of key predictors were identified. Some of these were associated with perceived positive and some with perceived negative outcomes. Among the large number of variables related to family and child characteristics, educational and communication factors, and the parents' implant decision-making process entered into the series of step-wise regressions, a number were found to be consistently associated with children's outcomes in the areas of the subscale domains.

Several variables related to oral communication and mainstream placement were shown to predict positive outcomes in many of the domains in both parent and teacher survey findings. This could be explained by sign language programs being largely associated with late diagnosis and the presence of additional disabilities, as well as the scarcity of comprehensive bilingual programs outside metropolitan cities. This combination of factors means that many of the students determined to require access to sign language or signed English were in fact placed in special education rather than regular class programs; in these contexts a high standard of oral communication outcomes is not the norm.

Consistent with other studies, a younger age at implantation was found to be a predictor of positive communication and social outcomes. The child having a bilateral implant was predictive of positive communication, social, and academic outcomes in parent reports and of future life outcomes in teacher reports, noteworthy findings adding to the still relatively limited knowledge of broader outcomes of bilateral paediatric implantation.

The child having additional disabilities was strongly predictive of less positive outcomes in all domains in both parent and teacher reports.

The regression findings also indicated that families' location in major city areas was associated with positive communication outcomes, and that living in regional or remote areas predicted greater rehabilitation stress for parents. In addition, teachers having high levels of communication with other professionals, such as audiologists and speech pathologists, about the child's use of and progress with the cochlear implant predicted positive outcomes in all domains. Some variations across States were found, with teacher data showing that being in Victoria was associated with higher academic achievements and being in Queensland was associated with less positive communicative and social outcomes. These differences may reflect differences between the states' systems and programs. Although programs providing Auditory-Verbal Therapy (AVT) are of recent origin in all states, NSW and Victoria have long traditions of auditory-oral programs in both preschool and primary school settings. This has not been the case in Queensland, and indeed, children who were not in special education settings were placed in the mainstream. The advent of the Hear and Say Centre in Queensland has, of course, added an option. The variations may also reflect the geographical dispersion of families, with some of the study participants in Queensland living at far greater distances from urban centres than families in Victoria. Further inquiry from the perspective of research and evaluation of current programs is required to elaborate on these differences.

A number of practical implications were drawn from the study:

### **Implications for cochlear implant programs**

Implant programs should continue to advise with caution about the range of likely outcomes but also be aware that families are likely to be influenced by their hopes and aspirations for their children as much, if not more, than by the information they have received. Consequently, information giving and receiving processes should be regularly repeated and evaluated through ongoing discussion and counselling. As well, the important role played by hope needs to be recognised, as parental hope and optimism can drive the action, determination, and hard work that contribute to children's progress and optimal outcomes from their cochlear implants. There seems to be no evidence in the literature that excessive hope is ever a 'bad' thing. Professionals, however, in implant, therapy, and educational programs need to find the difficult balance between working with parents' hopes to achieve optimal outcomes and ensuring parents have realistic expectations of their children's cochlear implantation.

For children to receive optimal benefits from their implants and for the demands and stress on parents to be reduced, it is necessary that continuing efforts are made to improve access to audiological, habilitation and ongoing device maintenance services for families who live in regional or remote parts of Australia. The trans-disciplinary 'case manager' approaches and outreach initiatives which several Australian states have been adopting following the introduction of newborn hearing screening have strong potential for offering non-biased and comprehensive support for families as they make decisions and monitor the progress of their child. However, these state systems need to access the full range of support and information services available to parents including, not only audiological and educational intervention services, but also parents' support organisations and social and cultural organisations representing the various perspectives of deafness

In this context, it may be important for information about sign language and the Deaf community to be more accessible to families both before and after their children's implantation, and for parents to be made aware that choice of a communication mode need not be an either/or option. In other words, sign language exposure and bilingualism is not solely something to be resorted to if children fail to develop oral-oral communication proficiency, but can be used to provide fuller access to cognitive development and communication competence across a range of situations and settings maximising the child's life experience and potential.

### **Implications for support services/counsellors**

It is important for service providers to sustain and encourage parents' hopes and to respond with flexibility when children's and parents' needs change over time, particularly when expected outcomes are not achieved and it becomes apparent that alternative strategies and approaches are necessary.

### **Implications for early intervention providers and education authorities**

From the perspective of their functional communication, children with cochlear implants should be supported by teachers and school authorities as if they were hard of hearing; that is, the children are likely to need supports similar to those provided to children with moderate or severe levels of hearing loss. This is not to suggest that their hearing status or spoken language capacity and proficiency is not high, but that they are likely to have

listening difficulties in particular contexts and will not have full access to the curriculum or to social inclusion.

