

Deaf education:
changed by cochlear implantation?

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Deaf education: changed by cochlear implantation?

Een wetenschappelijke proeve
op het gebied van de Medische Wetenschappen

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Preface: A Personal Journey

“an awful lot of people are giving a lot of time to this - I wonder whether anything will become of it?”

A teacher of the deaf in her diary in 1987 the beginning of cochlear implants for children in the UK

As a trainee teacher in the late 1960's, I was fortunate to have a tutor who aroused my interest in the psychology and philosophy of education. After qualifying I taught young hearing children for six years in the north of England and had the opportunity to observe child development at first hand. I also experienced unexpected satisfaction when the children I taught developed a passion for reading, and an enjoyment of books. Many of these children came from homes where reading was not a common activity and where books were unavailable. The importance of the acquisition of literacy skills in these children became apparent; however, I was teaching literacy skills to children who had already acquired the language of their home and one took for granted that they came to reading with appropriate linguistic skills. A friend's deaf baby made me think again - I had only experienced deafness in old people, and hence thought of it as a communication challenge for the elderly. My naïve assessment was that there was little more to deafness than that. I had overlooked the fact that children are not born with facility in their home language and that this develops, over years, through parent/child interaction, and that hearing usually has a significant role to play in this. This child, unable to hear the conversation of her family, was unlikely to develop the spoken language of her family and community. The frustrations of both child and parents were immense and the hearing aids of the time gave little auditory information. They chose to learn sign language, which supported her communication development but did not provide the ease of communication they had with their other child, who was hearing, or access to spoken English. For the first time I realised that the challenge of childhood deafness was not one of communication, but of spoken language development.

Relocating to Birmingham in 1976 I had the opportunity to train as a teacher of the deaf, and once more I was fortunate to have inspiring tutors and teachers of the deaf to work with. An introduction to the literature, for example the work of Myklebust and Furth on the impact of deafness on the linguistic and cognitive development of young deaf children proved absorbing and fascinating. At this time there was a growing interest in the psychology of deafness and the impact of deafness on the social and emotional wellbeing of the child and family; this

opened up areas of study previously unknown to me, as did reading the work of Chomsky and Crystal on “normal” language development. There were also huge strides being made in audiology services, with the first post aural aids being introduced, the first family services and peripatetic teaching services for deaf children supporting parents in the use of what were then the latest hearing technologies. The new work of Ling and Pollack in the 1970’s in utilising hearing through auditory training tapped into my previous knowledge of physics and maths, and enabled me to understand most of it.

However, at this time there was also a growing awareness of the deaf community as a minority group with its own language and culture. Visits to a range of schools for the deaf made me immediately aware of the passion which surrounded the controversies about how deaf children should be taught, whether orally or by sign language. Meeting deaf adults in schools for the deaf, and meeting those who espoused oral methods further complicated my thinking. If children couldn’t hear spoken language, how were they to develop it and how could oral methods work? Yet those learning sign language, with its own grammar, found it difficult to access the curriculum in English - or to communicate with parents and siblings or the hearing world. Additionally, within each modality were various teaching techniques with their own advocates. The conviction of the various proponents amazed me, coming from the more straightforward world of mainstream education, and were difficult to comprehend.

After qualifying as a teacher of the deaf, I worked in a residential school for the deaf which supported very challenging children from throughout the UK using sign language. Teaching deaf teenagers with very delayed communication skills and language levels taught me at first hand the impact that deafness can have on social and emotional development as well as linguistic and educational attainments. Moving to an oral day school for the deaf gave me opportunity to observe other methods at work and to observe the impact of deafness on early language development. I also came to realise the complex profession I had joined. These teachers were passionate about the children they taught and their needs and the controversies I had read about came to life daily in the staff room discussions. Deaf education was indeed facing major challenges but there was little consensus about how to deal with them.

Relocating again, in 1980, gave me the opportunity to manage a resource base, or unit, for young children in a mainstream school. This brought fresh challenges, to

manage deaf children with their hearing peers, within a non-specialist setting, and to work more closely with their families. Throughout these years of teaching deaf children one was constantly made aware that what had been taken for granted with hearing children was not possible with these deaf children, and teaching them within a mainstream environment made this apparent every day. Each new word or concept was taught by someone – either by their parents or myself, not learnt through hearing them in the usual way. Acquisition of language was not a natural process – it was a teaching process. I had initially thought that communication would be difficult because of the lack of hearing – that they could not hear me and I could not understand their speech. How much more was there to it than that. Parents and I shared home/school books in an attempt to share our knowledge of these children and to facilitate communication; without this it was impossible to understand what the children were trying to tell us. New vocabulary at home and school was shared – we could both make accurate lists of the words these children knew because we had taught them, the children had not acquired them by hearing them. I became adept at simplifying language to make it understandable. Yet I was determined that we should not concentrate on the “mechanics” of speech and language learning – the joy of communication and learning seemed essential and was not often present in some of the rote methods I had observed.

However, hard as one tried, enjoyment of reading seemed to be missing as reading sessions became reduced to language teaching sessions. Sharing a book with a young profoundly deaf child in the days before implantation, was impossible as the child could not look at the book and understand what the adult said at the same time, without visual clues. These children did not come to reading with a knowledge of the language or of its phonology – these had to be taught. Reading skills used by deaf children and their teachers were different to those I had used with hearing children, and clearly were not helping the children to read effectively – or with enjoyment.

Time and again one was faced with the impact of linguistic delay on cognitive understanding and hence on social and emotional development. For example, how did one explain in the playground that the push on the shoulder by another child had been an “accident” and not a deliberate act? These children had been taught that the word accident meant a car crash – what had that to do with being pushed over at play? The subtleties of language were lost and daily one was faced with the impossibility of in-depth discussions with those with delayed language competencies, and the effect of linguistic delay on cognitive development.

The negative impact of deafness and linguistic delay on emotional development was often increased by the behaviour of carers, and the effect of over protection. One observed children's behaviour being excused because they didn't have the language or vocabulary to understand the issue – how did they become mature adults if they weren't expected to take some responsibility from an early age? How did one generalise language learning, and facilitate progress through the cognitive stages I had observed occurring in hearing children? Often the teaching methods used with deaf children seemed at odds with what I knew of child development – and yet one felt instinctively that they were children first with the needs of a child – and deaf secondly.

While all this personal thinking and close observation was going on, the children I taught were frequently the subject of researchers, who would observe them in school. Their research reports rarely threw any light on the issues I thought were important, and rarely took account of the many factors which influenced the behaviour they were observing. Their interpretations were often simplistic – I became increasingly aware how many factors influence the development of deaf children – and how heterogeneous they were as a group. Levels of hearing loss, use of hearing aids, aetiology or parental input rarely appeared as significant factors in research reports. Most of all, I realised the responsibility of those of us in deaf education: hearing children usually acquire language with or without good teaching – deaf children did not. Educational attainments, social and emotional development, and later employment opportunities are grounded in the early development of communication and language skills, which cannot be taken for granted with these children.

During the 1980's the Deafness Research Group was established at Nottingham University, led by David Wood, and gave an opportunity for an objective assessment of the challenges in the classroom for deaf children, with practitioners being taken seriously and with rigorous academic input. The work of Wood with Margaret Tait, studying early communication with deaf children, looking at reading and storytelling techniques, caused me to think about a research degree. The option to carry out an action research degree allowed me to learn more about qualitative research techniques which seemed more appropriate to the observation of these children, and which threw light on the influences on their development, rather than hiding them.

While carrying out my research degree in 1986, I began teaching a boy who had lost his hearing following a fall, and his audiologist, Barry McCormick, began to think, with his mother, about a cochlear implant for him. The boy received only vibro-tactile sensations from the most powerful hearing aids available at that time; his speech deteriorated and accessing the curriculum in a mainstream class became almost impossible. The trauma of losing his hearing entirely at the age of six was devastating for him and his family. At that time, the only option was the RNID single channel cochlear implant, available in London, but only if he were an adult. If I had thought that deaf education gave rise to controversy, the consideration of a cochlear implant for a child was to arouse even greater passions. Investigations and meetings took place, with little family or local involvement, and operation dates came and went as the child and family became increasingly frustrated. After two long years of fighting and living an emotional roller coaster, he had his single channel implant in 1987 at University Hospital, London, performed by Roger Gray and Graham Fraser. The opposition to paediatric implantation was so great at that time that the family and myself were forbidden to discuss it with anyone, creating huge pressure for child and family. Following this we worked with the implant team and his family to maximise the benefit from the single channel implant – and wrote it up as a case study (Archbold et al, 1990). It seemed vital to recognise the importance of multi-professional team working and of the input of families – particularly mothers it seemed.

Another mother soon became important in the story – in 1988 a boy lost his hearing through meningitis, and his mother determined to obtain a cochlear implant for him – prepared to travel to the US if necessary. Barry McCormick, Director of Children's Hearing Assessment Centre, Nottingham and Mark Lutman of Institute of Hearing Research began looking into the possibilities of establishing a paediatric implant programme in the midst of the prevailing controversy and opposition. A surgeon, Gerry O'Donoghue, arrived in Nottingham, having carried out research into cochlear implants in US. The need for deaf young children in the UK to have the opportunity offered elsewhere was urgent – while the arguments persisted, these children were missing out, and the skills needed were available in Nottingham. A charity, The Ear Foundation, was established to make this happen: Gerry O'Donoghue had seen the effectiveness of the charity at the House Ear Clinic in the US in overcoming obstacles to progress. The Ear Foundation raised money for the first operations, and established the team to carry out the first multi-channel implants in the UK, supported by Ernst Lehnhardt of Hannover. As a teacher of the deaf, I was appointed as Co-ordinator, to establish protocols, and

coordinate the business management which was later to lead to Nottingham Cochlear Implant Programme, when the National Health Service took on the service.

The opposition to this development is unimaginable today - it came not only from the Deaf community, viewing paediatric implantation as a threat to their culture, but also from the voluntary sector, audiology services, educational services, medical services and from some in the cochlear implant community. Some felt children should not be implanted at all, others that they should wait until old enough to make their own decisions, and others felt that any implant team should implant adults first, and only then move to implanting children when experienced with adults. Very difficult meetings were held at which parents received very personal criticisms, and professionals on the team were threatened with professional ostracism and received personal hostility. At a personal level, it was professionally a challenging time: the majority of my colleagues did not support what I was doing and I felt professionally threatened. In addition, leaving the world of education and entering the medical world, where implantation was inevitably carried out, with its differing authority structures and differing priorities, was a huge challenge and one at which I felt not a little personal and professional disquiet.

However, the range of like-minded professionals necessary to implant children were in place, and, in the Nottingham team's view, there was enough evidence elsewhere to proceed with implantation in children. The challenges presented by assessing, implanting and programming young children, demanded particular paediatric skills, which had already been established in Nottingham. The skills demanded by implantation of children were felt by the team to be possible to acquire, given their extensive prior experience in paediatric audiology, and they set about doing so. They felt that adult experience, though valuable, had little to offer the specific skills needed in rehabilitating young deaf children.

This thesis results from that work: from the determination by all the team to capture from the beginning the evidence that was necessary to influence both policy and practice, and to ensure that the experiences of the families and children themselves were at the centre of the process. In this, the education of the children, and the influence of educators of the deaf, were paramount, both at home and at school. As Co-ordinator, and with my professional and personal background, it was a huge opportunity to ensure that these areas were included from the outset in both practice and the evaluations which were to be carried out. Much of the

sparse literature of the time reporting outcomes from implantation in children was taken from adult work and used language-based measures, many of which were inappropriate for the young population we were considering. With the skills and experience available in Nottingham, here was an opportunity to set up a unique facility which would have a new multi-professional approach to data collection including both quantitative and qualitative measures. For me, it was an opportunity to influence the impact of implantation on deaf education, and the experience I had had both as practitioner, and as a researcher were invaluable.

I set about ensuring that the outcome data to be collected included a range of measures to explore family perspectives, educational, and socio-emotional issues, rather than focus solely on clinic-based speech perception measures as was common at the time. Capturing data collection within the service context of an implant programme, rather than in a separate research programme, aimed to ensure that data was collected comprehensively on the implanted population, rather than on selected groups. This process was unusual in its thoroughness and completeness and in the involvement and commitment of a range of professionals over many years, both in the implant programme and in the community. It was also unusual in capturing educational data over a long time-frame, from the perspective of educators, families and the young people themselves. Thus the data and the papers which resulted from the collection, charted the period of greatest challenge and opportunity for deaf education – the introduction of cochlear implantation – and for me, a fascinating period as a teacher of the deaf.

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Chapter 1

Paediatric cochlear implantation:
establishing the intervention and its
context

1.1 Deafness and its impact on communication and language

Deafness from birth has a profound effect on the acquisition of early communication skills, the precursors of language development. Hearing neonates arrive with a range of auditory experience: the auditory system begins to function within the last trimester, with environmental sounds attenuated by the uterine wall, and the mother's speech patterns, particularly prosody, being heard before birth. Hence, hearing newborns can 'remember' what they have heard before birth, preferring their mother's voice, and can distinguish native from non-native speech based on prosody alone (DeCasper & Spence, 1986; DeCasper & Fifer, 1980; Jusczyk et al, 1994).

From the first days of life, they are able to detect small differences in speech sounds – and this ability changes as infants are exposed to native language. The effect of the native vowel system is demonstrated by six months and they can distinguish words from fluent speech at approximately 6-7 months. At 6-9 months they respond significantly to the dominant stress patterns of native language (Jusczyk et al, 1993). During the first year of life, children acquire the phonology of their "home" language, gradually producing speechlike sounds, until, by the end of the first year, the first words appear within the babbling sequences (Masataka, 2006).

This early auditory development facilitates the development of the early communication skills of shared attention and referencing, and of "conversational" turn-taking; crucial skills on which to base later language learning and cognitive development (Bruner, 1975). At 9 months, the infant points to objects in the environment and uses eye gaze and vocalisations to attract attention – enabling the child and parent to share "conversation" about the same topic (Crystal, 1997; Bruner, 1983) known as "joint referencing". However, it may be that these conversational abilities occur in hearing children earlier than previously thought: Masataka (2006), reports studies which reveal that vocal turn-taking increases between the ages of 12 and 18 weeks, and early exchanges may already be intentional. This progress in developing early communication skills continues through infancy: between 2 and 4 years of age children become true conversational partners, providing the basis not only for language learning but for later social and emotional development.

This is a vital development: early communication skills are a major predictor of later language ability and also of later interpersonal communication (Marschark, 1993; Koester & Meadow-Orlans, 1990). However, this process is not only reliant on audition: the integration of visual, auditory and motor stimuli are essential to the process of language learning and it can be easy to overemphasise the role of hearing in spoken language acquisition and to ignore the influences of speech reading and context in spoken communication (Blamey, 2003). For example, Kuhl and Meltzoff (1982) showed that 4-month old infants recognised the correspondence between the visual and auditory aspects of speech, and later studies support this: Campbell (2007) showed that infants are highly sensitive to seen speech. Hearing children integrate vision and hearing, able to live in parallel worlds with an adult in play, and sharing objects of joint attention through vision and hearing (Mellon, 2009). Speech-reading, integrating the visual components of speech, including lipreading, facial and contextual clues, has been shown to give visual access to spoken language structure, and to complement auditory processing (Woll, 2009).

If early communication and spoken language input is absent in these early stages there is a devastating effect on later spoken language acquisition in hearing children, and this appears to be irreversible after the ages of five or six. One example is *Le Sauvage de l'Aveyron*, who was found at 12 or 13 having had no human contact or spoken language input. It was not possible to teach him spoken language without previous exposure to it (Lane, 1976), in spite of the best efforts of Itard, an experienced teacher and in spite of being hearing.

What of the impact of deafness on this crucial early development of language? Over 95% of deaf children are born to hearing families (Mitchell & Karchmer, 2004) and the language of the home is likely to be a spoken one, and the language used by the mother to be an oral one. Young deaf infants do not respond to hearing mothers' interactions as hearing infants do and hence the problem is exacerbated as, without the usual response, mothers change their style of interaction and fail to provide the usual stimuli hearing babies enjoy. Adults frequently reduce the complexity of the language used with deaf children, fearing misunderstandings, thus compounding the effects of childhood deafness, and reducing the opportunities for advanced language learning (Calderon & Greenberg, 2003). Even deaf children fitted with hearing aids or implants early in life, have missed a significant part of the normal pattern of communication and language development described above. For them, the acquisition of spoken

language is negatively impacted by both the hearing loss and consequent lack of the usual conversational interaction with their carers.

Hence the problem of profound deafness in early childhood is not merely one of not hearing, but one of impaired communication and language development, with a further impact on cognitive development, and on later educational attainments and employment opportunities. In addition our social and emotional development is mediated by experience and language; for deaf children this is potentially another area of delay and difficulty (Calderon & Greenberg, 2003). To summarise: deaf children are likely to have lower linguistic competencies and educational attainments (Conrad, 1979; Marschark, 1993), higher levels of socio-emotional and psychological difficulties and later under-employment (Marschark, 1993). The huge challenge of overcoming this massive, and often unrecognised, impact of early deafness has been a source of fascination for educators over the centuries. How has deaf education endeavoured to meet the challenges of deafness?

1.2 Deaf education: meeting the challenge of deafness?

Deaf education has a long history: in the first century AD there was the first report of a father seeking education for his deaf son, Quintus Pedius (Lang, 2003), and it has been marked throughout by argument and controversy. In spite of the centuries of educational practice and debate, for the parents of deaf children, major issues of concern remain which have driven them to seek improved education over the years:

- Communication and language choices: how their child should be educated
- Where their children should be educated
- Their educational attainments

Communication and language choices: how deaf children should be educated

The very challenges brought about by the impact of early, profound deafness on communication and language development, and hence education, have stimulated great interest and been addressed in a variety of ways throughout the centuries, described by Lang (2003). The challenge of how to overcome the lack of auditory input in deaf children has long been a source of great conflict: the perceived great divide between whether to use visual communication or oral/aural communication.

Using visual means, and capitalising on the visual system, whether by using sign language or by using oral language with visual clues such as lipreading, was for many years the only alternative, prior to the introduction of useful hearing aids, and latterly implants. The polarisation of views between those who believe that all deaf children should communicate by spoken language alone, and those who believe that sign language is the first language of the Deaf, and that all deaf children have a right to be educated using sign language, has continued through the centuries to the present day and many would suggest has hindered educational progress for deaf children.

Many examples demonstrate the arguments over the years: throughout the 1600's works were published in Europe which either advocated the use of signed and visual communication (for example Bulwer) or that of speech to communicate (for example Johan Amman), beginning this ongoing debate about the relative benefits of such methods (Lang, 2003). In France, in the 1760's, the world's first government sponsored school for deaf children began, run by Abbe de l'Epee, who promoted sign language for deaf children's education. This was followed by Heinicke's school in Leipzig in 1778, which aimed to teach deaf children to speak. In America, the debate raged too during the nineteenth century, with Thomas Gallaudet, after training in Paris, establishing Gallaudet College in 1867 supporting sign language, and later Alexander Graham Bell establishing his own organisation to support oralism, and the growing number of oral schools in the US. Although their views were more complex than this simple distinction, the "war of methods" (Lang, 2003) began which continues to the present day, and to which cochlear implantation was to add further controversy. However, throughout those years, deaf people and their parents were shown to be able to contribute significantly to society, and bringing together deaf individuals in special educational establishments led to their achieving a strong identity and self-confidence (Woll & Ladd, 2003).

A major event in the debate occurred in 1880 to challenge this self-confidence, with the Milan conference on deaf education – the forerunner of the current International Congress of Education of the Deaf – concluding that spoken language was "superior" to that of sign language, and that deaf children should be taught using speech. This was an interesting decision, made at a time when there was little or no amplification available, and hence access to spoken language by hearing was virtually impossible for the profoundly deaf. The decision was to prove significant: it began the predominance of oral deaf education around the world, and

promoted the unfortunate polarisation of views. The decision aroused considerable emotionally laden arguments in deaf education. The fact that deaf people could not participate in the decision made at Milan added to the frustration of the Deaf community in the years that followed, as oralism gained ground. They began their own strong organisations to combat oralism – the National Association of the Deaf in the USA in 1880 and British Deaf and Dumb Association in Britain in 1890 (later the British Deaf Association). These organisations were also to prove significant later in the debate about cochlear implantation.

Although oralism held sway for much of the 19th and first half of the 20th centuries, the evidence of poor linguistic and educational attainments and of poor speech intelligibility challenged its methods and effectiveness, particularly the seminal study of Conrad (1979). At the same time, the increasing voice of the Deaf community, with its own language and culture, having flourished in residential schools for the deaf, strived to be heard. The distinction Deaf/deaf was first used in 1972 by Woodward in the US, to differentiate between the Deaf culture and deaf as an audiological description, and to lend support to the recognition of Deaf culture, with its own language.

During the 1980's, signed methods of communication were increasingly introduced into the education of deaf children whether in special or mainstream schools: however this was initially using total, or simultaneous, communication, where spoken language is used with signed support, rather than Sign Language itself. Total, or simultaneous, communication does not use the grammar of sign language, which is very different to that of spoken language, and therefore does not reflect Deaf culture, transmitted through its own language. In many countries, the Deaf community fought for the recognition of their Sign Language to be recognised as official languages, and, with the recognition of the linguistic success of many deaf children of deaf parents, the possibility of providing all deaf children with access to sign language as their first language became an educational philosophy. Thus, in the late 1980's, interest grew world-wide in the use of sign bilingualism in education, where the languages of the Deaf and hearing communities are both used in school, with differing emphases. For example, in Holland, where oralism in the form of the maternal reflective method, developed by Van Uden, had led deaf education internationally, the educational focus changed to that of sign bilingualism with the leadership of such organisations as Nederlandse Stichting voor Dove en Slechthorende Kind (NSDSK) in Amsterdam. In Sweden, all deaf children were educated in schools by Swedish Sign Language, with systems

in place by which parents could learn Sign Language, and with strong input by Deaf people to the curriculum and its delivery. In 1991, in the UK, British Sign Language was introduced into deaf education, and the group LASER was formed to support its implementation (Swanwick and Gregory, 2007). This was a very challenging model to deliver educationally, as the written form of language uses the spoken form graphically, and for those using sign language with its different grammar, there is no written form; to make the transition to a different language in its written form is a formidable challenge (Mayer & Wells, 1996).

These changes to deaf education involved more Deaf people in education than ever before: as Deaf role models, as support workers and as language teachers, and working with hearing parents of very young deaf children, thus placing them in more influential positions in education. It is also worthy of note that the development of the educational use of Sign Language, and its acceptance, occurred in the UK at the same time as the introduction of cochlear implantation for children. This interesting juxtaposition and competition for resources added to the controversies described later.

To summarise: the debate about which mode of communication to be used with deaf children has a long history and one, which shall be seen, has not ended with cochlear implantation. Although terminology may vary in different countries, communication approaches used in deaf education may be categorised as follows:

- Oral/aural – spoken language alone
- Those using speech and sign simultaneously (total communication)
- Sign-bilingualism (Lynas, 1984)

Within each category there are further subcategories: for example, oral communication methods include natural oralism, the use of cued speech, auditory verbal approaches, and maternal reflective methods. Comparing the effectiveness of differing communication choices is thus complex and this has impact later when discussing and evaluating the appropriate follow-up care for children with cochlear implants.

Where deaf children should be educated

With the passion aroused by communication choices, special schools for the deaf were established in most countries, led by educators supporting their methods of teaching, whether of the oral or signing tradition. Their names, such as Braidwood and Gallaudet, live on in the schools of today. These schools were often

residential, in remote areas, and deaf children were sent there as early as three years of age. Hence, they became not only centres for education, but places where the Deaf culture and language grew and thrived until the mid 20th century (Woll & Ladd, 2003). They also provided centres of excellence for educators of the deaf and where expertise could be transferred to new teachers.

During the second half of the 20th century, an increasing trend in national educational policies for the inclusion of all children with disabilities in mainstream schools led to the closure of many of these traditional schools. In the UK, for example, in 1972 there were 5781 deaf children in special schools; this had declined to 3808 by 1983 (Gregory et al, 1995). Similar trends were followed throughout Europe and in the USA; public education laws were changed in many countries to support the rights of all children to be educated in the “least restrictive environment”. The political trend to equity of provision was interpreted as inclusion in mainstream educational provision for all children with disabilities; however, for many deaf children this may not be “the least restrictive environment” (Powers, 1986). For deaf education this trend towards inclusion has been not only politically led, but was partly due to the increased provision of improved hearing aids, and the provision of FM systems which could potentially overcome the problem of background noise in schools, facilitating access to mainstream education.

Providing the necessary support in mainstream schools remained a challenge, and in some countries (particularly in the UK) there were units, or special classes, established in mainstream schools, staffed by teachers of the deaf. These provided opportunities for deaf children to benefit both from specialist teaching and from access to the mainstream curriculum and to hearing peers, with a rich language input. With the growing emphasis on mainstream education for all, increasing numbers of deaf children are now educated individually in mainstream education with varying levels of support – and support which varies greatly in quality, training and experience.

However, these trends were viewed by the Deaf community as a threat to their language and culture, which had thrived in special schools. For those working in deaf education, although academic attainments are important, the social and emotional well-being of the children they teach are also important, and in mainstream schools a deaf peer group is unavailable. Additionally, the expertise of teachers of the deaf was potentially diminished as more of them worked in

isolation in mainstream schools, without access to the insights and resources of more experienced colleagues.

To summarise the educational placement options for deaf children:

- A school for the deaf (residential or day)
- A unit or resource base in mainstream school (with varying degrees of integration into mainstream class, or withdrawal into the unit)
- Mainstream education (with varying degrees of support in quantity and experience) (Archbold, 2003)

The situations are not mutually exclusive, and huge variation exists in practice. They overlap to a great degree: for example, a child may be more independent as a learner in a class of 10 in a special school, than in a mainstream class of 30, with a full-time classroom assistant dedicated to their individual needs. This makes judgements about the relative effectiveness of differing school settings complex, and these trends are important when it came later to evaluating outcomes from implantation in real-life settings. These considerations became even more important to consider when researching the comparative benefits of differing educational systems in supporting children with cochlear implants, or when exploring the cost-effectiveness of implantation, which became an important issue. Could cochlear implantation, in providing useful hearing to deaf children, lead to the need for less specialist support in school, and hence prove cost-effective?

What about educational attainments of deaf children?

However, wherever children are educated, and at whatever cost, parents and educators are vitally interested in educational attainments – and these have traditionally been poor for deaf children. The changes which have taken place in deaf education over the years in terms of access to sign language or to mainstream placement have not resulted in any major measurable changes in academic attainments and therefore remain a major concern to parents and teachers (Hauser & Marschark, 2008). The classic study of Conrad (1979) showed that half of the deaf children leaving school at 16 had speech difficult to understand, and had a median reading age of nine years and there is little evidence to show that the reading levels of deaf children have moved on since then (Marschark & Harris, 1996; Musselman, 2000). Many studies have shown that the great majority of deaf children find reading difficult, achieving significantly

lower levels of reading attainment than their hearing peers (Allen, 1986; Harris & Moreno, 2004).

Hearing children come to reading with an age-appropriate knowledge of vocabulary and grammar of the language and a knowledge of the phonology of the language, unlike deaf children. Knowledge of spoken English has been shown to be an important predictor of reading ability for deaf children (Kyle & Harris, 2006). Deaf children are unlikely to come to reading with knowledge of the language, and of the text represented on the page and are likely to have delayed grammar and vocabulary levels. In addition, reading at higher levels involves world knowledge in addition to linguistic knowledge, an area in which profoundly deaf children traditionally have had difficulty, unable to overhear conversational comments, television and radio news for example.

For deaf children, phonological awareness has also long been a major area of difficulty, lacking access via hearing to the phonology of the language, and therefore it was hoped that the advent of cochlear implantation would change this, providing hearing across all the speech frequencies, with consequent improvements in reading skills. Writing has also been a challenge, with deaf children and adults displaying deviant forms of language in writing, unable to represent spoken language in its written form (Mellon, 2009; Mayer & Wells, 1996). As Spencer and Marschark (2003) commented “No place is the influence of cochlear implantation and its consequences..... more obvious than in school” and a major expectation for parents striving for the acceptance of implantation, was that useful levels of hearing would improve literacy and educational levels for their children.

However, the involvement of deaf education was not always apparent in the early development of cochlear implantation services. There may be several reasons, resulting from bringing together the medical and educational models of deafness: many teachers of the deaf saw implantation as a further threat to their role as special educators which had already been diminished by the mainstreaming of many deaf children, and the dissolution of special schools. They felt threatened by the apparent invasion of their “professional territory” by others and by this new technology. At the same time, some clinic-based cochlear implant teams saw cochlear implantation as a way to “cure” deafness; there would no longer be any requirement for deaf education. Thus the relationship between deaf education and cochlear implant services was not immediately an easy one, particularly as the

large amount of funding for implantation went to health budgets rather than educational ones.

Deaf education has had a long history, but within a very short period of time it was to be transformed by this surgically led intervention, cochlear implantation. If the impact of cochlear implantation on education was to be assessed, then long-term evaluation and research was to be necessary. What research tradition was there within the field of deaf education which could be utilised in the necessary multi-professional research to evaluate implantation and its effect?

1.3 Models of research and deaf education

Research into deaf education is interesting because it was notable by its paucity for many years; research which was reported was largely concerned with providing justification for specific approaches continuing the ongoing controversies about which was the most effective method of teaching deaf children. One example of change came about in the 1980's with the advent of the Deafness Research Group in Nottingham, led by David Wood, providing a rigorous research forum where practitioners were taken seriously, and where academics and teachers investigated the processes by which deaf children learnt in the classroom – and by which they were taught. Later Marschark, becoming editor of *Journal of Deaf Studies and Deaf Education*, again provided a forum where rigorous research into the practices of deaf education was encouraged and disseminated.

Educational research has typically involved the forms of research which may be classified as qualitative research, relying largely on skilled observations, questionnaires and interview techniques rather than on large scale quantitative research relying on large numbers for statistical analysis. This is particularly true for research in the field of deaf education, for two reasons:

- Deafness is a low-incidence disability, and hence numbers are small for statistical evaluation
- Deaf children as a group are heterogeneous – with many variables to account for including aetiology, age at diagnosis, fitting of hearing aids, cognitive ability, presence and influence of other disabilities, socio-economic status, parental input, early intervention, communication mode used and educational management. Following the advent of cochlear implantation, we now have to add type of implant, age at implantation, pre-implant hearing

levels, processing strategy, effectiveness of programming, functioning of internal and external devices to this list of variables.

Deaf children and young people thus represent a challenging population for researchers; defining homogenous groups to use traditionally rigorous methodologies may be attractive but does not represent the population educators work with, or produce research likely to change educational practice, continuing the divide between practitioners and researchers. (Leigh, 2008). Additionally, research is likely to be published in journals which are not read by educators and therefore even less likely to influence practice. Research into cochlear implantation is published in a particularly wide range of journals, reflecting the range of disciplines involved, and making accessibility even more difficult for practitioners.

Clearly all research needs to be rigorous, and in the case of research into deaf education a combination of quantitative and qualitative research provides methods which collect data for statistical analysis, but also provides data which, when analysed using qualitative methods more usually found in the social research literature, can explore the realities of the experiences of families and children and categorise them, enabling further analysis. Reliance on one method of research will either miss the potential to capture the realities of the experience, to capture something un-thought of by the researcher, or will provide only descriptive research without any attempt at numerical analysis on which basis to inform decisions and plan services.

However, there has often been a lack of the multi-professional approach to research which is essential in investigating how deaf children learn and which has become so important with the advent of paediatric implantation (Hauser & Marschark, 2008; Pisoni et al, 2008). It appears that often the work carried out in the related fields of psychology, of cognitive neuroscience and of linguistics for example, has not been linked to our investigations of deaf learning and deaf education, with researchers working in isolation. The work in centres such as that of Pisoni in Indianapolis, of Marschark in Rochester, and of Woll and colleagues in DECAL, London, show real progress in the field of multi-professional research, some of it inspired by the demands of research into the effectiveness of cochlear implantation.

The advent of paediatric cochlear implantation brought about interesting research challenges and opportunities, bringing together the strengths of both quantitative and qualitative research and the disciplines of medicine, audiology, psychology, sociology, speech and language and education with their differing priorities, methodologies and languages. To provide a paediatric implant service with inbuilt rigorous monitoring and data collection demanded sharing knowledge between these disciplines as never before, and was a challenge that was a priority when planning the Nottingham Cochlear Implant Programme.

1.4 Cochlear implantation: developing the technology

Historical background

Having discussed the impact of deafness on the development of language and cognition, and hence education, and some of that historical context, what of the surgical development of cochlear implantation? This was to offer both the single biggest challenge to the practice of the education of profoundly deaf children and the biggest opportunity. This technology, in a comparatively short time, compared with the previous history of deaf education, has changed the potential for these children as never before, providing them with useful hearing for the first time.

In a normally hearing ear, the acoustic signal is converted into electrical impulses which stimulates the auditory nerve by minute displacements of the hair cells in the inner ear, or cochlea. In the severe to profoundly deaf, with sensorineural losses, the damage to the hair cells is such that even the most powerful hearing aids are unable to provide full access to the range of speech sounds through hearing. Cochlear implants are designed to bypass the damaged hair cells, converting the acoustic signal into electrical pulses, providing the electrical stimulation to the intact auditory nerve. Cochlear implants consist of two basic parts:

- the internal device consisting of a receiver and electrode array, which is surgically inserted into the mastoid bone and into the cochlea (figure 1)
- the external microphone, processor and transmitter, usually worn behind the ear in contemporary systems, but may also be body worn. (figure 2)



Figure 1. Examples of the internal parts: the receiver and electrodes



Figure 2. examples of the external processor, and transmitter and a child wearing a speech processor

The processor converts the acoustic signal, collected by the microphone, into electrical pulses which are sent via the transmitter to the receiver transcutaneously and hence to the electrodes buried in the cochlea. Magnets in the receiver and in the transmitter ensure efficient transmission of the signals by holding the transmitter in place. The electrodes are stimulated by the electrical pulses, and are individually programmed by the audiologist. This set of rules by which the implant system is programmed is called the “speech coding strategy” and it varies according to manufacturer of the implant, and according to individual patient. However, the goal is the same: to provide access to spoken language via hearing which had not been possible through hearing aids.

Although cochlear implantation has only become routine provision for profoundly deaf children in the last decade of the 20th century and the first decade of the 21st, the first example of electrical stimulation to the auditory system was over 200 years ago, when Alessandro Volta inserted two metal rods in his ears and connected a battery. He described the result as a “boom in the head” and heard a “boiling-type noise” which was unpleasant. However, this was the first recorded example of electrical stimulation to the auditory system (Volta, 1800, cited by Simmons, 1966).

Progress in achieving today’s safe and reliable implants was long, arduous and marked with competition and disagreements. The success is due to significant people, including those deaf patients who used the first implants, and their commitment and hard work. In 1957 in Paris, Djournio, an engineer, and Eyries, an otologist, implanted a patient with bilateral cholesteatomas; when they electrically stimulated the auditory system the patient was able to perceive environmental sounds and some words (Eisen, 2006). This implant, and a second, failed and Djournio and Eyries did not continue the work. However, their work inspired Chouard who later produced one of the first functional implants (Eisen, 2006). Their work, translated from the French, also inspired William House and his colleague James Doyle in Los Angeles in 1961 to stimulate the auditory nerve electrically; they had encouraging responses but the devices were removed due to infection. Meanwhile, Simmons, at Stanford University, implanted his first device in 1964, but with disappointing results leading him to be pessimistic about the future of implantation. William House however, continued and, working with an engineer Jack Urban, at the House Ear Institute, developed a single electrode device, the 3M/House device, which gained Food and Drug Administration (FDA) approval for post-lingually deafened adults in 1982 (Chute & Nevins, 2006). In the UK, another single electrode device, the RNID/UCH device which was implanted external to the cochlea was also being developed in the early 1980’s and used with adults. These early implants single channel devices enabled post-linguistically deafened adults to detect environmental sounds and provided an aid to lipreading, by giving timing and intensity cues. . This was the device used with the first child to have a cochlear implant in the UK, whom I taught, before multi-channel implants were available. (see below, wearing the transmitter, which had no magnet to keep it in place).



However, several individuals saw the future of implantation in multi-channel devices: in San Francisco, at UCSF, Michelson, Merzenich and Schindler were working on developments to introduce multichannel intracochlear implantation, as was Clark, in Melbourne, Australia, and Hochmair and Hochmair-Desoyer in Austria. In Europe, Peeters was working on the Laura device, and in the USA Eddington on the Ineraid device, but both were later discontinued.

Graeme Clark's initiative with the collaboration of the Australian government, Nucleus Ltd and Melbourne University was to result in the Nucleus device, now widely used. In the early 1980's the Nucleus implant system began clinical trials, and in 1986, the FDA approved its use for postlingually deafened adults in the USA. For many years, the Nucleus device had over 90% of the world market and in 1990, the Nucleus-22 device (with 22 electrodes) was the first implant system to have approval for use in children in the USA by FDA. (Clark, Busby & Dowell, 1992). This was only for use in children over the age of 2; approval was granted for those over the age of 18 months in 1998, and it was 14 years later when approval in the USA was granted for children over 12 months, in 2002.

The Hochmairs' work resulted in the MED-EL device (Hochmair & Hochmair-Desoyer, 1985) first made available in the mid 1990's, initially more widely used in Europe but now with FDA approval in the US. The work of Merzenich and Schindler and collaboration between UCSF and the Research Triangle Institute led to the production of the Clarion implant in 1987 (Roland et al, 2006), now marketed by Advanced Bionics: it gained FDA approval for adults in 1996, and children in 1997. Currently there are three major manufacturers of the multi-channel implant systems: Advanced Bionics, Cochlear Limited and MED-EL. A company, Neurelec, based in France, took over MXM and now is marketing its own system.

During this time, the technology developed from single-channel devices to multi-channel, so as better deliver complex auditory information required to understand speech. The electrode arrays have changed from straight models to curved models, known as “modiolus hugging”, to enhance the interface between the electrodes and the nerve endings in the inner ear. Design changes in electrode arrays and changes in surgical tools and techniques have enabled surgery to take place more easily and insertion to be less traumatising to the cochlea structures. With changes in candidature over the years, and increasing numbers being implanted with some hearing, the preservation of residual hearing is rather more important now than it was in the early, more conservative stages of implantation. Developments in surgical techniques, including minimal access surgery, also ensure that implants are now safe for infants, and for those with malformations of the inner ear, who previously may not have been implanted; such approaches are also more acceptable to teenagers thinking about implants for themselves. See below an example of the first large incision, with stitches, alongside the minimal access incision now used, much more acceptable to parents and young people.



Developments in the receiver/stimulator packages mean that reliability is now increased in addition to performance (Waltzman, 2006). Although implant failures do occur, current implant systems have high reliability rates and re-implantation rates are low. However, with increasing numbers of infants being implanted, the need for re-implantation throughout an extended expected lifetime is recognised, and this is reflected in new design and insertion techniques (Waltzman, 2006). The design of systems has also changed to accommodate the changes taking place in candidacy; for example the trend to implanting in the first year of life, with the need for miniaturisation.

While developments were taking place in the internal parts of the system, the processing strategies used by the external processors also continued to develop. The first generation of multi-channel implants provided limited speech information

– hence “speech processor.” The Nucleus early system provided the fundamental frequency (F0) with the second formant (F2); only later was the first formant F1 delivered. Later, additional speech perception information was added to provide more high frequency information. Coding strategies now can use analogue and digital strategies, simultaneous or sequential stimulation, and a range of differing speech coding strategies (Waltman, 2006). Strategies include continuous interleaved sampling (CIS), spectral peak (SPEAK), advanced combined encoders (ACE), simultaneous analogue (SAS), high resolution and N of M (Number of maxima) (Clark, 2004); these developments having the goal of improved performance. Current devices include more than one of these strategies, and although there are now automatic programming systems which have made programming quicker, there is a heavy burden of continuing professional training for audiologists working on implant teams.

Changes in the design of the external hardware, the receiver and processor also continued. The first processors were so large that recipients had to leave the processor in the clinic and could only hear in that setting. The first body-worn portable processors were bulky and not sufficiently robust for children, nor had sufficient memory to provide more than one programme, limiting their effectiveness. Processors today can deliver several different programmes to suit differing listening conditions, are more reliable, provide a range of accessories, linking with assistive technology and, most importantly for paediatric implantation, are smaller, and robust. Most processors are now worn behind the ear (BTE), giving greater comfort and ease of wear.

Continuing developments in technology continue, and will continue, at a fast pace:

- changes in processing strategies continue to improve listening in noise, the provision of binaural hearing – through implant and contra-lateral hearing aid or with two implants
- the provision of binaural hearing – through implant and contralateral hearing aid or with two implants
- the development of electro-acoustic implants, where acoustic and electrical stimulation are combined in the same ear, for those who have useful low frequency hearing
- totally implantable devices, which are currently in their infancy and have just reached clinical trials, but are strongly desired by implant users

- hair-cell regeneration where implants can be used to deliver drugs which will facilitate tissue regeneration in the cells or in the organ of hearing

The early developments in cochlear implantation techniques which were to transform the opportunities for profoundly deaf children and their families, took place in a relatively small amount of time, driven by the passion of surgeons and scientists. However, initially, the potential for their use in children was not realised. Early efforts concentrated on their use with post-linguistically deafened adults, who had knowledge of spoken language, and whose auditory system had been already stimulated and who were able to give consent themselves. What about children where the goal was not that of sensory restoration but to provide hearing to enable the initial development of spoken language?

1.5 The development of paediatric cochlear implantation

Delivering the technology to children – the challenges and controversies

With implantation in adults realising greater benefits than had been expected, such as the use of the telephone, and the understanding of conversation without lipreading, pressure increased on those implanting adults to consider children. Pressure was particularly strong from parents; those whose children had been deafened by meningitis were particularly active in the 1980's. Their observations of the progress made by deafened adults and their experience of their own child's loss of hearing, and consequent loss of speech and language often in a matter of weeks after meningitis, made them vociferous about implantation being made available for their children. For hearing parents, the strong opposition which was expressed about implantation in children was incomprehensible.

The provision of implantation for children led to controversies of proportions that seem unimaginable now. Those in the Deaf community argued that deafness is not a disease to be treated by a medical intervention, but rather a cultural and linguistic identity, and hence children born deaf were part of that community rather than the hearing community. They claimed that a deaf child's first language is sign language, and that cochlear implantation, with its emphasis on hearing and access to spoken language, was removing their right to be deaf and to their cultural identity. Ladd, (1985) writing for the British Deaf Association, called cochlear implants "oralism's final solution".

It was argued that cochlear implantation in children would lead them to experience severe mental health problems as adults and to reject their implants and their parents who had chosen them (Lane & Bahan, 1998; NAD,1993; Lane, 1994; Danish Deaf Assoc, 1993). The National Association of the Deaf (NAD) in response to FDA approval of implants for children stated: “The NAD deplores the decision of the Food and Drug Administration which was unsound scientifically, procedurally and ethically” (NAD, 1993). It was considered that children were being made the subject of experimentation, that there wasn’t enough evidence on which to move forward and that implantation should wait until children were old enough to make the decision for themselves. (NAD, 1993; Blume,1995). Additionally, the cost of implantation was a problem: for those struggling to find funds for interpreters, and for access to other technologies, the money being spent on implantation, without guaranteed benefits, seemed unreasonable as reported by Christiansen & Spencer (2004). Tyler (1993) argued in “Cochlear implants and the Deaf Culture” that all deaf children deserved the same high quality of education, whether they use implant, hearing aid, or neither, acknowledging the concerns that children with cochlear implants were receiving more support than those without, creating a further inequity in the system.

While the Deaf community were strong in their opposition, they were also lacking in information, and organisations such as the British Deaf Association (BDA) refused to advertise information sessions on cochlear implantation, on the grounds that they might be seen to be supporting cochlear implantation, thus restricting the information available to deaf people to enable them to have equity of access to evidence. Media reporting of early implantation with phrases such as “Holly’s Bionic ear” and reports of “cures” for deafness did not help the quest for accurate information and exacerbated the misunderstandings.



Figure 3. An example of Bionic Ear reporting.

Hearing parents of deafened children, caught up in this, were in an invidious position, with most never having met a deaf person before, or even realising that a Deaf community existed. In the UK, parents considering implantation were ostracised by those from whom they could have expected support: the voluntary organisations for parents of deaf children and for deaf people. The National Deaf Children's Society (NDCS) in the UK strongly opposed implantation as did the Royal National Institute for the Deaf (RNID). The NDCS only agreed that implantation could be provided to those children over the age of 9, who had been deafened and who could be considered to be involved in the decision themselves (NDCS, 1988) after a great deal of heated debate, and after the first child had actually been implanted with the single channel device - at the age of 9. Only later did the organisations agree to produce information materials to support families.

Emotional public meetings were held where parents of deafened children were attacked for "denying their child's deafness" and where comments were made by leaders of the voluntary sector that implantation would be a "fashion like tonsillectomy". This was in the face of growing evidence from the US, from Germany and from Australia of the efficacy of cochlear implantation in children, and parents prepared to take their children abroad to be implanted. The Department of Health was lobbied and support from those experienced elsewhere provided useful evidence of the effectiveness of implantation.

However, if the opposition to implantation for children who were deafened was strong, the opposition to implantation for those born deaf was even more vociferous. Parents in the UK, unable to obtain cochlear implantation for their deaf children even at a team with experience, had to travel to Germany for implantation, with hugely increased stress, and expense. It was only after experience with deafened children that the Nottingham team finally, after great debate, implanted the first congenitally deaf child in the UK in 1993. Surgeons were accused of genocide, in the belief that cochlear implantation would eradicate the Deaf community (Niparko, 2009). The Nottingham implant centre, which led paediatric implantation in the UK in 1989, had its walls daubed with graffiti: “death to those who kill our deaf children”

For otologists, for whom the goal of implantation was the restoration of hearing, and for whom the operation itself was safe and successful, and who carried out complex operations on young children on a daily basis, such arguments were often difficult to understand. Having developed implantation in adults with better than expected outcomes, the controversies aroused by cochlear implantation in children was unexpected. For those coming from the medical or audiological model of deafness, where deafness is viewed as a disability to be cured, and hence cochlear implantation to be welcomed, the arguments of those of the Deaf community who saw deafness as a linguistic and cultural identity to be recognised and valued were hard to understand. Even for those who were experienced in working with deaf children and adults, the violence of the outbursts, the disruption of meetings and discussions and unwillingness by deaf people to access information were unexpected. Discussions continued, including public debates between otologists and proponents of the Deaf community such as O’Donoghue and Lane on a public television programme for deaf people, and in *Otology and Neurotology* between Lane and otologists Shannon and Balkany (1994), with recognition of some of the criticisms of the research evidence provided about implantation and of the rhetoric surrounding the topic.

In spite of some rational debate, the controversy continued throughout the 1990’s and into the 21st century, restricting progress in some countries. In Holland, where paediatric implantation began early in the 1990’s, progress was slowed by the influence of deaf groups and proponents of Sign Language for all deaf children. In the UK, the Federation of Deaf People, FDP, continued the debate: even in 2000, the FDP were comparing cochlear implants to “weapons of mass destruction” (FDP News, 2000).



However, in spite of the major opposition, in spite of huge political and financial pressures, cochlear implantation moved forward, relentlessly. It may be that the endeavours of particular individuals was the strongest influence in enabling this to happen: for example, the work of Prof Ernst Lehnhardt in Hannover, of Prof Graeme Clark in Melbourne, of Prof Manuel Manrique in Spain, of Prof Paul van den Broek in Holland, and of our own group in Nottingham, led by Professor Gerry O'Donoghue, Professor Barry McCormick and Prof Mark Lutman.. Surgeons took on the major legal responsibilities for the development of paediatric implantation, but key everywhere in the drive forward was the role of parents, and particularly mothers, as they became aware of the new possibilities brought about by the technology of implantation and fought for its implementation for their children.

Establishing the Nottingham multi-professional cochlear implant team

Given the opposition described above, implant teams who had become experienced in implanting adults, were faced with many challenges. Adults implanted after the loss of hearing are able to relate the new auditory signal to their stored knowledge of spoken language and to use the redundancies in language to make sense of the new signal (Spencer & Marschark, 2003). For young children born deaf, or before the acquisition of language, the challenge is different. These young children have to acquire the spoken language of their

culture through the hearing provided by the implant, which is an impoverished signal compared with that experienced by a normally hearing child. The criteria and protocols established for adults were inappropriate for young children, without language; for example, the accepted test batteries for speech perception and production to demonstrate benefit relied on the cooperation of the individual and on developed linguistic abilities to be able to perform them. Few tests used were appropriate for young deaf children without language skills; for example, the test battery established for FDA approval (Staller et al, 1991) in the USA.

Similarly teams established to implant adults rarely had the necessary specialist paediatric skills to assess, implant and habilitate young deaf children. Paediatric implantation in young deaf children demanded a new approach: teams with the paediatric audiology skills necessary to reliably assess the hearing of young deaf children, the paediatric surgical skills, and the skills in the habilitation team to assess, develop and monitor language development through the provision of hearing with an implant system. (Archbold, 2003).