It is apparent from the findings that ongoing, high levels of communication between teachers and other professionals contributed to positive outcomes in all areas of the children's lives. Given these findings as well as the finding of differences between parents' and teachers' perceptions of children's outcomes, the greatest possible connections among schools, parents, and implant programs should be forged. Indeed, it is likely that in some cases teachers may not be privy to much of the information that parents receive about the particular application of the implant in relation to their child. Teachers of the deaf may have a broad or even detailed understanding of cochlear implantation, but not the specifics related to any individual child, specifics which parents may be able to provide. In addition, the maintenance of the device necessitates strong communication links among teachers, parents and implant clinic professionals.

The effect on children's outcomes and parents' stress of living in regional and remote areas and thus at some distance away from easily accessible habilitation, early intervention and speech therapy services was clear in both the quantitative and qualitative findings. The current efforts of early intervention programs and educational authorities to expand their services to more distant geographical areas need to be continued and expanded.

Although parents and teachers reported better outcomes for those children who were not using sign, a substantial proportion of children were considered to need, and were using, Auslan or signed English, and many parents and teachers saw the use of sign as not incompatible with the main aim of the development of oral communication and cognition. However, parents' knowledge about sign language was often limited and access to information and direct experience with Deaf people was difficult for those families who did not live in metropolitan areas. Indeed, the impact of bilingual programs in Australia is relatively idiosyncratic and not pervasive, and the connections between parents and bilingual programs would seem to be relatively ad hoc in our data, particularly in comparison to some European contexts. The way in which parents might become associated with a bilingual program is not actively promoted in state policies and systems, nor is it by implant programs. State education authorities should be encouraged to more comprehensively explain the purposes behind their bilingual programs and particularly how they relate to processes of implantation. Deaf associations and deaf adults need to be more actively involved in this debate. Parent organisations such as Aussie Deaf Kids might well play a vital, yet perhaps insufficiently recognised, role in the process of connecting parents with deaf organisations, deaf adults, and bilingual programs. In addition, organisations such as Deaf Children Australia that promote the full range of communication and educational options and offer non-biased information and non-judgemental support to families of deaf children clearly have a valuable role to play, particularly in the early stages of families' decision making about cochlear implantation and the options, opportunities, supports and resources that are available. From our findings, organisations such as these would not seem to have been widely accessed by parents.

Both teachers' and parents' reports reflect limitations in the outcomes observed in relation to core elements (literacy and numeracy) of academic development. In addition, both groups of respondents reported delays or problems in aspects of social development. These two issues alone perhaps constitute the major challenge for schools, education authorities, and parents.

### **Forthcoming publications**

This is to date one of the largest studies of its kind in the world on the outcomes of children with cochlear implants. In particular, research that directly compares parents' pre-implant expectations with their later experiences of their children's outcomes on a range of communication, psychosocial, and academic items with a large sample has not been reported in the literature. The current study involved a sufficiently large survey sample of parents and teachers to allow a robust procedure of statistical analysis, and the in-depth interviews with parents, teachers and young cochlear implant recipients themselves extended and elaborated on the quantitative survey findings. The study is able to make an important contribution to the literature and reveals that studies that examine variables beyond those of auditory functioning and speech and language development indeed have an important role in investigating the nature of implant programs and their follow-up, family supports, and educational processes.

A great deal more detail will be provided in forthcoming publications. Articles in preparation focus on the following specific areas:

- parents' decision-making processes
- a comparison of parents' expected and experienced outcomes of implantation for their children
- factors predicting children's outcomes
- rehabilitation demands, stress, and the impact on families
- communication mode and the role of sign language in implanted children's lives
- teachers' perspectives of children's outcomes and the educational supports received and needed
- social outcomes from the perspectives of parents, teachers, and the young people themselves.

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## Appendix

### **Organisations participating in the research project**

Australian Research Council

Deaf Children Australia

NSW Department of Education and Training

Queensland Department of Education, Training and the Arts

Victorian Department of Education and Early Childhood Development

Sydney Cochlear Implant Centre

Victorian Eye and Ear Hospital Cochlear Implant Clinic

Royal Children's Hospital Cochlear Implant Clinic, Brisbane

Mater Cochlear Implant Clinic, Brisbane

Hear and Say Centre for Deaf Children

Royal Institute for Deaf and Blind Children

Taralye Oral Language Centre for Deaf Children

Parent Council for Deaf Education

Aussie Deaf Kids