In Nottingham, the first paediatric cochlear implant team in the UK was established in 1989 amid the opposition described above. It had no prior experience of adult implantation, but with considerable multi-disciplinary experience of working with young deaf children and their families, the team felt that the knowledge needed about implantation was easier to acquire than expertise with young deaf children and their families. It combined the surgical experience of Gerry O'Donoghue of implantation in the US (mainly in animal models at the University of California in San Francisco), the paediatric audiology skills of Barry McCormick's team at Children's Hearing Assessment Centre, experienced teachers of the deaf and speech and language therapists, the research experience at the Deafness Research Group at Nottingham University, electrophysiology of radiology at Nottingham University Hospital, and a world leading centre for hearing research, the Medical Research Council's Institute of Hearing Research. With such institutional and individual support and expertise, the team proceeded, driven by the demands of parents who were determined to ensure UK children had access to multi-channel implantation as elsewhere in the world. The team had no finance and faced huge political opposition, but, in March 1989, the first multichannel implant went ahead on a three year old boy, deafened by meningitis, supported by Prof Ernst Lehnhardt from Hannover.



Figure 4. The first child implanted in Nottingham, wearing one of the first speech processors

The team was funded by a charity, The Ear Foundation, and it was the first to include a teacher of the deaf, with myself as Co-ordinator. The team included:

- Paediatric audiologists
- Otologists / neurotologists
- Medical Physicists
- Radiologists
- Speech and language therapists
- Teachers of the deaf
- Educational psychologists
- Management team

From the outset it was considered important to include parents as members of the team, and also to include the professionals who supported the child in their local community: particularly the local education team, who in the UK are involved with deaf children from the time of diagnosis, and particularly other local professionals where a child has other complex needs. This is illustrated in figure 5. The team at the implant clinic may well be experienced in the management of deafness and increasingly in implantation, but parents, carers, and the local professional knew the child best and could provide information essential to the assessment and management of children. The child and family spend comparatively very little time at the implant centre: the long-term management resides with family and educators (Geers & Moog,1995), and the Nottingham team set about involving them in the process from the outset. The full team developed with its rationale is described in Archbold (2003).

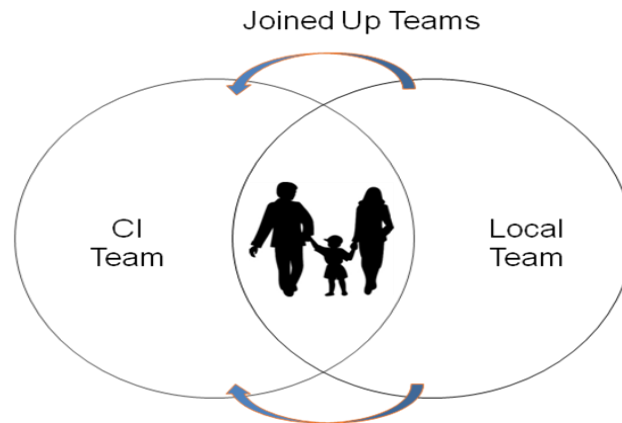


Figure 5. Joined up teams

Additionally, making the decision as to whether to implant a child was more complex than with adults, able to make their own decision. Parents making the life-changing and life-long decision on behalf of their child for this elective operation, required accessible information on which to base their decision, and initially this was unavailable. Together with the National Deaf Children's Society, information materials were developed to support families during this process.

Management protocols needed to be established which would enable progress to be monitored in the short and long-term, to show the tiny changes which were vital to mark progress, and that were understandable by all members of the team, including parents and local professionals. The final decision making needed to include the parents and local team – although the child is at the centre of the process, the decision making brings together the family, specialist implant team and local team. With a child with additional complex needs, the input of the local team is even more crucial to the decision making process, utilising their specialist knowledge in areas in which cochlear implant team members would be unfamiliar.

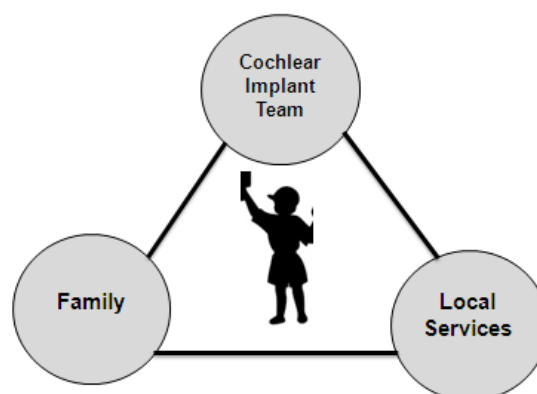


Figure 6. The child at the centre of the decision-making process

Monitoring progress: the rationale

Cochlear implantation in children is an expensive and invasive procedure and, given the controversies which surrounded it, one which demanded careful evaluation from the outset. However, evaluation was not straightforward: what constituted success for a surgeon may not be success in the view of a teacher or of a parent. For parents or the child in the long-term, success may be also viewed very differently. Measuring outcomes in the heterogeneous group of deaf children, using evolving technology, and establishing what constituted benefit from the process as opposed to mere child development over time, remains a challenge (Kirk and Choi, 2009) and in 1989 was a major challenge for the team. Implantation in children is unusual in that the outcomes are seen in the long-term and not wholly in the clinic setting. A hierarchy of outcomes over time can be seen, as illustrated below: changes in hearing perception as brought about by implant, in listening and the consequent development of speech and language, and thirdly, the effects seen in the areas of social and emotional development, and in educational and long-term employment benefits.

hearing	<ul style="list-style-type: none"> • improved perception of sound • responses to sound - environmental and speech • use of implant system
listening and language	<ul style="list-style-type: none"> • identifies sound in environment • understands spoken language • uses spoken language
social and educational	<ul style="list-style-type: none"> • personal changes: confidence and independence • family outcomes: communication within family • peer group interactions • educational attainments

Measuring outcomes from paediatric implantation required the establishment of suitable protocols which recognised the long-term nature of the process, the crucial input of parents and educators, and measures which reflected reality in everyday life. Measures were needed which provided information

- on which to base the decision whether to implant or not
- for monitoring the functioning and programming of the implant system
- to identify other learning difficulties which may be present
- which would influence appropriate management

- which was sensitive enough in the short-term to illustrate progress or lack of it
- which was appropriate to monitor progress in the short and the long-term
- for purchasers of health-care systems to illustrate cost-effectiveness

In addition, measures needed to be implemented in a time and cost-effective manner, given the increasing pressures for accountability in both education and health-care services world-wide. Developing appropriate measures was a challenge, but one which the team in Nottingham had the skills and experience to deliver.

1.6 Evaluating the intervention: data collection

At the outset of the Nottingham programme, a database was established with support from the Medical Research Council's Institute of Hearing Research, and it was used for the initial evaluation of paediatric cochlear implantation in the UK (Summerfield and Marshall, 1994). Multi-disciplinary protocols were established which were to be used with all children using the service, ensuring that the data gathered was consecutive, with minimal loss to follow-up and included those from the range of social, cultural and educational backgrounds found in the UK. The database was developed further (BCS) to both manage the programme and the process of implantation, and to provide clinical information and outcome measures over time. It included measures in the domains of:

- Medical assessment
- Surgery
- Audiology, including electrophysiology
- Speech and language therapy
- Education
- Administration

It was considered vital to include a management and administrative element to the database in order that outcomes could be related to the personal data held on the children, and also to enable cost-effectiveness studies to be carried out, including measures of time spent with the child, the technology used and the professional input (figure 7). A culture of data collection was established which involved all

staff, but crucially included parents and local professionals, particularly educators, in the collection of data from the outset.

The team was experienced in both qualitative and quantitative research with deaf children with implants, and included experienced teacher of the deaf researchers, as well as those experienced in research in the medical and audiological fields. The skills already developed with deaf children with hearing aids, were utilised in the development of the multi-disciplinary protocols, and of new monitoring tools, appropriate for those children with no formal, measurable, language skills.

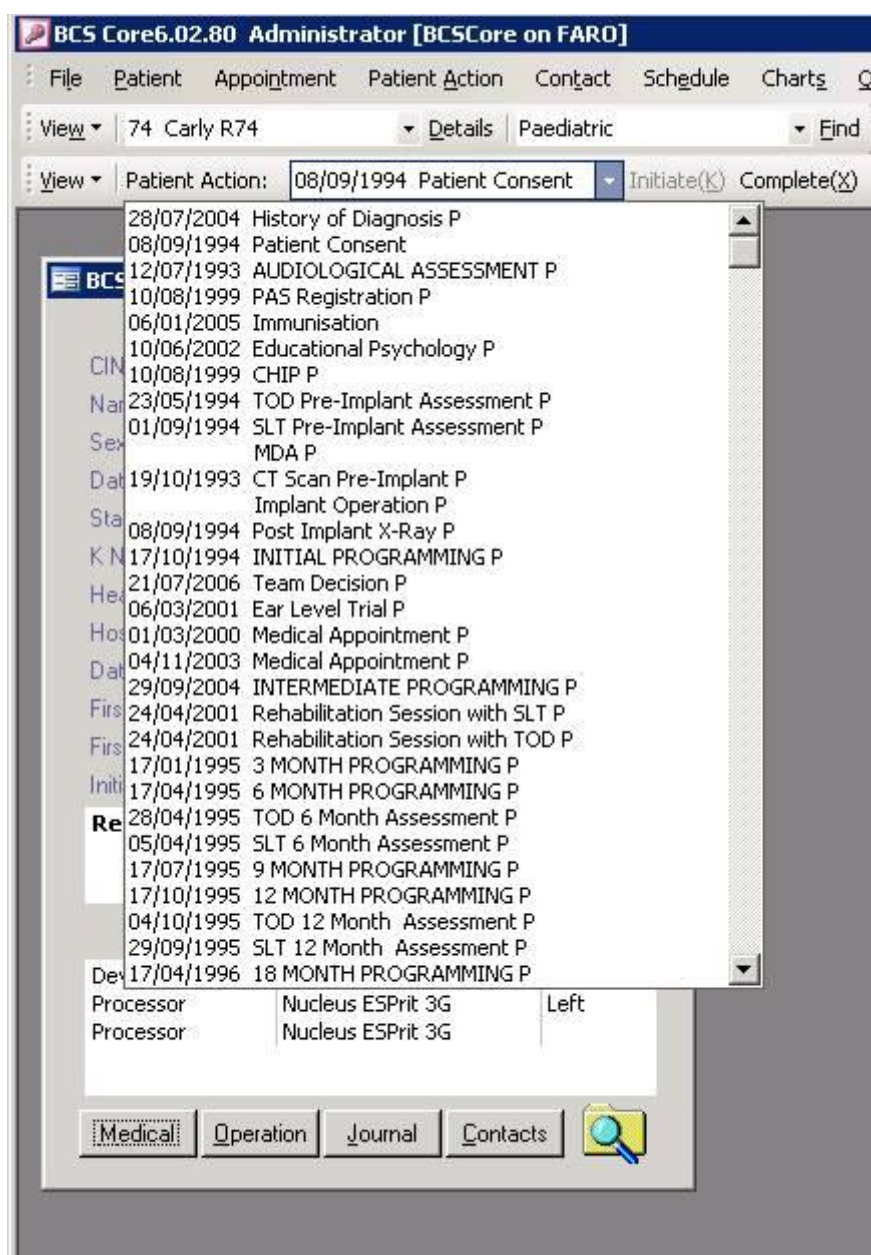


Figure 7. Patient Summary plus history of activity shown in the list of patient actions.

The combination of research skills and considerable experience with deaf children led to measures being developed (for example the Categories of Auditory Performance, CAP) which could be used by parent and teacher, which captured real-life data, yet were rigorous and subject to reliability and validity studies.

Data was collected pre-implantation and at 6 months and one year after implantation, and annually thereafter. Envisaging a long time-frame, the implant process was divided into:

- Pre-implant phase
- Implantation phase
- Rehabilitation phase (three years)
- Maintenance phase

I was particularly interested in the impact that implantation would have on deaf education and on the attainments of deaf children – and in 1989 we did not know. However, the combined experience of myself and Margaret Tait during our time working with David Wood at the Deafness Research Group enabled us to build up an educational protocol which used measures current in deaf and mainstream education, in the international cochlear implant literature, and to develop our own, with a rigour supported by our research colleagues. We wished to capture:

- The use of the implant system at home and at school
- Parental expectations before implantation
- Parental and family experiences after implantation – over the long-term
- Listening skills
 - Environmental sounds
 - Speech sounds
- Development of early communication skills, prior to language developing
- Auditory perception
- Speech perception
- Telephone use
- Educational functioning in the classroom, including behaviour
- Educational attainments, including reading and writing skills
- The views of the young people themselves as they grew up

To this end, the educational protocol (see figure 8) included standardised tests such as reading tests, video analyses of interactions, measures of non-verbal intelligence, criterion-based profiles, and open and closed questionnaires. They provided opportunity to obtain input from parents, community based professionals, and the children themselves, as well as implant clinic based professionals, in order

to capture what changes implantation was effecting in the lives of young deaf children at home and school.

- Had cochlear implantation changed the impact of deafness on communication skills, on educational choices and on educational attainments?
- What were the perspectives of patients and young people on the implications of cochlear implantation for deaf education?

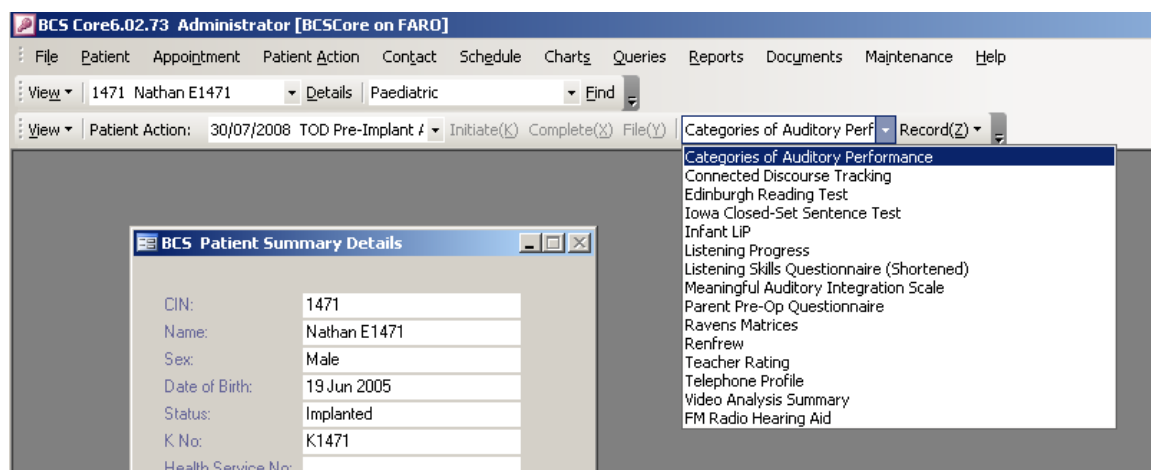


Figure 8. An example of teacher of the deaf Pre Implant Assessment battery (BCS)

The data collected using the educational protocol are the subject of the following papers, and address these issues.

The papers are divided into three chapters:

- evaluating young deaf children with implants
- educational outcomes from implantation
- parental and young people's perspectives

The 18 papers which comprise this thesis investigating the effect of cochlear implantation on deaf education arise from the author's work; they include six where others were lead author, reflecting the necessary multi-professional teamwork to achieve such complete data collection and analysis in this field.

Firstly, attention to issues of clinical governance was important, ensuring that the highest standards of continuing and comprehensive ongoing management and assessment were set by the Nottingham programme, while engaging the expertise of parents and the local professionals, as described in the following two papers.

1.6.1 Addressing clinical governance

Addressing clinical governance in paediatric cochlear implantation O'Neill, C, Archbold, S, O'Donoghue G, Gibbin, K, McCormick, B. *B Jnl Clin Governance* 2002: 7:13-21

1.6.2 Ensuring the long-term use of cochlear implants in children

Ensuring the long-term use of cochlear implants in children: The importance of engaging local resources and expertise. Archbold, S, O'Donoghue, GM. *Ear & Hearing*. 2007: 28: 3S- 6S

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Chapter 1

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Chapter 1.6.1

Addressing clinical governance in paediatric cochlear implantation

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Abstract

The protracted and multidisciplinary nature of paediatric cochlear implantation presents particular challenges in addressing issues of clinical governance. The implantation process is one that involves many disciplines in acute and community settings over several years. Reviews the difficulties presented by a protracted, multidisciplinary intervention for addressing issues of clinical governance within the context of paediatric cochlear implantation. Discusses the activities of the Nottingham Paediatric Cochlear Implant Programme in tackling these problems and gives some detail of its progress and success in these areas.

Introduction

A cochlear implant is a specialised form of hearing aid. It consists of two parts, the internal implanted device – positioned during surgery below the skin of the patient with electrodes inserted into the inner ear – and the external device consisting of microphone, speech processor and transmitter. Unlike traditional hearing aids, implants do not simply amplify signals to the ear. Rather they directly stimulate the auditory nerve and can thus provide a sensation of hearing to persons for whom traditional hearing aids are of no benefit. The device was originally used only in adults. More recently, however, it has come to be used in the management of young deaf children. Its efficacy in this group has been clearly demonstrated (Osberger et al., 1993; Waltzman et al., 1997; O'Donoghue, 1999) and it is in this context that the greatest benefits of implantation are now believed to lie.

The purpose of paediatric implantation is to ameliorate the difficulties experienced by a deaf child living in a hearing world, that is, to allow the child to function more fully within a hearing world than would otherwise be the case. Functioning in this context has many aspects. It includes the ability of the child to communicate with others using spoken language, to access hearing environments (for example, a mainstream school as opposed to a special unit or school for the deaf) and to access technologies (such as the telephone) that are an everyday part of modern life. Achieving such outcomes requires the skills of many professionals working in close co-operation with the child and its parents, not just the implant surgery itself (McCormick, 1997). Moreover, because aspects of functioning (such as speech skills) develop over time (McConkey Robbins et al., 1995; Allen et al., 1998) this partnership must be sustained over a prolonged period. For a child implanted at

aged two or younger, for example, the process can last for over 14 years with children not leaving the paediatric programme until age 16 when they transfer to the adult programme.

The prolonged and multidisciplinary nature of implantation presents particular challenges in fulfilling obligations of clinical governance. Specifically, these challenges arise in identifying and measuring outcomes pertinent to governance; devising a monitoring system spanning the duration of the process that will inform quality improvement and recognising in an appropriate manner the changing stakeholder interests. In this paper we review the activity of the Nottingham Paediatric Cochlear Implant Programme in meeting these challenges and demonstrate its success in this.

Multidisciplinary working and measuring

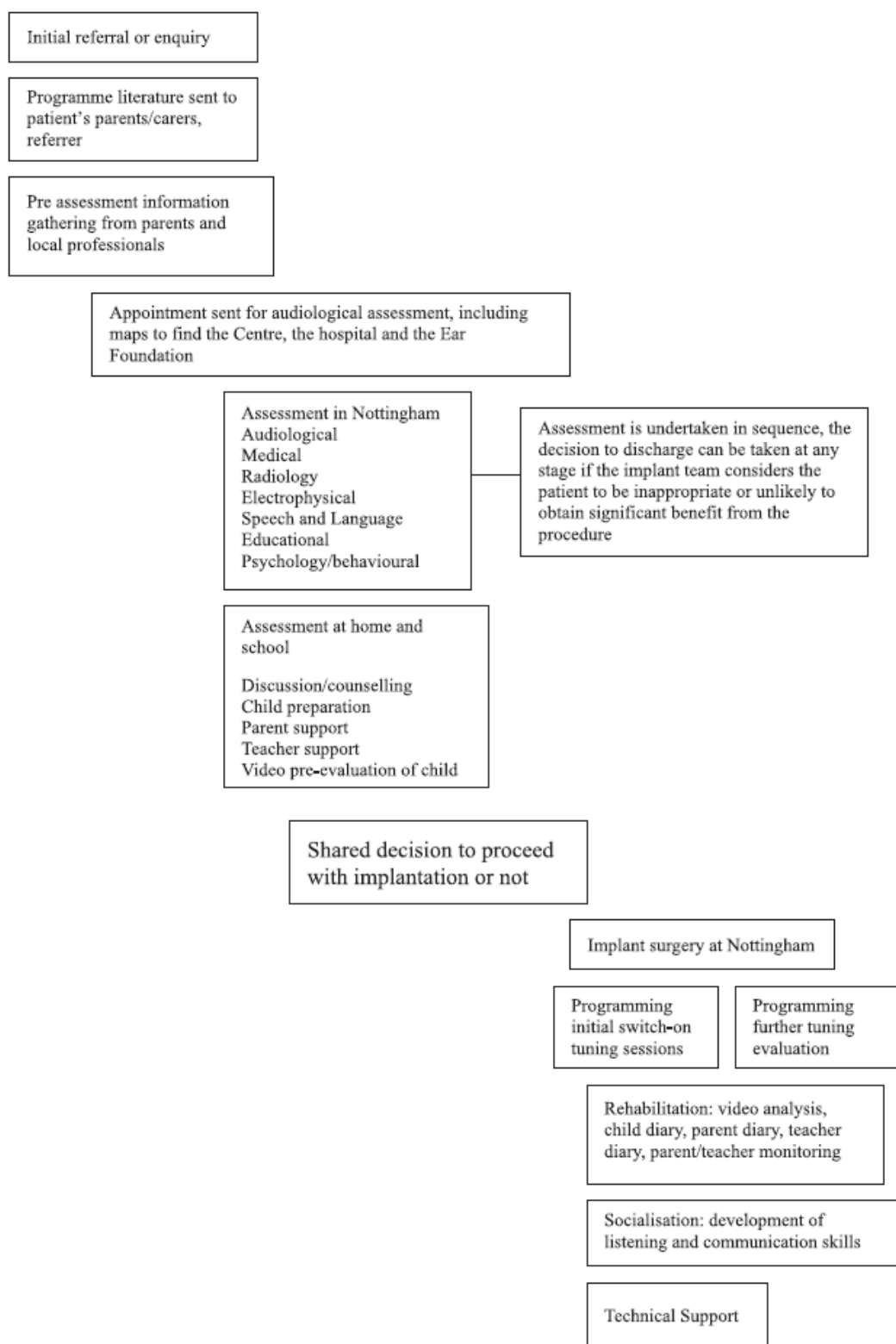
The number of disciplines involved in implantation, and the timeframe over which the process takes place, gives rise to many outcomes at many points in time. Thus surgical interventions give rise to surgical outcomes such as major and minor rates of surgical complications, audiological interventions give rise to audiological outcomes such as accurate detection of suitable candidates for implantation and accurate detection of electrode failure subsequent to implantation. Similarly, rehabilitation gives rise to rehabilitation outcomes such as development of audition skills, speech intelligibility, communication skills generally, self-reliance and general well-being. There exist, moreover, interdependencies in these outcomes. Failure of electrodes, for example, will impact on the efficacy of the device and thus affect the development of communication skills. For a variety of reasons, it may be important to measure each outcome as and when it arises. This may, for example, be useful in demonstrating the successful completion of a particular activity or the quality of a particular discipline's involvement in the process. For example, rates of surgical complications, instances where re-implantation is required or where communication skills develop at a slower rate with one child than another. Not all outcomes are, however, pertinent to meeting the obligations implicit in good governance. For example, it is possible to measure hearing loss in terms of decibels and demonstrate the effect of implantation in these terms. How meaningful this is to the average user or his/her parent is questionable, however. Its value in isolation as a measure of outcome relevant to the patient could, therefore, be questioned. Its value increases when the measure is shown to relate to everyday usage of hearing on a scale that can be understood by the lay person (for example, the ability to follow speech at normal conversational levels).

To ensure that those using the programme, as well as those scrutinising the performance from the patient's perspective, are not left uninformed, it is important that pertinent measures be distinguished from possible measures and a system to capture these data be devised. This the programme has done through a series of steps. First the implantation process was set out diagrammatically to provide an overview of the activities involved in implantation and the stages at which they occurred. All activities undertaken by programme staff, from the point at which a child entered the programme until it left, were described (see figure 1).

Second, key stages in the implantation process- defined as when a child moved from one phase in the implantation process to another – were identified. Analogous to a decision tree, these points identified critical junctures where an ability assess the quality of care delivered was required. For example, when the child passed from assessment by the surgical team to assessment by the speech and language therapists or when the child passed from implantation to rehabilitation. At these points, measurements relevant to the notion of governance, i.e. that characterise quality from a patient as well as a clinical perspective would be needed. A multidisciplinary management committee undertook both of these steps; the steering group of the programme consists of surgical, audiological and scientific, rehabilitative and management staff.

Third, at points where measures were considered appropriate, appropriate measures were devised. In some instances this was relatively straightforward. For example, in the case of surgery, this can occur with or without complication where complications can be major or minor in nature (or indeed result in death, though this has never occurred). These terms have meaning to the lay person as well as to the professional. It follows that quality of care from surgery could then be measured in terms of the number of procedures undertaken without complications or without major complications. For others, for example, when assessing the child's suitability for implantation or aspects of the overall success of implantation – i.e. how well the child was able to function – a range of measures was required to represent fully the various domains of functioning in a manner accessible to the no-specialist. On occasion this obliged staff to devise such measures which were then validated on early cohorts of children passing through the system. When validation was complete these were introduced as part of the measurement system. Examples here include the McCormick toy test as an assessment tool (Palmer et al., 1991) and categories of auditory performance (CAP) as an outcomes measure Archbold et al., 1995; Archbold et al., 1998a,b).

Figure 1



0-6 months	audiology
6 months	surgery
6 months +	maintenance/rehabilitation

(The later measures the impact of implantation using an ordinal scale on everyday activities such as awareness of environmental sound, ability to understand conversation without lip-reading and the ability to use a telephone).

Fourth, a database was designed in collaboration with the MRC Institute for Hearing Research that would capture all activity and outcomes for each child entering the programme. Each child accepted on the programme is assigned a unique identifier on entry. Their personal record is updated in terms of activities undertaken and outcomes generated as they move through the implantation process. As can be imagined given the range of activities and duration of the process, individual records can be of considerable length by the time a child leaves the programme.

Fifth, a system of reporting was designed to underpin maintenance of the database. Each professional reports the activity undertaken and the outcome achieved, if appropriate, each time they see a child. For some disciplines, this involves infrequent reports or reports only at certain stages of the process – thus, for example, the educational psychologist may be involved only in the assessment phase of implantation or at times of difficulty. For others, however, who are involved with the child throughout its time with the programme such as speech and language therapists (SLTs) or teachers of the deaf (TODs), this can involve more frequent reporting and updating of the database (time spent including analysis, etc.). For example, rehabilitation staff (SLTs and TODs) spend on average 40 hours in the first two years following implantation on activities related to the child and this continues on an annual basis while the child remains with the programme. While each contact hour is recorded as it occurs, an assessment of the child's progress in terms of communication skills only takes place on an annual basis. Thus, for example, CAP measures are taken at 12-months intervals and similarly in relation to assessments of speech intelligibility (Allen et al., 1998).

The database is updated continuously as reports are received. Where reports are not submitted in relation to a particular child, or from a particular member of the staff, they are followed up by the database manager.

Non-reporting is readily identified by appearance of gaps in the database relating to individual patients of staff members. At the time of writing detailed records on almost 300 children implanted by the programme exist. These span over ten years of its operation. Additional records on children accepted for implantation and

awaiting an implant, together with those assessed by the programme and not considered appropriate candidates for implantation are also held.

This system provides a means by which the activity and achievements of the programme pertinent to issues of governance can be measured. That the measures used by the programme are pertinent to quality as perceived by users is evidenced by the fact that purchasers, parents and teachers often request outcomes information in the form gathered by the programme – intelligible speech, ability to understand conversation without lip-reading, etc. As the timeframe over which post implantation outcomes can be measured increases, the database is expanded to incorporate additional measures such as reading age and more objective measures of speech perception and production.

Monitoring outcomes

In relation to monitoring two problems exist in establishing good governance, first the time frame over which the process must be monitored and second the complication created for improving quality by interdependencies in the implantation process. In relation to the first, as noted, implant staff are in contact with the child throughout its time with the programme and a rigorous system of reporting is operated by them. This allows staff to monitor activity and outcome attainment throughout the process thus overcoming the problem of the process duration.

In relation to the second, the problem is somewhat more involved. The success of the programme depends not just on activity at a particular point in time or of a particular discipline, for example, implantation of the device, but on that which has gone before it, (e.g. activities related to assessment) and of that which follows after it (e.g. activities related to rehabilitation and management). Within such a context identifying what and how a particular input contributes to overall performance as well as devising remedial action where this might be appropriate can be difficult. It follows that instigating continuous quality improvement will also be difficult.

Moreover, where a considerable time period is required before certain benefits can meaningfully be assessed (e.g. it is accepted that a minimum of two years is required before CAP gains can be meaningfully be assessed (Archbold et al., 1995)), gathering evidence to investigate the role of particular inputs can take time. A programme still in its early years, or a programme that has a small throughput, can experience difficulties in investigating how the process might be improved.

In Nottingham, the database that has been developed and the attention given to its maintenance, provides a means by which the quality of its care and ultimately outcomes can be monitored, analysed and improved. It has taken time for sufficient evidence to be amassed to do this. Improvements using such evidence are pursued at two levels: that of the individual, and that of the programme. At the level of the individual, experienced staff can form an expectation of the communication skills a child should achieve within certain timeframes. The database enables them to confirm the appropriateness of these expectations across many more children than they personally could see, frame expectations for a particular child they may not yet have encountered as well as educate less experienced members of staff on likely expectations. When in contact with specific children staff can then identify instances where these expectations are not met and thus initiate investigations as to the causes (for example, where electrode failure compromises the effectiveness of the device).

These cases can then be discussed at multidisciplinary team meetings held each month and where appropriate, remedial action or further investigation can be planned. In addition, if necessary, the database can be interrogated to investigate similar cases for any additional light it might shed. Thus by measuring and monitoring individuals, problems can be identified and responses devised. This helps ensure the potential of the implant (in so far as is possible) is realised.

At the level of the programme, performance is monitored and improvements sought in two ways: first through publication of a biennial *Progress Report* and an *Annual review* and second through the publication of research papers, both of which are available to the public and parents. Again, the ability to produce these hinges on the existence and maintenance of the database. In relation to the former, the programme's progress report gives details on a range of measures relating to service quality and service outcomes. These include surgical complications experienced by the programme, audiological changes, rates of device usage, attainment of various communication skills by children (measured at various time intervals) and of educational placements (mainstream school, unit in a mainstream school, or school for the deaf). It thus provides a snapshot of the programme's performance across a range of measures that can be compared against the performance of other programmes and with performance of the Nottingham programme in previous years. As with individual patients where performance is less than that considered acceptable, the report – made possible

by the database – allows management to identify this, investigate why it may be the case and address identified difficulties.

The second way in which performance is monitored and improved is through research. The database provides an opportunity to investigate the relationship between patient characteristics, the manner in which the intervention is delivered and the overall success of the process, using multivariate techniques. Through this, specific determinants of outcome within the control of the programme can be identified and action planned to improve upon success. For example, one research project undertaken by programme staff has identified the existence of an inverse relationship between the age at which implantation of the child takes place and the subsequent communication skills (Nikolopoulos et al., 1999a, b). This has enabled the programme to seek earlier referrals to it and hence to implant children at an earlier age, where possible, in pursuit of greater benefits. To date the database has been used in the production of over 50 papers in peer reviewed academic journals including papers in the *British Medical Journal* (O'Donoghue, 1999) and *The Lancet* (O'Donoghue, 2000).

Thus, it can be seen how through a process of mapping, identification of pertinent measures, data capture and review, the challenges of a protracted multi-disciplinary intervention for continuous quality improvement can be overcome.

Addressing accountability

The measurement and monitoring activities of the programme are important to issues of governance in as much as they permit continuous quality improvement to be pursued. Accountability is of importance to issues of governance in as much as it requires the programme to pursue such improvements. There are three major stakeholders in the programme:

1. the parents/children to whom services are delivered;
2. the staff who deliver services; and
3. the taxpayer, who pays for the services.

The nature of the relationship between the programme and each of these differs, as does the sense in which the programme should be accountable to them. Moreover, in relation to parents, the protracted nature of the process and the changing mix of disciplines with whom they come into means that the relationship between parents and the programme changes through time. This complicates the

activity of the programme in establishing good governance practices relating to accountability.

As with measurement and monitoring, the programme sought to address these challenges in stages, first clarifying the nature of the desired relationship and then identifying how it might honour this. These tasks were initially undertaken by a multidisciplinary management team within the programme. The manner in which the programme has addressed accountability, however, continues to evolve, as the programme acquires experience through interaction with parents, children and professionals outside the programme.

Accountability and the parent/child

For parents/children the programme has responsibilities to those being considered for implantation, those being implanted and those who have been implanted. The relationship between these and the programme differs, as should, therefore, the sense in which the programme is accountable to them. Parent information days are held annually. At these, implantation and the implantation process, are described to parents of prospective implantees. For children referred to the programme and found to be unsuitable for implantation, the programme has identified its responsibility as being the explanation of the basis for shared decisions and counselling these parents on the implications of it for their child. This responsibility is fulfilled, by discussing decisions with parents and the implications of these. That a consensual approach to decision making is taken is emphasised to reassure the parent that it is a considered decision. Where, despite the programme's explanation, the parents remain determined to proceed with implantation, parents are offered the option of a second opinion and can seek implantation at another centre.

For those children considered as appropriate for implantation, the programme has responsibilities to educate the parents as to what constitutes reasonable expectations from the intervention, what the intervention will entail and what their role will be in securing the outcomes hoped for. It does this in three main ways. First a variety of pamphlets (in various languages) and videos as well as the programme's *Annual Progress Report* are circulated to parents prior to assessment. Second, during the process of assessment, staff educate parents informally as to reasonable expectations for their child and how they can interact with the child to help secure these. Third, opportunities for parents to speak to implant staff informally at "clinics" organised in the community through a charitable

support organisation, The Ear Foundation, are provided. Parents and grandparents of children are represented on the board of trustees of the Ear Foundation to help ensure appropriate representation of this constituency in defining its role. To assess how well the programme meets its obligations in this regards, parents are surveyed as to their experiences of this process. Data from the survey is entered onto the database and forms part of the monitoring system operated by the programme. Issues covered here include communication, well-being and happiness and the proces of implantation. In relation to well-being and happiness, for example, parents are asked using a five-point Likert scale to identify how strongly they agree with the following statements:

- he/she continues to be a happy child and good fun to be with;
- he/she is less frustrated than before he/she had the implant;
- his/her behaviour has improved since he/she had his/her implant;
- he/she still shows signs of frustration in his/her behaviour;
- he/she has become argumentative since getting his/her implant.

For implanted children the programme has responsibilities to support the child and its parents in their use of the implant and to facilitate the realisation of the procedure's full potential. In recognition of this the programme has developed a comprehensive package of support measures. This includes maintenance of the device and its accessories, speech and language therapy (SLT) support as well as educational support from TOD. TOD and SLT are delivered mainly in the local community of the child. Regular audiological and medical checks are also performed by the programme; medical support is available and provided whenever required as well as regular review appointments. All these measures remain in place while the child remains with the programme and are personally tailored to the child's needs. For example, assessment of the child's performance, made in the community, help to identify needs on the part of the child or the parent. The programme practices can then be adjusted accordingly. Examples here include simple reassurance where parents are "doing everything right" through to assistance in learning sign language.

The programme also provides a variety of initiatives designed to facilitate peer support and exchange among parents. These include parent and child residential summer schools and weekends, teenage and other age group "get together", support clinics and social events. These provide opportunities for parents/children to share experiences and information. They are often located away from the centre being hosted or organised through the programme's support charity. As with pre-

implantation, opinions relating to post implantation experiences by parents are surveyed by the programme, entered onto the database and form part of its monitoring process.

Accountability and the staff

In relation to staff, the programme has two main responsibilities:

1. to create an atmosphere in which staff take ownership of the goals of the programme and;
2. to foster an environment conducive to the pursuit of excellence.

The programme's measurement and monitoring activity allows individual disciplines to identify the relationship between their contribution to the process and the impact of this on its overall success. This enables them to better identify with the overall goal of the programme as well as their contribution to attaining that goal.

Multidisciplinary working on publications and training events as well as on everyday tasks also facilitates this while actively requiring staff to keep abreast of developments in their field and fostering an ethos of collegiality. (Virtually all of the papers published by programme staff share authorship with other members of the programme, for example). This is further fostered through the links the programme maintains with international specialists, formally, via conferences hosted in Nottingham (for example a conference on the economics of implantation in June 2001) and elsewhere and visits to the programme as well as informally through the contacts these facilitate.

Through an annual appraisal system, the programme provides a mechanism through which staff can raise issues of concern, discuss career development and identify major courses of study that they might wish to undertake. Throughout the year staff are also given the opportunity to identify and attend where appropriate with support of the programme short courses and conferences. This has included international conferences in Antwerp and Australia as well as conferences nearer home, in Birmingham.

Accountability and the taxpayer

In relation to the taxpayer the programme has a responsibility to maximise the benefits that arise per pound spent on implantations and to provide evidence in this respect to the taxpayer. Work undertaken by the programme, has estimated

the cost per quality adjusted life year (QALY) at between approximately £8,300 and £12,300 (O'Neill et al., 2001). Estimates from the USA and Australia put the cost per QALY at between £3,500 and £6,200 (Cheng et al., 2000) and between £1,700 and £4,100 (Carter and Hailey, 1999) respectively. This information, together with information on costs and changes in costs through time are routinely made available to health authorities working with the programme.

The activities of the programme in respect of measurement, monitoring and quality improvement (discussed above) ensure that it meet its responsibilities in respect of value for money. That some of these activities are undertaken in collaboration with the Ear Foundation – a charitable organisation that raises its own funding – effectively means that some of the programme's work is subsidised. This is similarly, the case in relation to aspects of its research activity which is funded through charitable trusts such as the Royal National Institute for the Deaf and Defeating Deafness.

Value for more money is demonstrated through the publication of the annual *Progress Report* and the publication, in peer reviewed journals, of economic evaluations of programme services (Summerfield et al., 1997; O'Neill et al., 2000). As noted above, these identify how the costs of the programme are constructed, what that resource buys in terms of health outcomes and how that compares with other health care interventions. All such data are made available to purchasers, whom the programme have also invited as groups to information days in the Implant Centre.

Through this range of activity the programme has identified its responsibilities, monitors its performance in relation to these (i.e. is accountable for its achievements in relation to them) and revises how it responds to stakeholder needs.

The success of the programme's clinical governance procedures

From the above it can be seen that the programme has designed and implemented a comprehensive system to address issues of quality improvement and accountability. The success of the programme in this respect can be assessed by the year on year improvements in the outcomes it delivers (published in leading journals); its status as one of the world's leading paediatric implant programme; and the high levels of patient satisfaction its services achieve. Each year the

programme implants approximately 40 children as well as operating maintenance agreements for those it has already implanted.

This ongoing activity is testament to purchaser satisfaction with the programme's services. High levels of device usage among implantees (99.3 per cent use rates at 36 months postimplantation) and of confidence among parents at 36 months post-implantation, 96 per cent of parents agreed or strongly agreed that "the implant centre will sort out any problems that occur") are also indicative of the programme's ability to provide a quality service that commands patient confidence.

Despite the protracted and multidisciplinary nature of the service it provides, the Nottingham approach does appear to allow it to address issues of clinical governance successfully. The need to take a rigorous and long-term approach when embarking on this activity, especially given that outcomes are not fully apparent for many years, is however, worth noting. This has implications both for the commitment other programmes will have to display to address similar issues and for the role of bodies such as the Commission for Health Improvement in identifying and popularising best practice. Where at least five years must elapse before a programme can demonstrate the quality of its outcomes and investigate how these can be improved, patience on the part of all concerned is clearly going to be required before evidence of quality is forthcoming. By the same token, that the commission may have a particularly important role to play in popularising insights gained from the hard won experience of others, is apparent. Only through a combination of the two, and taking lessons from elsewhere while striving to address issues of governance locally can health gain be maximised.

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Chapter 1.6.2

Ensuring the long-term use of cochlear implants in children: The importance of engaging local resources and expertise

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G. O' Donoghue

Abstract

Cochlear implantation for children is now a mature service, recognized as being safe and effective. Early identification is enabling implantation to be undertaken in the first years of life, with the likelihood of better outcomes. Traditional models of service delivery provided excellent clinic based services, with intensive early habilitation. However, the current challenges extend beyond this time frame, and clinic-based services are overstretched with the growing numbers of children with implants. Needs analyses of parents and teachers in Europe provide evidence that they are keen to have regular links between implant center and home and school and that for both parents and teachers a major concern is the long-term management of the technology. There are major challenges, not in the implant clinic, but at home and school where implant systems are used. Implementing complex technology in the child's community in the long term is only possible by engaging parents and the local professionals, particularly teachers, from the outset, and using their expertise. This calls for a critical appraisal of the traditional approach to service delivery. Such engagement of local professionals does not happen automatically but can be achieved by educational programs for parents and local professionals that are adapted to local needs and cultures. Communication between implant center and home and school is essential, ensuring that the technology of implantation is used effectively at all times and is accessible to all wherever they live. This article recommends ways in which parents, teachers, and local professionals can play a central role in the management of children with implants to ensure the successful long-term use of their implant systems. Engaging and using the skills and expertise of those who know the child best, parents and teachers, will not only ensure that implantation is sustainable in the long term in diverse cultures, but is also cost-effective.

Cochlear implantation is now an accepted management for deaf children, with the major goal being to provide sufficient hearing to support the development of spoken language. Outcomes in terms of speech perception and production are published (Thoutenhoofd et al., 2005), with age at implantation being a major factor in outcomes (Nikolopoulos et al., 1999, O'Donoghue et al., 2000; Svirsky et al., 2000, 2004). With Newborn Hearing Screening and early diagnosis established in many parts of the world, very early implantation is much more likely with the consequent expectation of even greater benefit.

Implantation is unusual in having major outcomes in terms of spoken language developed in home and school rather than in clinic, and over years rather than months (Beadle et al., 2005). The process of implantation is one that has lifelong implications for these children and their families and fundamentally changes their communication and educational options. It also makes new demands on families and on non-specialist teachers who are not part of the cochlear implantation team, but who are essential for successful long-term use. As the technology changes, traditional models of service delivery are challenged to provide the long-term support for the growing numbers of children.

Traditional models of cochlear implant service delivery

Traditional clinic-based services have provided intensive (re)habilitation in the short term, often with early encouraging results. However, many of the outcomes measured from implantation are clinic based and do not reflect the real effects of this surgical procedure in daily life (Watson & Gregory, 2005; Wever, 2005). Additionally, as numbers grow, intensive provision becomes unsustainable, with implant centers questioning their methods of service delivery as an effective means of providing for long-term management, for example, Backous (2005).

Cochlear implantation has been led by medical and audiological specialists for whom the main focus may be an improvement in hearing levels. For those working in the educational field, other issues such as language competence, educational attainments, and psychosocial issues are important and demand more than successful speech perception and production. The linguistic, educational, and socio-emotional challenges of moderate and unilateral hearing losses are well documented (Most, 2004) and are likely to be similar for those with implants. Tobey (2006) and Spencer and Marschark (2003) demonstrate that the language delays of deaf children have not yet been completely overcome by cochlear implantation. Where there is little contact between the implant center and home and school, the child's teacher may not realize the possibilities, or limitations, of the hearing provided by the implant or have the skills and knowledge to manage the change in the sophisticated technology. Many teachers feel devalued when not engaged in the selection process for implantation or involved in the tuning process, but being seen as responsible for reported outcomes and long-term management.

Supporting implanted children in the community

The situation in which the child uses the complex technology daily may be very different from the acoustically treated environment of the implant clinic. The reality of classrooms where deaf children spend most of their time the world over is that they are busy places, acoustically challenging, with curricula that are increasingly demanding. Mainstream non-specialist teachers are now managing those with disabilities other than deafness in their classrooms (Nevins and Chute, 1996), and, in the United Kingdom, inner city classrooms may have up to 40 home languages, making the needs of the child with an implant difficult to meet. Additionally, up to 40% of deaf children have at least one other difficulty in addition to deafness, adding to the educational challenges. The demands of managing the changing sophisticated technology in such environments are challenging and may lead to ineffective use of the implant system. If appropriate support is not available to meet these challenges in the community, non-use or ineffective use may result. Such nonusers are unlikely to present at implant clinics, but remain in the educational system and the true prevalence of non-use is unknown.

Cochlear implantation is an intervention in which outcomes are yielded over many years. Many published studies have small numbers over the long term; the data on those children who are not included are not known and not reported. Beadle et al. (2005) reported on all children implanted at one center over a 10-to 14-year period, with no exclusions, and there is one other such prospective study in press, but these reports are unusual. The gap between implant center and the local community of the child may have led to this paucity of long-term robust outcomes studies in children with implants.

These concerns are not new (Archbold & Robinson, 1997; Geers & Moog, 1995; Hasenstab, 1997; Nevins, 1995), but we have yet to find ways of making the technology accessible and manageable in the long term as numbers of children with implants have grown, including those from developing countries and those without the committed support of parents and local professionals.

Needs analysis: what do parents and teachers want?

Surveys of parents (Archbold et al., 2002; Sorkin & Zwolan, 2004) show that one of their main concerns is liaison between school and implant center and that they are particularly aware of the demands of managing the technology successfully in

the long term. A recent survey of European teacher of the deaf organizations (Archbold, O'Donoghue, & Simpson, 2006) revealed that teachers of the deaf feel that they lack knowledge of the implications of implantation for their children and that they are keen to have training. One of the areas in which they wished to receive training was in managing the technology, and they preferred this training in their own community. Watson and Gregory (2005) reporting on a small number of nonusers of implant systems, considered that one of the important factors in promoting long-term use was the liaison between clinic and family and local professionals, with the implant center responding to local concerns. In the study of Beadle et al. (2005) 10 yr after implantation in this non-selected group, there was only one non-user; in this group, there was considerable liaison between clinic and education, which was thought to have been a factor in ensuring this high level of use.

Making the technology work in the community – the way ahead?

To make the opportunities brought by cochlear implantation available to all and sustain them in the long term, alternative models of service delivery should be considered. A move from clinic-based specialist services toward community-based services could engage the knowledge and skills of those who know the children best—their parents and teachers. Engaging them fully in the process ensures sustainability of culturally and linguistically appropriate support, wherever the children live. Using the local skills of parents and established educational services rather than providing new services for children with implants also makes economic sense. How are the implant habilitation and basic technical support skills transferred to the community-based carers, while using and valuing their own skills and knowledge?

There are three areas to be addressed if cochlear implants are to be successful in the community in the long term.

First, parents now expect to be partners in the care of their child; they are now being confronted with decisions that were not an option in the recent past and are expected to deal with them at a time when they are emotionally vulnerable, before they have any knowledge of the impact of deafness on their lives (Luterman, 2005).

Parent programs the world over are ensuring that parents are fully partners in the process, and cochlear implant clinics can learn from such models. We need to ensure that parents have appropriate early support in developing early communication skills with their child; we know that good early communication skills predict progress after implantation (Tait, 2000) and that the provision of parent interaction courses leads to improved parent-child interaction (Harrigan and Nikolopoulos, 2002).

Second, with regard to educational services, Cowan (1997) described three models of rehabilitation delivery: that solely provided in the implant center, that provided in special schools with liaison with implant center, and that provided by outreach professionals from implant centers. Nevins (1995) and Archbold (2003) described educational outreach models of service from implant centers, and in the United Kingdom, implant center teachers of the deaf meet regularly to provide a forum to improve educational support in the community. Initiatives such as that provided by ONICI in Belgium and the Lennhardt Foundation recognize the roles of teachers in the continuing use of implant systems. The Ear Foundation's Continuing Education Programme provides services for parents and professionals together and targets those working in mainstream classrooms who are key personnel, but who may be untrained in deafness or in cochlear implant management. Delegates to this program have doubled in numbers year by year (Ear Foundation Annual Report, 2005) and content evaluation is consistently above 90%.

Third, with regard to the technology, current technology is not easy to understand or intuitive to use and changes frequently. The instructions are frequently incomprehensible to most parents and teachers. Additionally, an individual teacher may have several children with different implant systems to manage. Systems that are user-friendly in the child's environment would simplify daily management. The addition of assistive listening devices, such as radio hearing aids, adds to the challenges in providing a child with a good listening signal in acoustically challenging classrooms (Wood & Popplestone, 2005).

Conclusion

If implants are to be sustainable in the long term for deaf children wherever they live, we need to ensure that:

- parents are supported in the development of early communication skills with their child,
- parents and local professionals are fully engaged in the implantation process and their expertise is valued and used,
- the liaison between implant center and home and school is on a regular basis, with accessible reports from the center after tuning sessions, clear guidance as to the implications for listening on an everyday basis, and clear guidance on the management of the child's technology routinely available,
- education and training are provided and made accessible to local professionals in culturally and linguistically appropriate forms and the new communication technologies make this more feasible than ever before,
- the technology is designed to be robust and userfriendly.

Cochlear implantation is now a mature service, and it is time in its evolution to move services for deaf children back to where they belong—at home and at school. This is the real world for deaf children and where implantation is to be successfully managed in the long run.

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Chapter 2

Evaluating outcomes from paediatric implantation in young children

In order to measure the impact of cochlear implantation on deaf education, it was first necessary to evaluate the children's changes in communication, their access to spoken language and the use of their implant systems. This chapter contains papers which describe some of the measures used and developed to evaluate and their resulting outcomes over time.

Evaluating outcomes in the young population of deaf children being considered for implantation was challenging: many measures used in the field of implantation were unsuitable for this group, without established language and unable to carry out formal clinic-based tests. The Nottingham protocols and the associated database were designed to address this challenge, and to include measures which reflected progress in everyday life, which were accessible to a range of stakeholders, and would be useful in the short and long-term. They also needed to be robust, reliable and valid, to bring together the concerns of both researchers and practitioners. The following papers first describe the Nottingham Early Assessment Package, designed to cover the areas of communication, auditory perception and production, and go on to give more details about two profiles now widely used, Categories of Auditory Performance, and the Listening Progress Profile. The fourth paper included looks at the determinants of speech perception, using Connected Discourse Tracking, a measure first used with adults, but adapted by the author for use with children. The final two papers consider perhaps one of the most important outcome measures: are the children continuing to wear their implants in the long-term and what are the factors which influence this?

Chapter 2.1

Young deaf children with hearing aids or cochlear implants: Early assessment package for monitoring progress

T.P. Nikolopoulos
S.M. Archbold
S. Gregory

Summary

Background:

Very few assessment measures exist for evaluating progress in young deaf children with hearing aids and cochlear implants.

Objective:

To introduce and describe an early assessment package that covers auditory perception, communication/language development, and speech production in very young deaf children.

Main outcome measures:

Seven of the assessment measures (Listening Progress Profile, Categories of Auditory Performance, Tait Video Analysis, Stories—Narratives Assessment Procedure, Profile of Actual Linguistic Skills, Speech Intelligibility Rating, and the Profile of Actual Speech Skills) have been specifically developed at the Nottingham Cochlear Implant Programme, and a further one (Meaningful Auditory Integration Scale) was modified for use within the package. Moreover, two commercially available tests (Pragmatics Profile of Everyday Communication Skills and Preschool Language Scale) are included to complete the package.

Methods:

The present paper describes each measure, how to use it, and its time frame. In addition, two case studies demonstrate the usefulness of the package as a whole.

Results and conclusions:

The Nottingham Early Assessment Package (NEAP) offers a framework with which to assess in young deaf children the use of audition and language and communication in real-life situations. Being simple, reliable, and time effective can be used in everyday clinical practice. NEAP is innovative in design and offers a structured approach to monitor very young deaf children, both in short and long term. In addition, it allows the identification of additional problems and areas of difficulty as well as specific abilities and skills. This enables the clinician to determine appropriate intervention strategies.

Introduction

The advent of pediatric cochlear implantation necessitated the development of assessment measures appropriate for very young deaf children to inform the decision making process, to monitor device functioning, the appropriateness of support and help identify the presence of any additional learning difficulties. The Nottingham Early Assessment Package (NEAP) is a collection of measures which have been chosen to meet this need. Having been initially developed for use within an implant programme, the package focuses on the use of audition in the development of communication and spoken language skills. However, it is an important feature of the package that the development of audition is not viewed in isolation, but in its role in the development of communication and language by the child.

The package is particularly useful in providing a structured way of looking at development at the pre-lexical and early word stage, before the period when most standardized tests of linguistic skills can be used. NEAP offers a range of assessments providing a profile of the child at a stage when most tests are limited in their application or require more formal assessment procedures. Some of the assessments included in NEAP can be used regardless of mode or language, and focus on communication itself. The development of the package took place within a multi-disciplinary context and it reflects this philosophy in working with young children.

The package

The measures developed by Nottingham Pediatric Cochlear Implant Programme over the years for assessing young deaf children both before and after cochlear implantation, now form the Nottingham Early Assessment Package. NEAP can be used from the first months of life, providing useful markers in that early period, guiding decision making about appropriate intervention and providing a tool for continuing assessment and monitoring. The package uses video analyses, observational profiles, interviews, and questionnaires. Some of the measures can be used from early infancy right through to adulthood, providing continuity and the basis for long-term comparisons in the various areas of development.

NEAP covers the following areas:

- communication and language development;
- auditory perception; and
- speech production.

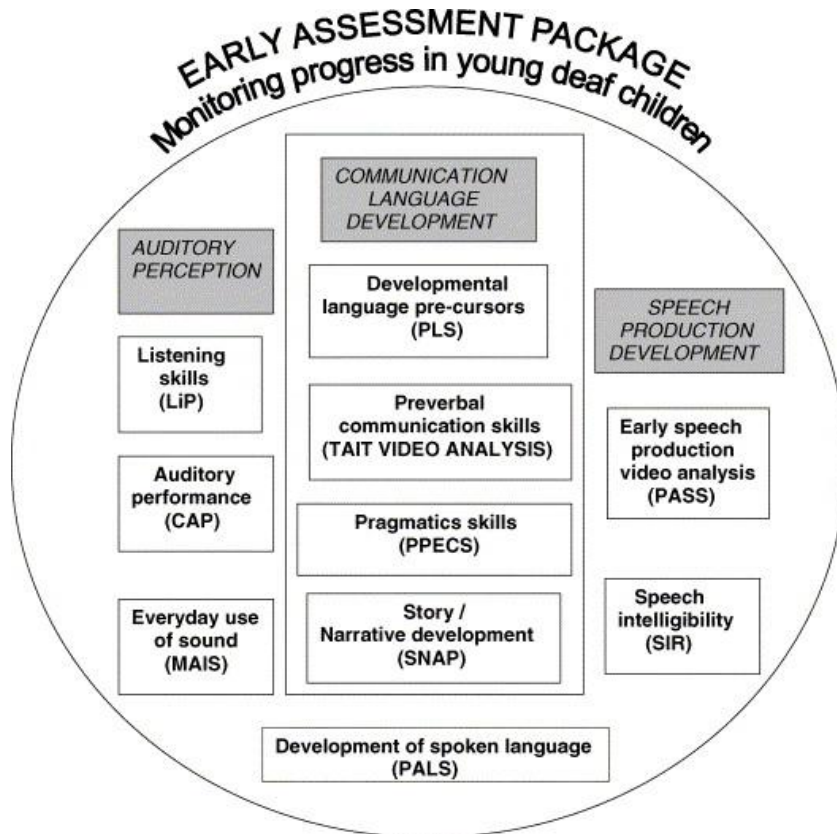


Figure 1. The measures used in the Nottingham Early Assessment Package (NEAP).

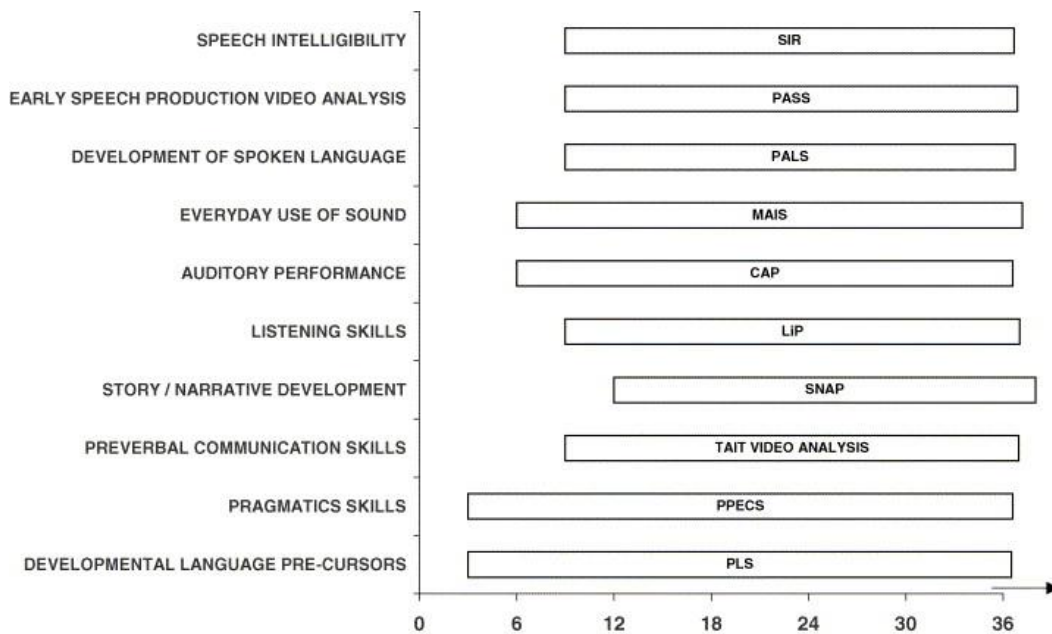


Figure 2. Nottingham Early Assessment Package (NEAP) time frame in children's life (months) for the use of the assessment measures.

Figure 1 illustrates the measures used in these areas of focus. Figure 2 demonstrates the use of the measures over time, and the time-scales for which they are applicable, showing the range of each. Seven of the assessments have been specifically developed at the Nottingham programme, and a further scale (MAIS) was modified for use within the package. Two commercially available tests are included to complete the package.

The present paper describes each measure and concludes with two case studies, which demonstrate the usefulness of the package as a whole.

The measures

1. Communication and language development

Fundamental to any early assessment of young children is a consideration of communication and language development. The measures used in this area have been chosen to cover the range of areas of early communication skills, from the preverbal stage through to the development of spoken language. They are:

- Tait Video Analysis: preverbal communication skills;
- Preschool Profile of Early Communication Skills (PPECS): pragmatic skills;
- Story/Narrative Assessment Procedure (SNAP Dragons): story/narrative development;
- Profile of Actual Linguistic Skills (PALS): development of spoken language; and
- Preschool Language Scale (PLS): developmental language pre-cursors.

Tait Video Analysis (TVA): developed by Margaret Tait (Nottingham Pediatric Cochlear Implant Programme)

Tait Video Analysis assesses, in a video sample, deaf children's preverbal communication skills: responses in an interaction with a known adult, eye contact, turn-taking, vocal initiative, gestural initiative, and auditory awareness.

TVA is very useful in the early stages of assessing communication skills is a sensitive measure which can monitor changes over short time frames, months rather than years. It measures the developments which take place before understanding of spoken language is evident and certainly before the emergence of speech.

Preverbal development is measured in four areas: turn-taking, initiative, eye contact and auditory awareness. *Turn-taking* can be either 'vocal', with or without the addition of sign/gesture, or 'gestural' without vocalization. *Initiative*, which can

also be vocal or gestural, is judged to be shown if a child's turn contains elements that cannot be predicted from the adult's preceding turn. *Eye contact* notes when the child looks at the adult and when the child looks elsewhere. *Auditory awareness* of the adult's voice is considered to be shown if the child 'replies' when they have not been looking at the adult for the adult's last few words. Such a reply might be an attempted repetition of a recognized word, or just a vocalization. This is termed a *non-looking vocal turn* (Tait et al., 2001).

TVA has been shown to be repeatable and been found to predict to a significant extent the later development of speech perception in children with cochlear implants (Tait et al., 2001; Tait et al., 2001; Tait et al., 2000). Thus, in this difficult area of preverbal assessment, it is a proven tool.

The Pragmatics Profile of Everyday Communication Skills: preschool version: developed by Hazel Dewart and Susie Summers (NFER–NELSON Publishing Co. Ltd., Widsor Be, UK, 1995)

The Pragmatics Profile of Everyday Communication Skills (PPECS preschool version) is an informal interview carried out to explore a child's communication in everyday interactions at home or at school. The information is obtained indirectly through interview. The person responding is encouraged to describe *in his or her own words* the way the child typically behaves and this description is recorded on the PPECS interview schedule. The child's current communication strategies are recorded under four main headings:

- a. Development of Communicative Functions: the way the child comes to express a range of intentions, such as requesting, greeting and giving information.
- b. Response to Communication: the way the child reacts to and understands communication from other people.
- c. Interaction and Conversation: how the child participates in social interactions involving initiation, turn-taking and repair strategies when communication breaks down.
- d. Contextual Variation: how the use of pragmatics is affected by variations in context, such as time and place and the people involved.

Stories/Narratives Assessment Procedure (SNAP Dragons): developed by Helen Starczweski and Hazel Lloyd (Nottingham Pediatric Cochlear Implant Programme)
Stories/Narratives Assessment Procedure (SNAP Dragons) is a child centered assessment which has been specifically developed for deaf children in order to monitor their narrative abilities. Using picture-based stories, written and illustrated

specifically for preschool deaf children, children are asked to retell a story using their preferred communication mode and language and this is video-recorded. SNAP Dragons consists of a set of 14 picture-based stories, written and illustrated specifically for preschool deaf children. The books feature a family of dragons involved in every day events throughout the year which are familiar and appealing to this age group. The narrative analysis of the video is carried out in two stages: (a) story grammar analysis; (b) narrative stage (Table 1).

Table 1. Narrative stages (“SNAP Dragons rating”)

Narrative stage	Story grammar	Narrative behavior
1	Pre-analysis	Child is not ready to respond to the task
2	Pre-analysis	Child is happy to look at the book while the adult tells the story, but is not ready to retell the story
3	Child labels or comments on pictures	Child needs prompting/scaffolding to retell the story (>3 prompts)
4	One or two story categories used. Not a complete episode	Some prompting needed (<3)
5	One complete episode	Spontaneous retelling. No prompting needed. Can include a “verbatim” stage
6	One episode complete and second nearly complete (2/3 categories)	Verbatim stage may persist
7	Two complete episodes	Confident story telling
8	Greater than two episodes. Internal responses used increasingly to show reasoning of characters	Confident and creative story telling

Story grammar analysis looks at the structure of information in the child's story. It is particularly concerned with the identification of setting information, initiating events, actions of the characters, consequences and any internal responses of the characters in the story. Each utterance of the child's story is coded on the transcription. Analysis then goes on to determine whether a complete episode is present. This is a story unit or episode represented by the presence of an initiating event, action and consequence (Naremore et al. (1995; Roth et al., 1986). The developmental sequence is described elsewhere (Starczewski et al., 2000; Starczewski et al., 2000; Nikolopoulos et al., 2003).

An inter-rater reliability study has been carried out on the SNAP rating with excellent results. The SNAP rating is easily undertaken and shows high inter-observer reliability. Moreover, the progress of young implanted children in the

narrative skills using SNAP as the assessment method has been demonstrated and a shift towards more speech orientated communication modes following cochlear implantation has been found (Nikolopoulos et al., 2003).

Profile of Actual Linguistic Skills (PALS): developed by Dee Dyar (Nottingham Pediatric Cochlear Implant Programme)

The Profile of Actual Linguistic Skills is a criterion-referenced procedure that assesses a deaf child's ability to use oral language, effectively, in every day linguistic and learning environments. The PALS profile looks at the child's rate of progress at five inter-related linguistic levels: social and pragmatic skills, receptive skills, expressive skills, voice skills, and speech skills.

PALS has been found to be a sensitive means of 'profiling' changes in the spontaneous communication/linguistic skills of profoundly deaf children who are functioning at the pre-lexical stage of language acquisition.

The developmental framework approach of PALS makes it an appropriate precursor to norm-referenced language performance measures. It can provide global data on the linguistic status of children and identifying "gaps" enables the user to plan immediate communication priorities and goals for the deaf child.

The PALS profile is usually completed by a speech and language therapist. After preliminary training, it can be used by other experienced professionals.

The outcomes obtained on the five inter-related levels of the PALS individual profile can be collated further to provide *an overall classification* of the child's *current linguistic effectiveness* in a spoken language at a specified assessment interval: (1) preverbal; (2) transitional; or (3) functional language (Table 2) Allen et al., 1997).

Table 2. PALS: outcome categories preverbal, transitional and functional language

Preverbal	Transitional	Functional language
The deaf child is functioning at the 'pre-lexical' stage of oral language acquisition	Recognisable words and simple formulaic expressions are <i>reported</i> by the deaf child's parents/carers/support professionals. Some single words or phrase patterns may be <i>elicited</i> on a minimum of two occasions in an assessment context	The deaf child demonstrates the ability to use language(s) spontaneously and in a systematic way. A knowledge of meaning and the rules of the ambient spoken language is apparent

Preschool Language Scale: 3 (UK): developed by I.L. Zimmerman, V.G. Steiner and R.E. Pond, UK, adaptation by J. Boucher and V. Lewis (Psychological Corporation Limited, London, 1997)

The Preschool Language Scale (PLS3) measures the pre-cursors to language as well as a broad range of early language skills; early interaction and early vocal development. It can be used to test children aged from 3 months to 6 years 11 months or for older children functioning developmentally within this age range. This scale has been included to enable us to evaluate the deaf child's relative ability in receptive and expressive language when compared to a hearing peer (UK and US norms are available). It looks at receptive language pre-cursors, for example, a child's shared attention abilities, and also at expressive language pre-cursors, for example, social communication and vocal development.

This commercially available test can be used by speech and language therapists, educational psychologists, specialist teachers and other professionals who may work with communication impaired children in the preschool years, and has a comprehensive manual.

2. Auditory perception

The relationship between degree of deafness and auditory perception is not a simple one and the ability to use hearing aids or cochlear implants effectively will vary considerably. In order to complement the formal audiological measures taken within the clinic, indicators of the functional use of audition in everyday life are necessary. The three measures of auditory perception are:

- Listening Progress Profile (LIP): measuring early listening skills.
- Categories of Auditory Performance (CAP): measuring auditory performance in everyday life.
- Meaningful Auditory Integration Scale (MAIS): measuring everyday use of sound and hearing aid or implant.

Listening Progress Profile (LIP) developed by Sue Archbold (Nottingham Paediatric Cochlear Implant Programme)

The Listening Progress Profile measures the developing listening skills in young deaf children, in everyday situations. Specific activities are used to enable completion of the profile, in observation and play, rather than by testing. It covers a range of abilities from first response to environmental sounds and first response to voice, through to discrimination of environmental sounds and discrimination of voice, to identification of the child's own name (Nikolopoulos et al, 2000; Nikolopoulos, 2002; Nikolopoulos et al, 1997).

A prospective and longitudinal study found that all the children studied following implantation could be assessed by LIP; no child scored 0 as early as 3 months post-operatively. The study included children implanted under the age of two. LIP has also been useful in highlighting those children who may have a potential device problem (Nikoulopoulos, 2002; Nikolopoulos et al, 1997).

The inter-observer reliability on LIP as a measure of auditory perception has been formally validated and has shown high levels of agreement between different observers (Archbold, 1994).

Categories of Auditory Performance (CAP): developed by Sue Archbold (Nottingham Pediatric Cochlear Implant Programme)

The Categories of Auditory Performance is a global outcome measure of the developing auditory skills in deaf children, designed to give a readily accessible measure for non-specialists. It is carried out by observation, using standard criteria, and assesses the functioning of the child in everyday situations at home and at school covering a range of abilities from awareness of environmental sounds to discrimination of speech sounds and from understanding common phrases and conversation without lip-reading to telephone use with a known speaker. Table 3 shows the categories. CAP is useful in all the stages of assessing hearing skills, whether use of hearing aids or cochlear implants. When used following implantation it shows changes over the short and long term (Nikoulopoulos, 2002; Nikolopoulos et al, 1999; O'Donoghue et al., 1998; Nikolopoulos et al., 1999; O'Neill et al., 2002; Nikolopoulos et al., 2000) .

Table 3. Categories of Auditory Performance (CAP)

Category	Criteria
7	Use of telephone with known listener
6	Understanding of conversation without lip-reading
5	Understanding of common phrases without lip-reading
4	Discrimination of some speech sounds without lip-reading
3	Identification of environmental sounds
2	Response to speech sounds (e.g. "go")
1	Awareness of environmental sounds
0	No awareness of environmental sounds

CAP is simple, easily undertaken, and easily understood by professionals, parents and ordinary people who have no experience in tests or other assessment methods for deaf children.

The inter-observer reliability of CAP has been formally validated and has shown high levels of agreement between different observers (Archbold et al. 1998).

Meaningful Auditory Integration Scale: developed by Amy McConkey-Robbins, modified with permission by Nottingham Pediatric Cochlear Implant Programme

The Meaningful Auditory Integration Scale was developed to evaluate the meaningful use of sound in everyday situations by profoundly deaf children (McConkey et al., 1991). Nottingham Pediatric Cochlear Implant Programme has extended it to include the opinion of their teachers as well as parent. Ten questions are given ranging from the child's initial adaptation to using the hearing aid or cochlear implant, through response to name, to sounds in the environment through to more sophisticated levels of hearing such as identifying speakers and the ability to identify emotions from vocal tone.

In the early days after the fitting of hearing aids or cochlear implants, the MAIS may provide early evidence of the use of the system, when other signs are few. Parents and carers can be encouraged to consider the ways in which their child is using the hearing system in everyday life, and to be observant of changing behaviors. Its use may alert carers and professionals to early signs of the child not adapting to the use of the system; for example, where the child is not happy wearing the device, or not aware where there are any problems with its functioning. Similarly, its use over the long term may highlight a child who may be becoming an intermittent user.

3. *Speech production*

It is important to monitor the developing speech skills, from the early stages of vocalization in communication through to the emergence of spoken language. The two measures in this area cover speech production from the earliest vocalizations through to intelligible speech. They are:

- Profile of Actual Speech Skills (PASS): early speech production video analysis.
- Speech Intelligibility Rating (SIR): a profile of speech intelligibility.

Profile of Actual Speech Skills (PASS): developed by Dee Dyar (Nottingham Paediatric Cochlear Implant Programme)

The Profile of Actual Speech Skills is a systematic recorded sampling technique that enables a speech and language therapist to establish a developmentally and linguistically appropriate *baseline measure of speech production* in profoundly deaf children, and to transcribe and analyze any changes that occur at the speech production level. A key emphasis of the PASS is to describe the *actual* spontaneous speech patterns produced by deaf children at the pre-lexical stage of spoken language development.

The PASS summary of findings consist of three *quantitative level* outcomes and two *qualitative level* outcomes. The quantitative level outcomes include the change in quantity of overall tokens over time through the transition from silent articulation postures through non-speech through speech-like to speech. The qualitative level outcomes look at changes in the child's vowel and consonant repertoire.

PASS is a developmentally and linguistically appropriate technique for 'profiling' the spontaneous speech patterns of young profoundly deaf children. It can influence the choice of short term (re)habilitation goals for individual deaf children (Dyar & Nikolopoulos, 2003).

Speech Intelligibility Rating (SIR): developed by Dee Dyar (Nottingham Paediatric Cochlear Implant Programme)

Speech Intelligibility Rating measures speech intelligibility of deaf children who use hearing aids or cochlear implants. SIR is a five-point hierarchical scale (Table 4) describing various degrees of speech intelligibility from unintelligible speech through to speech that is intelligible to all listeners.

Table 4. Speech Intelligibility Rating criteria

Connected speech is intelligible to all listeners. Child is understood easily in everyday contexts	Category 5
Connected speech is intelligible to a listener who has a little experience of a deaf person's speech	Category 4
Connected speech is intelligible to a listener who concentrates and lip-reads	Category 3
Connected speech is unintelligible. Intelligible speech is developing in single words when context and lip-reading cues are available	Category 2
Connected speech is unintelligible. Pre-recognisable words in spoken language, primary mode of communication may be manual	Category 1

SIR measures progress in speech intelligibility from before the first words until connected speech is established over the long term. It is not intended to monitor small changes in intelligibility over a short time frame. SIR is a rating of a child's everyday spontaneous speech and has been found to be a practical clinical measure which can be readily applied to large groups of young deaf children over time irrespective of children's age and speech abilities (Allen et al., 1998), and has been shown to be reliable between observers (Allen et al., 2001). There is no need for children to have language skills or to be able to produce a speech sample. Moreover, the overall pattern of development produced is easily understood by parents and non-professionals, fostering realistic expectations.

4. Case studies

The two case studies below of contrasting young deaf children implanted below the age of two, illustrate the use of the measures described above. These case studies demonstrate the use of these assessments to establish base-line measures before implantation, and to monitor progress over the following year, or longer if necessary.

Case study 1

The first (C) is an example of a child who has made good progress with her implant. She was born profoundly deaf and received a cochlear implant with full insertion of the electrode array at the age of 19 months. Her preimplant assessments took place over the preceding 3 months. The only reliable response to sound observed before implantation was an elicited response to drum; no responses to environmental sounds or to the sound of voice were observed. She was therefore rated on the lowest category of the CAP ('no awareness of environmental sounds'), and scored only 5% on the LIP (elicited response to drum). She scored 0% on the MAIS, both parent and teacher versions, as she had no interest in her acoustic hearing aids, being unaware of sound through them.

Her preverbal communication skills were well established. Tait Video Analysis showed her to be taking all her conversational opportunities, but to be as likely to do so silently (53%) as vocally (47%). She had begun to show initiative, again both silently and vocally. No auditory response to the sound of the adult's voice was observed (NLVT 0%). On the PALS she was rated as 'preverbal'. Her SIR level was category 1 (pre-recognisable words) and her PASS rating showed 10% speech sounds, 26% speech-like sounds and 63% non-speech sounds.

By the 6-month interval C had made rapid progress in her listening skills. On the CAP she had gone up four levels (to 'discriminates some speech sounds without lip-reading') and on the LIP she scored 100%: for example, she was observed to be recognizing, and spontaneously repeating, all Ling's five sounds without lip-reading, and recognizing family names, again from the sound alone. She also scored 100% on the MAIS (parent and teacher versions), for example, knowing who had spoken to her by the sound of their voice, and recognizing the sound of a cross or excited voice from the vocal tone, without looking. PALS and SIR are not used at this interval, but PASS showed her to be using far more speech (58%) and speech-like (7%) than non-speech (25%) sounds. Tait Video Analysis showed her to be becoming predominantly vocal in her turn-taking (76% vocal compared with

12% gestural) and to be beginning to respond vocally to the sound of the adult's voice (NLVT 35%). Vocal initiative remained at a low level at this stage.

At the 12-month interval the 100% ratings on the LIP and the MAIS were maintained, and she had moved up a further category on the CAP ('understands common phrases without lip-reading'). Tait analysis showed her to be taking 100% of her conversational turns vocally, with 68% of vocal initiative and 58% of non-looking vocal turns. By this stage the vocal turns were not simply vocalizations, but consisted mainly of phrases such as 'Where she gone?', 'There it is!', 'What is it?' and so on. On PALS she was rated as transitional, with some functional language features. On PASS she had 77% speech sound, 21% speech-like sounds and only 2% non-speech sounds. Finally, her SIR rating had improved to category 3: 'intelligible to familiar listeners who know the context'.

To summarize, C's ratings on all the assessments are at a high level by the 12-month interval. Two ratings (LIP and MAIS) have already reached the maximum level by the 6-month interval; in children of this age the majority would be expected to take 1 year to achieve these levels. Clearly, C has not only reached a high 12-month level, but her 6-month ratings show that the rate of progress has been rapid.

Case study 2

The case study of the second child, R, gives an example of monitoring a child who has made slow progress with her implant over the first 12 months. She became profoundly deaf following meningitis with resulting ossification of both cochleas. In addition, cerebral palsy was identified after meningitis. She received a cochlear implant at the age of 10 months, with partial insertion of the electrode array (6 electrodes). She had no response to sound before implantation and was therefore rated at the lowest level on the CAP ('no response to environmental sounds') and at 0% on the LIP. She was reluctant to wear acoustic hearing aids and did not respond to sound through them, so scored 0% on the MAIS also. Tait analysis showed that at this stage there was little real turn-taking. Her mother followed the normal procedure with young infants, i.e. waiting for any vocalization or body-movement from the child and then responding 'as if' R had communicated. It was estimated that communication from the child had taken place in 39% of the possible opportunities, evenly divided between vocal turn-taking (20%) and gestural (19%). No instances of initiative or auditory awareness were observed. She was rated as preverbal on the PALS and category 1 on SIR (pre-spoken language). PASS showed her to have 0% speech sounds, 0% speech-like sounds, 89% non-speech sounds and 3% other.

By the 6-month interval it was possible to observe some changes. R was at this stage responding to the sound of voice and turning if called, and could therefore be given the CAP rating of 'responds to speech sounds'. On the LIP she scored 36% as she was responding to musical instruments and (sometimes) to her own name. She scored 40% on the MAIS (both parent and teacher versions) as she clearly liked to wear the speech processor, responded to some environmental sounds, and sometimes alerted to the sound of her name. Tait analysis showed her turn-taking to have increased to 59% vocal plus 41% gestural, with some display of initiative (29% vocal), but with no vocal responses to the sound of the adult's voice when not looking (NLVT 0%). However, by this stage R's vocalizations and gestures were becoming more clearly communicative, and there was less need for the adult to 'engineer' the turn-taking structure. Her PALS rating remained 'preverbal', but PASS showed her to be using sounds which were more speech-like in quality: 23% speech and 58% speech-like.

The 12-month assessment showed further improvement on all profiles. R had gone up one level on the CAP, to 'recognizes environmental sounds'. Her LIP score had increased to 52%, as her responses to musical instruments, to the sound of voice and to Ling's five sounds had become reliable. Her MAIS score had gone up to 83% (parent) and 68% (teacher), as she was by this stage showing clear indications that she liked the speech processor, for example, clapping her hands and getting excited when it was put on, and looking at the adult's face with a puzzled expression if the battery went flat. Tait analysis showed more positive and purposeful turn-taking with a definite vocal bias (75% vocal compared with 25% gestural). Her vocal initiative remained at a similar level to the 6-month interval, and she still displayed no vocal indications of auditory processing, preferring to maintain eye contact with the adult. PASS showed a continued improvement in her vocalizations, with 43% of her tokens now being classified as 'speech'.

Comment on case studies

The implant situation was different for these two children from the start, in ways that were like to affect progress. Child C was born profoundly deaf and received her implant at 19 months, when full insertion of the electrode array was achieved. Child R was born hearing, and became deaf due to meningitis, which also resulted in cerebral palsy. She received her implant at 10 months but only partial insertion of the implant was achieved. Significantly, she was younger at the time of the various assessments than child C.

Figures 3-5 compare the progress of the two children on the three measures of auditory perception used: CAP, LIP and MAIS, from before implantation until 6 and

12 months later. Both children make progress in this area, although there are clear differences. Before the implant, neither child shows evidence of significant auditory perception, although child C registers a score on the LIP, using what little residual hearing she has. After implant, the benefits of this residual hearing become clear, as by 6 months she has reached ceiling performance in both the MAIS and the LIP, and on the CAP, progresses from a score of 4 at 6 months to a score of 5 at 12 months. However, while child R shows steady improvement in all areas, it is at a much slower rate.

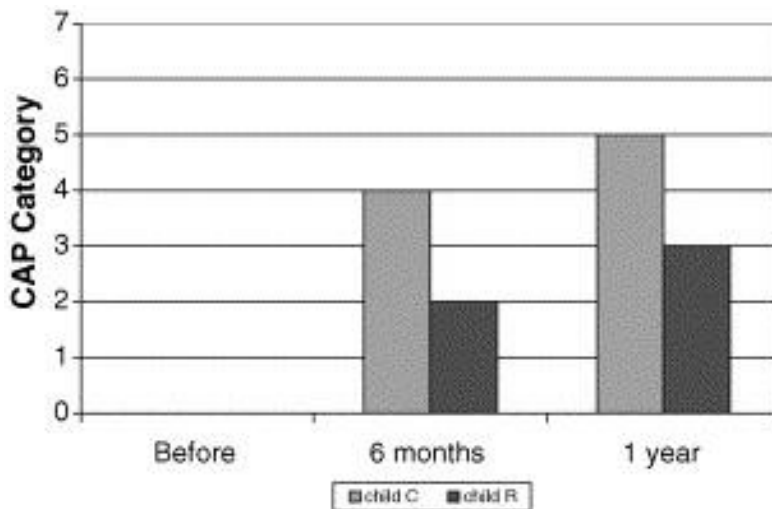


Figure 3. Progress of children C and R using categories of auditory performance (CAP).

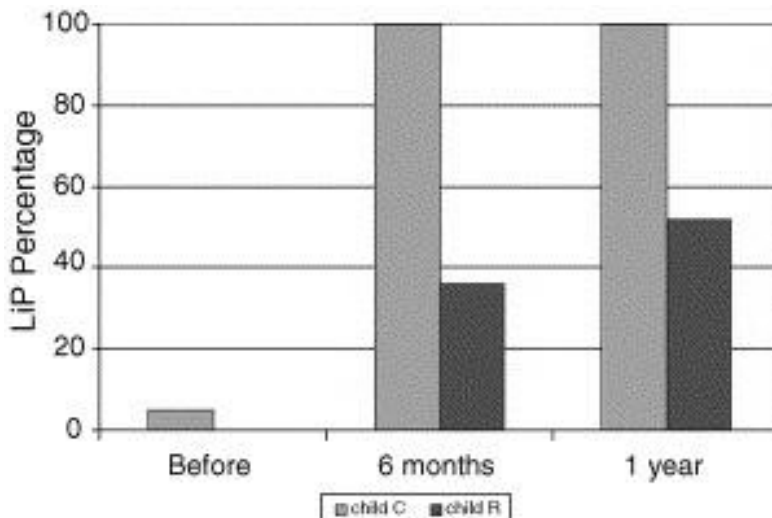


Figure 4. Progress of children C and R using listening progress profile (LIP).

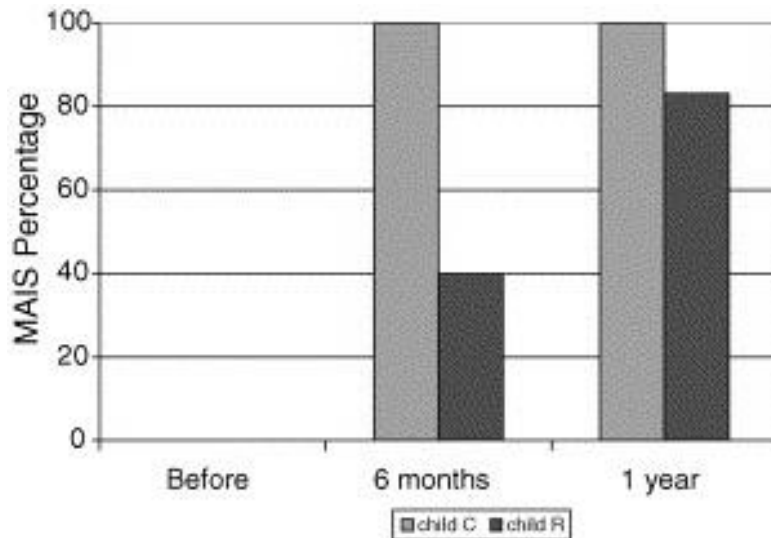


Figure 5. Progress of children C and R using Meaningful Auditory Integration Scale (MAIS).

The TAIT Video Analysis of developing communication skills is shown for each child separately. Figure 6 shows development for child C, and Figure 7 for child R. Child C shows a decrease in gestural turns which start at 60% prior to implant, and decreased to zero by 12 months after implantation. However, vocal turns and non-looking vocal turns (NLVT) increase over the 12-month period. By contrast, although child R increases her vocal turns over the same period, she still uses gestural turns and has not developed non-looking vocal turns. The relationship between the various turn-taking responses is complex, but the analysis indicates that child C's developing communication skills are encouraging, while child R requires further careful monitoring.

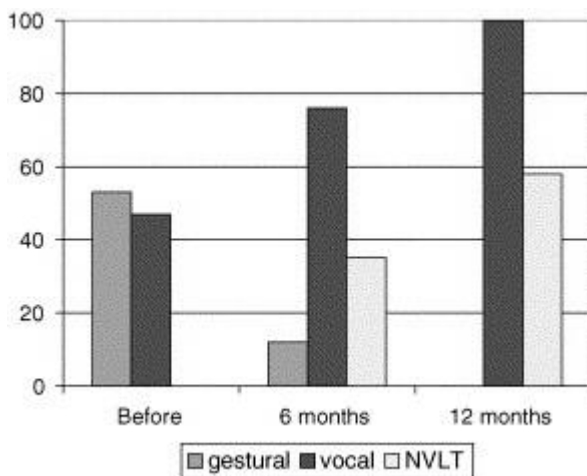


Figure 6. Child's C progress using Tait Video Analysis.

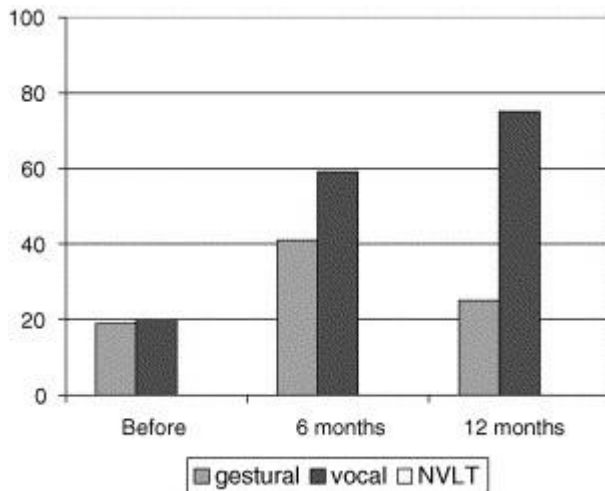


Figure 7. Child's R progress using Tait Video Analysis.

Figures 8 and 9 compare progress for both children using PASS and SIR, measures of speech production. SIR measures at 6 months are not available. Neither child has any intelligible speech before implant but child C shows progress over 12 months on both measures, and has some speech tokens before implant. One year after implant, she has progressed to SIR category 3, which means she has speech intelligible to an experienced listener. While child R is beginning to develop speech tokens over the first 12 months, she is not yet developing spoken language and therefore remains at category 1 of SIR. This is consistent with her results of assessments in the other two areas of communication and language development and of auditory perception.

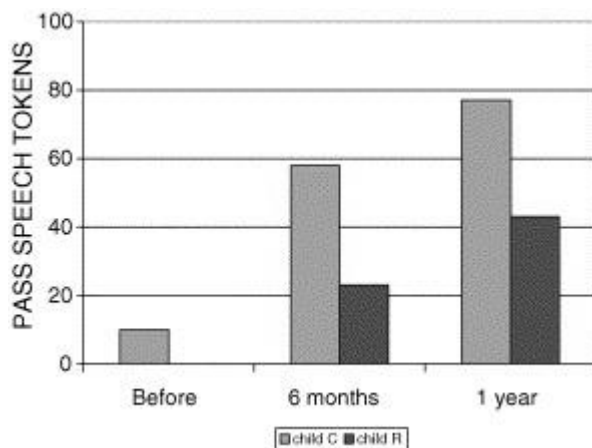


Figure 8. Progress of children C and R using Profile of Actual Speech Skills (PASS).

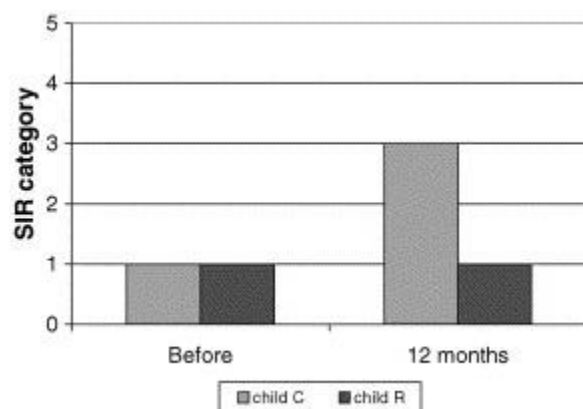


Figure 9. Progress of children C and R using Speech Intelligibility Rating (SIR).

Overall, child C is making good progress and we would expect this to continue, although of course monitoring will continue. Child R is making much slower progress than child C, and the assessments will need to be used for at least a further year to monitor the pattern of the development of her listening and speech and language skills. The assessments lead us to have confidence of device functioning, but the slow progress in some areas such as no vocal indication of auditory processing or use of auditory initiative indicate areas that need continuing monitoring. However, there are measurable changes, and it is particularly important in the case of slower progress to be able to document these early indications that the implant is providing access to sound.

Discussion

NEAP offers a framework with which to assess language and communication in real-life situations. It is innovative in design and offers a structured approach to the behavior of very young deaf children. Although designed for use within a cochlear implant programme, it can be used with a range of deaf children where information is required about their development in auditory development and speech production as well as aspects of communication and language development. It also provides a means of monitoring development both in the short term, looking in detail at small changes in behavior; and in the long term, looking at significant changes over time, an essential requirement when considering young deaf children. The package is not time-consuming and can be incorporated into standard practice and procedures.

NEAP includes observational reports involving parents and other caregivers, with a focus on interaction. This means it does not depend only on elicited behaviors which can be unreliable with very young children. It is most suitable for deaf

children from 12 months although there is some flexibility and many of the assessments can be used from 6 months or even earlier. Some assessments are designed to monitor progress in the short term (TVA, LIP, PASS) although the actual age span over which they are used would depend on the development of the child. Other assessments, such as CAP, SIR, and SNAP, are designed to look at changes over the long term.

Within the cochlear implant programme itself, NEAP can be used to assist in the assessment of candidates for cochlear implantation. It is particularly valuable with very young children and those who are audiologicaly borderline. Following implantation it is also essential to monitor progress in order to inform the tuning process. In young deaf infants it is very difficult to monitor the functioning of the device, and one of the uses of this package is that it can help to identify areas of difficulty to explore further.

The package is useful because it focuses on a child's strengths as well as weaknesses, providing a comprehensive assessment as a basis for management. In addition, in monitoring the child's development, it allows the identification of additional problems and areas of difficulty as well as specific abilities and skills. This enables the clinician to determine appropriate intervention strategies, and modify them according to the observed progress. It also provides indications of where other assessments may be necessary to explore areas of difficulty further. For example, a child may not be demonstrating good auditory skills, but communication skills not be developing as expected, warranting further investigation. In another child, auditory and communication development may be progressing well but no speech be emerging, again requiring further, more detailed, assessment.

Clear information about a young deaf child's progress is needed for a number of purposes. For example, parents of young deaf infants require information on which to base the decisions they make about the management of their child. The information obtained from the assessments included in NEAP provide clear, objective and accessible information on an individual child's development. As a more general resource, it provides both parents and professionals with information on large groups of children in terms of expected rate of progress as a basis for management decisions for an individual child. This information may also help highlight areas in which progress does not meet expectations and which may need further investigation. For local professionals working with deaf children it is very helpful to have means to measure change; one strength of NEAP is that many of its measures can be used in a variety of settings, at home in the nursery, or in school, where formal assessments are often not appropriate or are difficult to

undertake. Moreover most of the measures are easily understood by non-professionals and can be translated into other languages making international comparisons possible. The data obtained from the package also contributes to the more general information required concerning the children's progress for audit and predictive purposes.

Although these measures are based on observation, rather than formal testing and clinic-based assessments, they have been demonstrated to have clinical application and to be robust. Reliability and validity for many of them are well established as described previously in this paper. Moreover, a number of the assessments have already been shown to have the ability to predict outcomes and work continues in this area.

NEAP has thus been shown to be innovative, time-effective, user friendly, informative, reliable and valid assessment for young deaf children with cochlear implants. Because its strengths lie in the assessing of development of spoken language and use of audition it is clearly significant for all young deaf children. However, it may need to be modified in some circumstances. In other contexts a more detailed look at language development would require the assessment of sign language skills and the use of gesture and vision in communication. A more comprehensive assessment would require assessment of cognitive development and consideration of symbolic and other play and social and emotional development. In future it may be possible to extend NEAP to cover these areas.

In this paper we demonstrated the use of NEAP with two significantly different young children and shown its sensitivity in monitoring changes in development. The use of a variety of assessments allows a more comprehensive view of the child and their strengths and weaknesses. Such profiles can alert us to any particular problems or areas requiring further investigation.

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Chapter 2.2

Categories of auditory performance: inter-user reliability

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Abstract

Categories of Auditory Performance (CAP) describes a scale used to rate outcomes from paediatric cochlear implants in everyday life. It differs from more technical measures by being readily applied and easily understood by non-specialist professionals and by parents. Being based on subjective assessments, there is a need to establish whether ratings by different persons are comparable. Therefore, an analysis of inter-user reliability was undertaken using ratings from 23 children followed up at various intervals after implantation. Analysis relating scores by local teachers of the deaf and the teachers of the deaf at the implant centre revealed very high inter-user reliability (correlation coefficient 0.97). This result establishes the reliability of CAP as an outcome measure for use in cochlear implant programmes.

Introduction

Paediatric cochlear implantation in the UK has grown rapidly in recent years, with 600 children implanted by the end of 1996 (Summerfield, personal communication). There remains a need for standardized assessment of outcomes on a national basis (Summerfield & Marshall, 1995). Few measures of benefit from cochlear implantation are readily understood by parents involved in making the decision for their child to proceed, or by non-specialist professionals who may be in the position of advisors, or by health-care purchasers who have to prioritize public expenditure. There is wide variation among children in progress following implantation, and there is a shortage of measures that can be applied successfully for use with all children, both prior to implantation and for a number of years after implantation. This is required to demonstrate progress over a prolonged period of time. Such measures need to have a wide range of outcome levels in order to avoid floor and ceiling effects, and to be scaled in a way that spreads milestones as evenly as possible across the range. Thus, a child progressing according to the generally expected timescale will achieve milestones at somewhat regular intervals.

While formal objective measures are important, they may not generally be understood by non-specialists, and may not reflect the functioning of the child in everyday situations at home and at school. Vidas, Hassan and Parnes (1992) found that clinical tests of speech and hearing may not reflect performance at home and school following implantation and, like Selmi (1985) and Cunningham (1990), that the assessments by parents, teachers and clinic-based therapists differ widely.

Cunningham (1990) found that parents considered their children performed significantly better in structured (training) situations than in unstructured (real-life) situations. Parents, health-care purchasers and consumers may find it more valuable to know how the child is functioning at home and at school rather than the results obtained in a clinical setting.

The difficulties of assessing young deaf children are well known; tests that are available have problems of low test/re-test reliability and in consistency of presentation (Boothroyd, 1991; Osberger et al., 1991; Staller et al., 1991). Categories of Auditory Performance (CAP) was designed to provide an outcome measure that would be accessible to parents, professionals and health-care purchasers alike (Archbold et al., 1995). It is now used in many cochlear implant centres in the UK and Europe. Some teachers of the deaf are also finding it useful for hearing aid wearers. It provides a scale on which children's developing auditory abilities can be rated in eight categories in order of increasing difficulty. The categories are:

- Displays no awareness of environmental sounds
- Awareness of environmental sounds
- Responds to speech sounds
- Recognizes environmental sounds
- Discriminates at least two speech sounds
- Understands common phrases without lipreading
- Understands conversation without lipreading with a familiar talker
- Can use the telephone with a familiar talker

The guidelines (see Appendix) for completion have been revised following use by implant centres and teachers of the deaf, to ensure that ambiguity is minimized. Although the guidelines aim to standardize the measure, there is a danger that different users may rate the same child differently, which would limit its usefulness. Therefore, the aim of this study was to test the reliability of this measure by determining its inter-user repeatability.

Methods

Children in the Nottingham programme are categorized prior to implantation, at 0, 3, 6, 12 months after implantation, and thereafter annually. In this context, 0 months means within a few days of initial stimulation. In this study 23 children, selected at random, were categorized by their implant centre teacher of the deaf,

and independently by their own teachers of the deaf. Although the implant centre and local teachers would have discussed each child in many ways concerning the abilities mentioned in the CAP, they did not discuss the completion of CAP itself in any respect. Four implant centre teachers and 23 local teachers were involved in the study; opportunity was given for clarification of the categories, but this was not found to be necessary. A range of children were included in the study, including those with congenital and acquired losses, those with short and long durations of deafness, and those in a variety of educational settings. Details of the children are provided in table 1.

Table 1. Biographical details of the children used in the repeatability study (n=23)

Sex	Age of onset (months)	Age of implant (mths)	Duration of deafness	Educational setting	Communication management
M	17	43	27	P	TC
F	0	52	52	U	TC
M	0	53	53	S	O/A
F	0	88	88	S	O/A
M	0	51	1	S	TC
F	0	41	41	M	TC
M	2	37	34	P	O/A
M	0	81	81	S	TC
M	0	62	62	U	TC
F	0	62	62	S	TC
M	0	74	74	S	TC
F	0	186	186	U	TC
F	12	38	26	P	O/A
F	0	52	52	M	TC
M	0	44	44	P	TC
M	15	25	10	P	TC
M	4	21	17	P	TC
F	0	48	48	P	TC
M	0	64	64	U	TC
M	33	78	45	U	O/A
F	4	21	18	P	TC
F	17	84	67	S	TC
M	0	69	69	U	O/A
mean	4.5	59.7	55.3		

Educational placement: P = Pre-school; M = Mainstream; U = Unit/Resource base in mainstream school; S = school for deaf or hearing impaired

Communication management: O/A = Oral/Aural; TC=Total Communication

(We recognize this term is contentious, but it is used here to describe the use of sign with spoken language).

The children had a range of duration of implant use, and assessments were compared at a variety of intervals from pre-implant to five years post-implant to ensure that the conclusions would be applicable over a range of intervals. Thus, ratings for 23 children at different intervals were cross-checked, and the results for the implant teachers compared with the local teachers.

Results

Table 2 compares the scores of the local teachers and the implant centre teachers of the deaf, and clearly demonstrates a high level of agreement. There were only three discrepancies out of the 23 cases; the choices of categories only varied by one in each case. Regression analysis carried out on the scores revealed that the correlation coefficient between the two assessments was 0.97. The three discrepancies in categorization were at the immediate post implant interval, six months after implantation, and four years after implantation. In two instances the local teacher of the deaf rated the child in a higher category, and in one instance, the implant centre teacher of the deaf rated the child in a higher category.

Table 2. The ratings of the local teachers of the deaf (LTOD) and the implant centre teachers of the deaf (ICTOD) for the same children at the same intervals using Categories of Auditory Performance; differences are given in bold type.

Assessment interval	Pre	Pre	Post	Post	3 mth	3 mth	3 mth	3 mth	6 mth
LTOD	0	0	1	1	2	4	4	4	4
ICTOD	0	0	1	2	2	4	4	4	
Assessment interval	6 mth	6 mth	6 mth	6 mth	6 mth	12 mth	12 mth	12 mth	
LTOD	4	4	4	4	3	4	4	4	
ICTOD	4	4	4	4	4	4	4	4	
Assessment interval	12 mth	12 mth	24 mth	36 mth	48 mth	60 mth			
LTOD	5	6	5	5	5	6			
ICTOD	5	5	5	5	5	6			

Discussion

The agreement between the local teachers, who often see the children daily, and the implant centre teachers, who see the children less often, indicates that CAP gives a repeatable measure, and hence is reliable. This is demonstrated for a

group of children who illustrate the range of children presenting for implantation, in terms of both biographic data and communication management. The results demonstrate that the assessments of the children's local teacher and that of their implant centre teacher are very similar; there are few discrepancies in score, and these are small. It is useful to note that while the implant centre teachers of the deaf had access to the formal measures of benefit such as the IOWA Closed-Set Sentence Test, the local teachers did not, and completed the rating from their own observations. In summary, the ratings were repeatable, whether completed from clinic-based tests or from observations in everyday life.

The repeatability of CAP has also been demonstrated across a range of intervals, from before implantation to five years after implantation. This is important, given the need for outcome measures that are easily understood, and can also be used for large groups of children and for children over a long period of time. While CAP does not replace formal clinic-based measures, it provides a global measure that can be readily understood by non-professionals, thereby demonstrating the benefits seen from implantation and the time-scale over which they are achieved. This information is important to parents, professionals and health-care purchasers to help them make informed decisions. It also gives insight into the long-term commitment that will be necessary.

Conclusion

With increasing demands being made on health-care and educational resources, those of us working with deaf children must be able to present evidence of their achievements through readily understood measures. Categories of Auditory Performance provides one means of rating and presenting information that is quick and easy to use, and illustrates progress in a group of children with a wide range of achievement over a long period of time. The present study has demonstrated its repeatability, with an extremely high degree of agreement between users, attesting to the robustness of the measure. CAP is already used for many children with cochlear implants, and this study has illustrated its ability to be used by professionals who are working with the children in home and local schools, as well as those who are more clinic-based. It would be interesting in future to provide parents with the scale, and notes for completion, and compare their results with those of the professionals working with their children.

Work is currently in progress to compare the results on CAP with those of formal performance-based measures, such as the IOWA Closed-Set Sentence Test, and

also to look at those factors known to influence progress following implantation, such as length of deafness.

Meanwhile, it continues to be a useful measure of outcome from cochlear implantation, illustrating benefit to parents and purchasers in a readily understood form.

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Appendix: Categories of auditory performance

Working definitions

0. *Displays no awareness of environmental sounds.* Wearing appropriate aids with good earmoulds, the child does not alert spontaneously to any environmental sounds. Nor has the child been reported to alert to environmental sounds.
1. *Awareness of environmental sounds.* The child has been observed to make a spontaneous reaction to about half a dozen different environmental sounds (at home, at school, in the clinic or outdoors). The reaction need not indicate that the child recognizes the sound, only that he or she has detected it.
2. *Respond to speech sounds.* The child will obey a simple command, such as the instruction 'go' to perform an action such as rolling a ball at a skittle, when delivered in a normal conversational sound level at a distance of 1-2 feet.
3. *Recognizes environmental sounds.* The child has been observed to identify a range of about half a dozen environmental sounds consistently in everyday life (e.g. doorbell, telephone, parent's voice, traffic etc). Observers are confident that the child is monitoring his or her environment via audition.
4. *Discriminates at least two speech sounds.* The child can discriminate consistently any combination of two of Ling's five sounds (/ss/, /sh/, /ee/, /oo/, /aa/) presented with live voice at a conversational level without lipreading.
5. *Understands common phrases without lipreading.* The child is able to identify common phrases in a familiar constraining context. For example, the child can perform the IOWA Closed-Set Sentence test at Level A; or the child can identify simple, familiar questions in a known context (e.g. 'What's your name?', 'Where's mummy?', 'How old are you?'); or limited set when the picture is described verbally.
6. *Understands conversation without lipreading with a familiar talker.* The child can carry out a simple unscripted conversation with a familiar talker (e.g. a parent or teacher) without lipreading in a quiet setting. The child must be able to respond correctly to simple questions without interaction breaking down.
7. *Can use the telephone with a familiar talker.* The child can sustain a simple unscripted conversation on the telephone with a familiar talker. The child must be able to respond correctly to simple questions without interaction breaking down.

Chapter 2.3

Using Listening Progress Profile (LIP) to assess early functional auditory performance in young implanted children

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Abstract

Listening Progress Profile (LIP) is a profile devised to monitor changes in the early auditory performance of young implanted children. The profile covers a range of abilities from first response to environmental sounds, through discrimination of environmental sounds and discrimination of voice, to identification of own names. This study, prospective and longitudinal, involved 68 prelingually deaf children (congenitally deaf or deafened before the age of three years and implanted before the age of five years). Prior to implantation the median score of LIP was zero. By the 3-month interval it had increased to 20; at the 6-month interval to 32; at the 12-month interval to 40; and at the 24-month interval it reached the maximum score available (42). The increase in scores at each interval following implantation was statistically significant. In conclusion, LIP was found to be a sensitive tool with which to measure the progress of auditory skills in young implanted children. The profile may help the implant programme and local professionals working with young implanted children, as well as parents, to obtain a measure of progress of auditory performance in the early stages following implantation, where other, more formal, measures may be inappropriate.

Introduction

Cochlear implants have proven to be effective for children with acquired and congenital deafness (Uziel et al., 1996; Lenarz, 1997; Waltzman et al., 1997; Nikolopoulos et al., 1997; Nikolopoulos & O'Donoghue, 1998; Allen et al., 1998; O'Donoghue et al., 1998a; 1998b). Age at implantation has been shown to be one of the most important predictors of post-operative performance (Waltzman et al., 1997; Nikolopoulos et al., 1999). Therefore, the age at which children are implanted is declining and substantial numbers are being implanted under the age of two. Many of these young, profoundly deaf children will have limited communication skills, and little spoken language. Traditional tests of speech perception are therefore unsuitable for monitoring developing auditory perception in the early stages after cochlear implantation in such children. However, it is important to assess their auditory skills in order to monitor functioning of the system and the development of speech and language following implantation. The Listening Progress (LIP) is a profile devised to help fulfil this objective (Archbold, 1994a). The aim of the present study was to assess the use of LIP to

monitor changes in early auditory performance in a large group of young implanted prelingually deaf children.

Subjects

This prospective and longitudinal study involved 68 children, consecutively implanted within a large paediatric programme and fulfilling the criteria of being congenitally deaf or deafened before the age of three years, and implanted before the age of five years. Of the 68 children in the study, 38 (56%) were male and 30 (44%) female. All subjects received the Nucleus multi-channel cochlear implant. The approach to communication before implantation was classified by the children's local teacher of the deaf in a pre-implant questionnaire. Fifty-three (78%) children were classified as being placed in Total Communication settings and 15 (22%) in Oral/Aural communication settings. The main demographic details are illustrated in Table 1.

Table 1. Details of all the subjects included in the study

Aetiology	Congenital Meningitis Other causes			
	Mode	Mean	Median	Range
				30 children (44.1%) 33 children (48.5%) 5 children (7.4%)
Age at onset of deafness (months)	0	7.8	2	0-33
Age at implantation (months)	44	43	44	21-60
Duration of deafness (months)	44	36	39	8-60
Numbers of electrodes inserted	20 or more Between 10 and 20 10 or fewer		63 children (92.6%) 4 children (5.9%) 1 child (1.5%)	

Prior to implantation, testing of subjects in the best binaurally conventionally aided condition had demonstrated aided thresholds greater than 60 dB across the speech frequency range. Care was provided free of charge on the UK's National Health Service, and hence ability to pay did not determine access to the service (O'Donoghue, 1996); as a consequence the children in the study were drawn from the full range of social environments. The children came from throughout the United Kingdom, and they represented the full range of educational and communication environments.

Material and methods

All 68 children were assessed using the Listening Progress Profile (LIP), before implantation and at 3, 6, 12 and 24 months following implantation. No child was lost from follow-up and no child was excluded due to low performance.

LIP is a profile of developing listening skills which comprises 21 items (see Appendix 1). The items cover a range of abilities from first response to environmental sounds and first response to voice, through to discrimination of environmental sounds and discrimination of voice, to identification of own names. Children are scored according to whether the behaviour is demonstrated always (2), sometimes (1) or never (0). The total score is the sum of the above. If there is any uncertainty in their response, 'not known' is recorded and a score of zero given. The maximum score is thus 42.

The LIP profile was completed by the implant programme teacher of the deaf, during activities in the home, school, or clinic. At each interval the child was assessed based on the performance in the 'auditory alone' condition, using the scoring criteria given in Appendix 2.

The inter-observer reliability on LIP as a measure of auditory perception has been formally validated and has shown high levels of agreement between different observers (Archbold, 1994a).

To assess how effective the Listening Progress Profile was in helping to identify children who may be experiencing difficulties in the first year of implant use, the distribution of the scores at 12 months post-implantation was calculated, and those children performing at or below the 10th percentile of the distribution were further investigated.

For the statistical analysis of the data, Wilcoxon test for paired samples was used to compare the results at each interval. Statistical significance was accepted at $p < 0.01$.

Results

The results of the LIP before implantation and for each of the follow-up intervals following implantation are summarized in Table 2. Rapid improvement in the detection of sound and speech was evident in the first three months. Prior to implantation the median was zero and by the 3-month interval it had increased to 20; at the 6-month interval it was 32.5; at the 12-month interval it had risen to 40; and at the 24-month interval it reached the maximum score available, 42. The

mean and median ratings at each interval are shown in Figure 1. The increase in scores at each interval following implantation was statistically significant (from pre-implant to 3 months, $p < 0.0001$; from 3 months to six months, $p = 0.0001$; from six months to year 1, $p < 0.0001$; and from year 1 to year 2, $p < 0.0001$).

In this study, eight children were performing at or below the 10th percentile at one year post-implantation. Four of these children (50%) experienced device problems and were subsequently re-implanted. In the remaining 60 children, only two (3%) were re-implanted.

Table 2. Group data showing auditory performance of the implanted children using LIP. (Maximum score 42)

	Before	3 months	6 months	12 months	24 months
N	68	68	68	68	68
Mean	0.6	20.6	30.3	37.9	41.4
Median	0	20	32.5	40	42
SD	1.9	9	8.6	5.5	2
Mnimum	0	3	10	19	27
Maximum	13	42	42	42	42
Lower quartile	0	14	24	36	42
Upper quartile	0	26.5	38	42	42

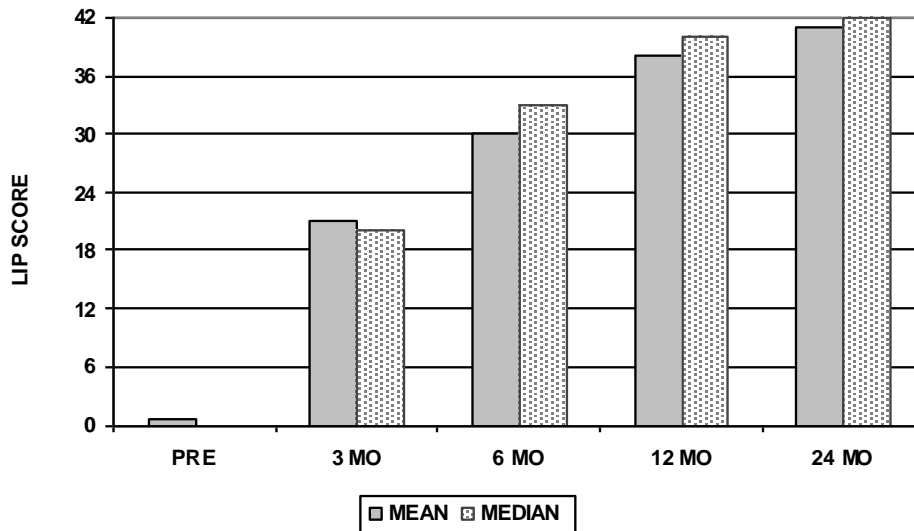


Figure 1. The mean and median LIP scores before implantation and at the follow-up intervals. (Maximum score 42).

Discussion

Increasingly, very young children are being assessed and accepted for cochlear implantation (Gibson et al., 1997; Waltzman & Cohen, 1998). However, there are few measures appropriate for very young profoundly deaf children with limited or no linguistic skills, especially in the early intervals following implantation.

The results of the present prospective and longitudinal study suggest that LIP is able to monitor early auditory performance in young implanted children. It was interesting to note that as early as three months post-operatively all the children studied could be assessed by LIP, and no child scored 0. This is very important in view of the fact that 85% of the implanted children in the Waltzman et al. (1997) study could not perform the widely used GASP sentence test, even two years following implantation, and 78% of the implanted children in the O'Donoghue et al. (1998a) study were unwilling or unable to perform the Iowa Sentence test, the easy version, at the first-year interval following implantation.

LIP was found sensitive to measure the progress of auditory skills in the young implanted children. The scores improved significantly at each interval and all differences between intervals were statistically significant. Ceiling effects were noted only at the two-year interval, when the mean score was 41.4 and the median score was the maximum of 42. Therefore the usefulness of LIP lies within the first two years following implantation; this may be when other, more conventional tests may be inappropriate. For this reason, it was included in the EARS Test Battery, an assessment battery devised especially for young children by MEDEL Cochlear Implant Company.

LIP may also be useful as an early warning of potential problems and the results of the present study suggest that children performing at or below the 10th percentile, one year post-implantation, should be monitored carefully. Poor performance on the Listening Progress may be related to tuning that is not yet optimal, or device functioning may need to be reassessed to confirm its integrity. In the absence of any identified technical faults, the children's global functioning should be reviewed in case of additional difficulties, and their daily use of the system examined. These results highlight the importance of close liaison between audiological staff and teachers of the deaf in the management of children with cochlear implants.

Parents and professionals need to know what progress to expect in the first few months and years following implantation, when the ability to carry out formal tests of speech perception may be limited. The availability of the data of the study under question makes it possible to use LIP to set rehabilitation goals and develop realistic expectations both at home and at school. For local professionals working

with implanted children it is very helpful to have a means to measure change; one strength of LIP is that it can be used in a variety of settings, in the home, in nursery, or in school, where formal assessments are often not appropriate or are difficult to undertake. In the initial phase after implantation parents and professionals working with a child need reassurance

that the device is functioning and that progress is acceptable; use of the LIP may be able to provide such evidence. Children who are not performing as well as the expected norm warrant further investigation.

In addition, particularly with current interest in the introduction of neonatal screening, and the assessment of young infants, it may be that the development and use of LIP may have relevance for the management and monitoring of young deaf infants with hearing aids.

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Appendix 1: Listening progress profile for completion and scoring

Nottingham paediatric cochlear implant programme Listening progress
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Name:		CIN:	
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I/O	D/O	Key: I/O = Indirect Observation (left box); D/O = Direct Observation (right box) (Both have equal scores)
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	Pre		6mth		12 mth		24 mth		36mth	
Behaviour										
Response to environmental sounds										
Response to drum (elicited)										
Response to musical instrument (elicited)										
Response to voice - elicited										
- spontaneous										
Discrimination between 2 different instruments										
Discrimination between: loud/quiet drum										
Discrimination between: single/repeated drum										
Identification of environmental sounds										
Response to: oo										
ah										
ee										
sh										
ss										
Discrimination between: long/short speech sounds										
single/repeated speech sounds										
loud/quiet speech sounds										
2 of Ling's five sounds										
All of ling's five sounds										
Discrimination between 2 family names of different syllabic length										
Identification of own name in quiet										

Scoring:	Scores:
N (never/not known)	Pre — 24 —
S (sometimes)	6 — 36 —
A (always)	12 —

Appendix 2: Listening progress (LIP): Notes for completion.

Listening Progress (LIP) is a profile of developing skills and listening, completed by the implant teacher of the deaf, using activities designed to elicit appropriate responses as part of the rehabilitation programme. Observations are carried out during the rehabilitation programme; a specific 'test' situation will not necessarily be accepted. The skills must be observed without lip-reading or visual clue. (See our rehabilitation book for ideas for suitable games.)

The word 'response' is used to describe the detection of sound: 'discrimination' is used to describe the ability to choose correctly between two differing sounds: 'identification' to describe the ability to choose correctly the target sound from the open set of sounds. The child may be scored:

- N (Never/not known) if the skill has never been observed
- S (Sometimes) if the skill is becoming established and has been observed by the implant teacher of the deaf at more than chance level
- A (Always) if the skill is reported to be well established and the implant teacher of the deaf has observed it consistently in more than 2 situations.

Behaviour/skills	Accepted response
Response to environmental sounds	Any awareness of environmental sounds shown by spontaneous behavioural response.
Response to drum (elicited)	A behavioural response to loud drum elicited in play format, e.g. emerging from playhouse on sound of drum.
Response to musical instruments (elicited)	A behavioural response to at least 2 different musical instruments: maracas, bells, tambourine, etc, e.g. child rolls ball at skittles in response to sound.
Response to voice (elicited)	The child performs a task on the spoken signal, for example 'go' or 'boo' with voice at conversational sound level.
Response to voice (spontaneous)	Reactions to voice in stories, singing, games formats have been observed.
Discrimination between 2 different instruments	The ability to discriminate (without being able to watch when the sound is made) between 2 differing musical instruments.
Discrimination between loud/quiet drum	The ability to discriminate between loud and quiet drums, for example, by pointing to appropriate picture, or imitating sound.
Discrimination between single/repeated drum	Again, pictures may be used to denote a drum being played once, or several times, and the child indicates by pointing at the picture. Alternatively, the child may be given a drum of his own and imitate the sound being made by the teacher out of sight.
Identification of environmental sounds	Score S if the child is reported as identifying some environmental sounds at home/school and the implant teacher of the deaf has observed the child identifying by

	sound alone at least one environmental sound. Score A if the implant teacher of the deaf has observed the child identifying a range of environmental sounds at home/school and the child is monitoring his environment auditorily.
Response to Ling's Five Sounds (oo, ah, ee, sh, ss)	The implant teacher of the deaf, in a variety of game formats, observes the child's detection of the five sounds. For example, does the child move the sleeping baby on the sound 'sh'? Score S if the skill is becoming established; score A if the child has been observed to carry out the tasks consistently.
Discrimination between long/short sounds	The child can discriminate, for example, between the large toy dog giving a loud 'woof woof' and the toy puppy giving a quiet 'woof woof'.
Discrimination between two of Ling's Five Sounds (for example oo versus ee, sh versus ss)	Score S if the child can discriminate between at least one combination of 2 of Ling's Five Sounds. Score A if the child can discriminate between any combination of 2 of Ling's Five Sounds.
All of Ling's Five Sounds	Score S if the child is becoming able to identify any one sound out of the five. Score A if the child is consistently able to identify all five sounds.
Discriminate between 2 family names of differing syllabic length	Using family pictures, written names or the people themselves, can the child discriminate between 2 names of differing syllabic length, e.g. John v. Mummy.
Identification of own name	Score S if the child has been observed to identify his own name at home and school on at least one occasion. Score A if the child can identify his own name (in reasonable listening conditions) consistently. The child may, of course, choose to ignore his name!

Chapter 2.4

Determinants of speech perception in children after cochlear implantation

G.M. O'Donoghue
T.P. Nikolopoulos
S.M. Archbold

Summary

Background:

Cochlear implants provide access to the speech signal in those profoundly deaf children who derive no material benefit from acoustic hearing aids. Speech perception after implantation can vary widely - we have analysed the contribution of several factors.

Methods:

We examined 40 children with mean age at implantation of 52 months who were either born deaf or became deaf before 3 years. All patients received the same multichannel implant system and were followed up for 5 years.

We used connected discourse tracking (CDT) as the measure of speech perception. The effect of five potential predictors (age at implantation, number of inserted electrodes, origin of deafness, mode of communication, and socio-economic group) on speech perception was analysed.

Findings:

The mean number of words per minute perceived increased from 0 before implantation to 44.8 (SD 24.3) 5 years after implantation. Repeated-measures ANOVA showed that children significantly progressed over time ($p=0.001$). Age at implantation was a significant covariate ($p=0.01$) and mode of communication was a significant between-individuals factor ($p=0.04$).

Interpretation:

Young age at intervention and oral communication mode are the most important known determinants of later speech perception in young children after cochlear implantation. Early identification of candidate children necessitates implementation of universal neonatal screening programmes for hearing impairment.

Lancet 2000: **356**: 466-68

Introduction

Most children with impaired hearing can hear speech through acoustic hearing aids. However, some profoundly deaf children cannot, and as a consequence, their ability to develop spoken language and intelligible speech is severely

restricted. For these children, cochlear implants are the only means of hearing speech and thus developing spoken language. Cochlear implants differ from hearing aids because they bypass the damaged inner ear and directly stimulate the residual auditory nerve fibres in the cochlea. An implant system has two components: an external component worn on the body and resembling a walkman, and an internal receiver that is surgically implanted behind the ear. The speech processor, which is either worn on the body or at ear level, converts speech into electronic signals and has a transmitter coil to send these signals to the implanted receiver package. The receiver package then carries electronic signals along several electrodes that can selectively stimulate the auditory nerve fibres in the cochlea.

Initially, only children who had lost their hearing after acquisition of spoken language were judged candidates for implantation, but the procedure has proven effective for the much larger group of children who are deaf from birth. Cochlear implants do not restore normal hearing, but are individually programmed to provide the recipient with hearing sensitivity within the speech range. Several years are needed for a child to learn to interpret what is heard through an implant and combine it with lip-reading to understand conversational speech. Worldwide, over 10 000 children have been the recipients of a cochlear implant. In Britain, the National Health Service (NHS) commits about £10 million yearly to the immediate and long-term management of implanted children, which is about a fifth of the annual NHS expenditure on permanent hearing impairment in childhood (Summerfield et al., 1997).

The primary measure of benefit from cochlear implantation is the ability to perceive speech. Previous studies have shown that a wide range of speech perception abilities are achieved by implanted children (O' Donoghue et al., 1998; Mondain et al., 1997; Miyamoto et al., 1995; Nikolopoulos & O'Donoghue, 1998; Waltzman et al., 1997; O'Donoghue et al., 1998). We aimed to explore this variability to identify the contribution of several possible predictors on the ability of these children to perceive speech.

Methods

We did this prospective and longitudinal study in one paediatric cochlear-implant centre. The children underwent extensive audiological testing to confirm lack of benefit from acoustic hearing-aids. Wearing hearing aids, all children had hearing

losses greater than 60 dB from 500 Hz to 4 KHz, which is equivalent to unaided thresholds greater than 100 dB. Our study was confined to those children who were born deaf or who lost their hearing in the first 3 years of life. Only children who were aged less than 7 years at time of implantation were entered in the study. All 40 children met the study criteria and were followed for 5 years. Each child received the Nucleus (Cochlear Ltd, Sydney, Australia) multichannel system. None of the children had cochlear or other malformations. Full electrode insertion (20 electrodes or more) was achieved in 34 children and less than 20 electrodes were inserted in six (mainly because of postmeningitic ossification). Once the cochlear implant system was programmed, children received most of the rehabilitation in their own districts through local services, with regular outreach visits from specialists. The educational setting and communication approach varied between children, and depended on factors such as parental choice and local educational policy.

24 children (60%) were male and 16 (40%) were female. Mean age at onset of deafness was 11.8 months (median 8 months, mode 0, range 0–34 months). Age at time of implantation ranged between 30 months and 7 years (mean 52 [SD 15] months; range 30–82). The origin of deafness was congenital in 13 (33%), meningitis in 23 (58%), and four (10%) were deaf from other causes. Before implantation, 26 children used a total communication approach (ie, communication included a signed input of whatever degree) and 14 just communicated orally. Social class of the children was identified according to the standard occupational classification of the government statistical service (Government Statistical Service, 1991).

Speech perception was measured with connecting discourse tracking (CDT) DeFilippo Scott, 1978; Tye-Murray & Tyler, 1988; Plant, 1998), which assesses understanding of speech in conversation without lipreading. Unfamiliar text is presented by means of live voice to a listener. The listener repeats the text word for word without lipreading and the task is scored by number of words per minute correctly identified. Age-appropriate texts that engaged the child's interest were chosen. These texts had simple vocabularies, syntactic structures, and varied from session to session to limit contextual clues. If a child were unable to identify a word after three repetitions, the word was left out. For consistency, the same person tested each child throughout the study. Children who could not do the test were scored zero.

The independent variables in the study included age at implantation, number of inserted electrodes, origin of deafness (congenital or meningitis), mode of communication at the assessment interval (oral or total), and social class. We used correlation analysis and repeated-measures ANOVA, and SPCC for Windows version 9.0).

Results

Table 1 shows the results of CDT before implantation and at 3, 4, and 5 years after implantation. Age and mode of communication were significantly related to CDT results at 5 years after implantation (table 2). The correlation analysis at 3 and 4 years also showed significant correlations of CDT results with these factors. Number of inserted electrodes, origin of deafness, and social class did not correlate with CDT results. Repeated-measures ANOVA showed that children significantly progressed over time ($p=0.001$). Age at implantation was a significant covariate ($p=0.01$), and mode of communication was a significant between-individuals factor ($p=0.04$). However, both of these factors combined could not explain more than 43% of the variance.

Table 1. CDT results at each test interval after cochlear implantation

CDT	Mean words per min (SD)
Preimplantation	0
3 years	26.6 (21.5)
4 years	35.4 (23.0)
5 years	44.8 (24.3)

Table 2. Correlation analysis of CDT with variables at the 5 year interval

	Age	Number of electrodes	Origin of deafness	Communication mode	Social class
Correlation coefficient	-0.55	-0.10	-0.17	0.62	-0.10
Regression coefficient	-0.88 (-1.32 to -0.44)	-1.10 (-4.42 to 2.21)	-9.01 (-26.71 to 8.69)	29.56 (16.63 to 42.48)	-2.15 (9.40 to 5.08)
P value	0.0002	0.50	0.30	0.00005	0.54
Percentage of variance	30%	1%	3%	38%	1%

Discussion

Contemporary cochlear implant systems provide substantial auditory information to children with profound hearing impairment who are unable to benefit from conventional hearing aids (O' Donoghue et al., 1998; Mondain et al., 1997; Miyamoto et al., 1995; Nikolopoulos & O'Donoghue, 1998; Waltzman et al., 1997; O'Donoghue et al., 1998). Development of appropriate test materials for young implanted children has proved a major challenge. In this study, we selected CDT as the measure of speech-perception since it closely simulates the real-life situations in which children need to understand speech in conversation. The results clearly show that young congenital and prelingually deaf children can develop substantial speech-perception abilities up to 5 years after implantation. Our findings have not been artificially inflated by exclusion of poor performers and non-users. Before intervention and wearing the most powerful hearing aids, none of these children could manage open-set speech-perception tasks, and critics of implantation doubted if these children could ever do so (Lane, 1995). For this reason, assessments of speech perception are especially important since they measure a benefit that is directly attributable to the implant (Tyler, 1993). Besides, without the ability to perceive speech, it is unlikely that the implanted child would ever develop the necessary competence to communicate effectively through spoken language (Tye-Murray et al., 1995).

The outcome of paediatric cochlear implantation is characterised by its variability. Young, prelingually deaf children are a notoriously heterogeneous population with great variation in their auditory, cognitive, and linguistic maturity, which may be impossible to quantify before intervention. For instance, there are as yet no reliable measures of the central processing mechanisms that are critical to the recognition of speech presented through an implant. The follow-up required for outcome studies extends up to 5 years at least, which is difficult to achieve in clinical practice, especially when samples of sufficient size are needed for statistical analysis. Indeed, in our study, there was no evidence of ceiling effects at 5 years, and future studies of speech perception will need to consider assessment even beyond this interval. To control for confounders such as maturation and linguistic ability, study populations need to be limited to well defined age-groups. In some studies, 15 children implanted at 16 years were included with those implanted as young as 3 years, making outcome assessment very difficult. Differences in outcome from these studies are probably attributable to pre-existing differences in linguistic ability and maturation. Shea and colleagues' (1994) findings, that age at implantation was positively correlated with test performance in

prelingually deaf children contrasts with ours, but are probably attributable to the fact that older children do better on performance tasks than younger children. Thus, our inclusion criteria for age was strictly defined. Social class was not noted to have a substantial bearing on outcome, but we did not analyse the effect of additional resources on implant use in difficult domestic circumstances.

Although we focused on speech perception, this factor alone does not define success or failure of implantation. Other benefits, such as relief from auditory isolation, help with lip reading, or awareness of warning sounds can make major contributions to a child's quality of life, even if speech perception remains poor. Although decisions about implant candidacy should give due consideration to age at implantation and mode of communication, other factors yet to be identified might also have a bearing on outcome. Implementation of universal neonatal-hearing screening programmes are imperative to ensure early identification of deaf children and their timely referral to implant centres.

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Chapter 2.5

Cochlear Implants in children: An analysis of use over a three-year period

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Abstract

Objective:

This study aimed to determine whether children continue to wear their cochlear implant systems 1 and 3 years after implantation.

Study design:

The design was a prospective study based on the analysis of forced-choice questionnaires on implant use completed independently by parents and teachers.

Setting:

The study was performed at a dedicated pediatric cochlear implant program in a tertiary referral center in the United Kingdom.

Patients:

All 85 consecutively implanted children who had reached the 1-year interval after implantation and 37 children who had reached the 3-year assessment interval after implantation participated. The patients represented all socioeconomic status groups, the entire range of educational settings, and often lived at a considerable distance from the implant center.

Main Outcome Measures:

Parents and local teachers were asked to describe implant use in the following categories: 1) all of the time; 2) most of the time; 3) some of the time; and 4) none of the time.

Results:

One year after implantation, parents and teachers, respectively, rated 79 (93%) and 82 (96%) children as full-time users (category 1). Parents rated six children (7%) as users most of the time (category 2), and teachers rated three children (4%) as users most of the time. No child was rated as an occasional or nonuser (category 3 or 4). At 3 years after implantation, 33 (89%) and 34 (95%) children were rated as full-time users (category 1) by parents and teachers, respectively. Parents judged four children (11%) and teachers rated two children (5%) to be users most of the time (category 2). Again, no child was rated in category 3 or 4 as an occasional or nonuser.

Conclusions:

The majority of implanted children use their implant systems all of the time over a 3-year period after implantation when selected appropriately and given appropriate follow-up.

Introduction

Cochlear implantation now is a widely used procedure in the treatment of deaf children and gives greater benefit than hearing aids in appropriate cases (Tait & Lutman, 1994; Osberger et al., 1993). When compared with hearing aids, cochlear implants demand considerable financial resources. These resources are needed not only initially at the time of implantation, but also for the lifetime of the recipient to maintain the device and to provide the necessary upgrades. Unlike other implantable biomedical devices, such as pacemakers, a user of a cochlear implant system has the option of discontinuing use. Continued use of a cochlear implant should be considered a primary measure of outcome from implantation because other benefits, such as speech and language acquisition, follow only after years of regular usage (Summerfield & Marshall, 1995). It is important that continual use of an implant should be evident not only in visits to the implant clinic but also evident in the home and the classroom, where the implanted child spends the majority of time and where language normally is acquired.

The cost effectiveness of pediatric implantation has not been proved formally. Significant non-use of cochlear implants would have a major impact on the cost utility of the procedure by inflating the cost of generating each successful user. There are little data in the cochlear implant literature, however, on the degree to which children continue to use devices in everyday life. Rose et al. (1996) report 47% of adolescent cochlear implant users in schools for the deaf in the United States are non-users, suggesting a figure of potentially 1,800 non-wearers. The high reported rate of non-use raises a major issue of concern to cochlear implant professionals. We, therefore, undertook a systematic analysis of implant use made by consecutively implanted children using their devices at 1 and 3 years after implantation.

Table 1. Biographical details of children (N = 85)

Characteristic	Amount
Gender	
Male	43
Female	42
Age at implant (months)	
Average	63.6
Median	53
Mode	44
Range	21-203
Age at onset (months)	
Average	10.2
Median	1.5
Mode	0
Range	0-79
Progressive	1
Duration deafness (months)	
Average	52.5
Median	48.5
Mode	44
Range	8-203
Progressive	1
Etiology	
Meningitis	38
Congenital	37
Other	10
Mode of communication*	
Oral	29
TC	56
Educational placements (at 12 month interval)	
Unit	38
Mainstream	14
School of the deaf	21
Preschool	12

*Oral/aural is taken to describe communication based on spoken language;
TC, total communication, communication using sign language with spoken language.

Methods

The Nottingham pediatric cochlear implant program, established in 1989, had implanted > 140 children by January 1997; the most common age to be implanted now is 3 years old. All children implanted at the center follow a detailed program of evaluation before implantation (McCormick et al., 1994). The program is funded by the National Health service the United Kingdom, eliminating socioeconomic status issues as all candidates are eligible for funding. Children came from the full range of social backgrounds, were not preselected, and the majority of children lived at

considerable distances from the implant center. All children were implanted using the Nucleus-22 channel device (Cochlear, Australia), apart from one child who was implanted with a Medel single-channel device.

Because the aim of this study was to evaluate the elective use of a cochlear implant over time after implantation, parents and teachers of all children reaching 1- and 3-year intervals after implantation participated. Biographic data of the 85 consecutively implanted children are listed in table 1; the 37 children at the 3-year level are included within the group of 85.

After cochlear implantation, the philosophy of our program allows children to spend as much time as possible at home and school, minimizing the visits to the implant center and disruption to daily lives. To minimize disruption, teachers of the deaf and speech-language pathologists provide regular visits to the child's community to update and engage the skill of local professionals to fully support children. As part of the long-term follow-up, parents and teachers of cochlear-implanted children annually complete a questionnaire about the child's use of the implant system. Parents and teachers make their judgements independently by rating the child's implant use with four categories: category 1, all of the time; category 2, most of the time; category 3, some of the time; and category 4, none of the time.

Results

Ratings were completed by all parents and only one child failed to receive a teacher rating, because the child had moved to Africa and had no teacher of the deaf; however, she returns to the implant center for annual review.

Figures 1 and 2 show the response to the questionnaires 1 and 3 years after implantation, respectively.

At 12 months after implantation, 79 children (93%) were reported by their parents to be full-time users of the device and 82 children (96%) were full-time users in the judgement of their teachers. Six children (7%) (all female) wore the device most of the time in the opinion of their parents, and three children (4%) wore the device most of the time in the opinion of their teachers. No child was rated to wear the device occasionally or to be a nonuser.

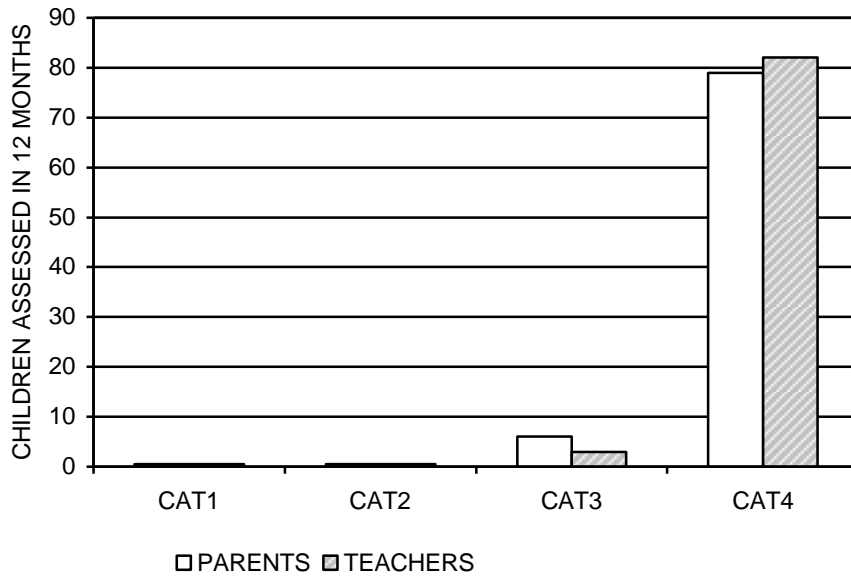


Figure 1. Numbers of children wearing their devices 1 year after implantation
 Category 4 = all of the time, 3 = most of the time, 2 = some of the time, and 1 = none of the time, as judged by their parents and teachers.

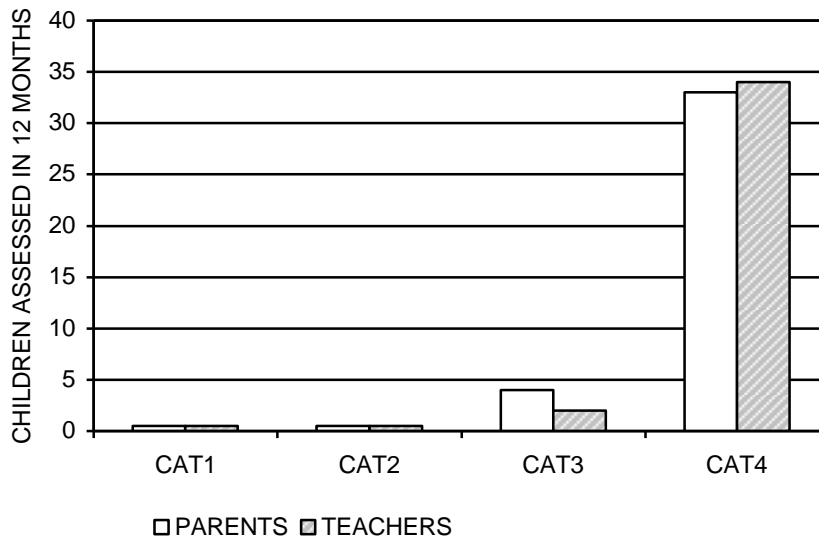


Figure 2. Numbers of children wearing their devices 3 years after implantation
 Category 4 = all of the time, 3 = most of the time, 2 = some of the time, and 1 = none of the time as judged by their parents and teachers.

Three years after implantation, 33 children (89%) wore their devices all of the time, and 4 children (11%) wore their device most of the time, as judged by their parents. Teachers rated 34 children (95%) using their devices all of the time, and 2 children (5%) were rated to use their device most of the time. Again, there were no occasional or non-wearers at the 3-year interval.

At the 12-month interval post-implant, five teachers rated implant use by the children more frequently than did parents, and two parents rated the children to use their device more frequently than did the teachers. At the 36-month interval post-implant, four teachers rated more frequent device use by the children than did the parents and two parents rated their child's use more frequently than did their teachers.

We compared children in category 1 (all of the time) and those in category 2 (most of the time) regarding age at implantation, age at onset of deafness, duration of deafness, and etiology of deafness. The only statistically significant parameter (at the $p < 0.05$ level) was the duration of deafness. This was smaller (mean, 44 months) in category 1 than category 2 (mean, 63.5 months) in the parents' assessment 36 months after implantation. However, the value of the statistical analysis is limited by the small numbers of children in category 2. There were no significant differences between the teachers' and parents' perceptions of these groups.

Discussion

These results are encouraging because implant use is a vital requirement to obtaining any benefit from cochlear implantation. It appears that parents' assessment of device use is borne out by teachers of the deaf. Even after 3 years of use, there are no poor or non-wearers in this sample. Our data sharply contrast with the rather disturbing figures of Rose et al. (1996), who reported 47% non-users in schools for the deaf in North America, implying that there may be up to 1,800 children not wearing their implant systems. In the study by Rose et al., only 3 (7%) of the schools, of the 45 responding, contributed 65% of the children wearing their implants. These schools were all operating strong oral programs. This observation suggests that a supportive educational environment contributes to continued device use. Rose et al. (1996) suggest that educational setting should be a major part of the assessment for cochlear implantation. Their conclusion that congenitally and pre-lingually deaf children have a low rate of acceptance clearly is not supported by the figures reported in this article. Whereas we would again agree that educational considerations should form part of the assessment process, we think that the ongoing liaison between the implant clinic and educators over the ears after implantation also is crucially important in ensuring continued use. The high usage rates reported in this article are not unique; Uziel (personal

communication, 1997) reports no case of non-use in a series of 80 children in the Montpellier pediatric cochlear implant clinic.

There are many factors that may contribute to high levels of implant use. The pre-selection phase is crucially important to ensure that all aspects of a child's needs, including family and educational background, audiologic, and medical considerations, are assessed. In our outreach program, our implant professionals visit the child's home and school before a decision is made about implantation to make the fullest possible evaluation of the child's environment. It may not be possible to solve these domestic or social issues, but it may be possible to lessen their effect by putting some additional input to the family or local support service, or by being sensitive to family circumstances in the appropriate timing of implantation. This type of service would be more difficult to achieve from a clinic-based service alone. For example, considering the importance placed on hearing aid use by the local educators may give an indication of their likely commitment to supporting the wearing of the cochlear implant system after implantation by the child.

Various factors may influence the wearing of the device including disillusionment in the early months after implantation when early expectations may not be met: domestic pressures within the family may not have been foreseen, peer pressure in adolescence, inappropriate educational support and low expectations, and technical difficulties that may go undetected in a young child. Each of these factors may lead to occasional or non-use of the device. These factors may all be addressed by careful preparation of family and local professionals by implant center staff to ensure expectations are realistic and the support provided by the local professionals is appropriate. Close contact and liaison with the implant center are vital to identify any technical problems quickly and respond to them, so that the child's implant system functions optimally at all times. This service necessitates educating local professionals and families in trouble-shooting the system and ensuring that such practical details as having the correct spare leads available at all times are addressed. This attention to detail requires specialist pediatric programs that provide the expertise in all areas: medical, audiologic, scientific, and rehabilitation. The lack of these support services may partially explain the non-use reported in the series by Rose et al. (1996).

The implications of non-usage of an implant system have great significance not only for the effectiveness of the system for the child and his or her psychosocial well being but also for the system's cost effectiveness. In the study by Wyatt et al. (1995) of post-lingually deafened adults, the procedure was found to be moderately cost effective, assuming at high level of use. If the reported non-use

rates of Rose et al. (1996) were representative of the pediatric population, the cost effectiveness of cochlear implantation would be seriously challenged, because the cost of generating each user include the costs of implanting those who become nonusers. Currently, the National Health Service in the United Kingdom is spending £20 million annually on cochlear implantation. Should a large proportion of implanted children become nonusers, the opportunity costs are significant, and this is a factor that healthcare purchasers increasingly consider.

Although the financial aspects of non-use are considerable, the psychosocial effects of non-use for the child and family may be of much greater significance. Cochlear implantation is an elective surgical procedure and one that involves a great deal of commitment on behalf of child and family. Should the child elect to become a nonuser, there may be long-term effects on behalf of their child.

Although this study was based on the subjective ratings of parents and teachers, the teachers of the deaf were not employed by the program and had no vested interest in reporting unduly favourable rates of implant use. The children and their teachers came from the entire range of educational and communication settings found in the United Kingdom. It may be possible to carry out more objective studies by building a data-log into the implant systems and conducting further long-term studies.

Conclusions

These results clearly show that children appropriately selected for cochlear implantation and given necessary support choose to wear their systems and continue to do so. Further studies of implant use are required in a range of implant clinics and over a longer period of time.

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Chapter 2.6

Long-term use of cochlear implant systems in paediatric recipients and factors contributing to non-use

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Abstract

The aim of the present paper was to assess children's long-term use of their cochlear implant systems and to explore factors influencing the extent of daily use. The parents of 138 deaf children who had been implanted for seven years completed an annual questionnaire about the extent of their child's use of their implant system. The results revealed that seven years after implantation 115 children (83%) were wearing their implants full-time, 16 (12%) most of the time, three (2%) some of the time and four (3%) were non-users. The children were categorised into those who were full-time users (group F) and those who were not full-time users (group N). The mean age at implantation in group F was 4.4 years with a median of four whereas in group N the mean age at implantation was 5.8 years with a median of 5.5 years. This difference was highly statistically significant. There were no children who were total non-users implanted below the age of five. The predominant mode of communication was oral in group F and signed communication in group N and the difference was also statistically significant. In group F, 90 (78%) were in mainstream education, either mainstream school or a resource base in a mainstream school, whereas the respective percentage in group N was 57 per cent and this difference was statistically significant. Further investigation of those in group N shows a fluctuating pattern of use over the years prior to becoming complete non-users seven years after implantation. The four children who were complete non-users at seven years after implantation were all implanted at five and had other difficulties with all having complex family issues, three having significant other learning difficulties and one experiencing pain on stimulation. None had experienced device failure.

In conclusion, this study of 138 children showed very high levels of full-time use seven years after implantation. Factors linked with full-time use seven years after implantation were early implantation, oral mode of communication and mainstream educational placement. Additional difficulties were not significant. Psycho-social issues such as family and educational support appeared to be important in facilitating continued use of the implant system. Non-use may occur after several years of use and in this group non-use followed a fluctuating pattern of use over time. The regular monitoring of device use may enable cochlear implant teams to be alert to potential non-users and to provide appropriate and timely support to the child, family and educational service.

Introduction

Cochlear implantation is now a widely accepted option for profoundly deaf children; over 70 000 children have received cochlear implants worldwide. Very young children are now implanted, before they are able to give informed consent, or be involved in the decision (Hehar et al., 2002; Miyamoto et al., 2005; Nikolopoulos et al., 1999a; O'Donoghue et al., 2000). However, although the internal device is surgically implanted, older children are later able to decide whether or not to wear the external parts of the implant system, irrespective of pressure from adults. If they continue to choose to wear the external equipment it could be taken as an indication of the benefit that they obtain from the implant system.

For parents making the decision about implantation, information on long-term usage rates of other children would also provide an indication of the value that those already implanted place on their device. Additionally, cochlear implantation is an expensive procedure demanding life-long maintenance, and those funding implantation also require evidence of the long-term use of the intervention they are funding. Healthcare services have limited funding and as interventions compete for the available resources, substantial numbers of non-users in the long term would indicate a waste of public money and could discourage further funding for the procedure.

Now that cochlear implantation has been carried out for a number of years, there are sufficient numbers to evaluate long-term usage rates of implanted children as they grow to adulthood and independence. Very few papers explore this issue, particularly in the long term; some reports of those implanted early in the development of implantation show high levels of non-use, for example, Rose et al. (1996) show non-use rates of 40 per cent. Of the 27 students studied by Spencer (2004), 29 per cent did not maintain full-time use in the long term. However, the factors which may lead to non-use are rarely explored. Watson and Gregory (2005) investigated reasons for non-use but this was in a small group of five children. Raine et al. (2005) evaluated usage of cochlear implants in a group of 180 children and found nine (5%) not using their devices. In a previous paper (Archbold et al., 1998b) the use rates in a group of implanted children were reported but the follow up was rather short (three years) and the number of children at the three year interval only 37. Ray et al. (2006) reported low non-usage rates (2.9%) in the paediatric population, although their study did not focus only on children as they included recipients up to 86 years old.

The aim of this paper is to assess the extent of daily use of cochlear implant systems, as reported by parents, seven years following implantation, by an unselected, large group of implanted children, and to explore some of the factors related to whether they continued to use their implant system.

Material and methods

Nottingham Paediatric Cochlear Implant Programme is publicly funded by the National Health Service in the UK and open to all. Many children live at a considerable distance from the implant centre. All children were implanted using the Nucleus 22 cochlear implant system (Nucleus, Lane Cove, Australia), and had hearing thresholds greater than 95 dB across the speech frequencies prior to implantation.

Following cochlear implantation, they do not receive intensive, clinicbased rehabilitation; rather follow-up support is provided by local services supported by an educational outreach programme from the clinic. The philosophy of the programme allows children to spend as much time as possible at home and school, minimising visits to the implant centre for tuning of the system. Teachers of the deaf and speech-language therapists provide regular visits to the child's home and school to provide direct liaison between the implant centre and home and school and to update and engage the skills of local professionals to encourage the full support of children on a daily basis. Parents and local teachers are fully involved in the ongoing monitoring process of the use of the implant system.

Parents and teachers annually complete a questionnaire about the child's use of the implant system and make their judgements by rating the child's implant use with four categories:

Category 1: All of the time (A)

Category 2: Most of the time (M)

Category 3: Some of the time (S)

Category 4: None of the time (N)

The data of all children who were implanted for at least seven years were analysed, using the data from the parents' reports, in order to reflect usage rates in everyday life in general, not only in school. Only two children who had

emigrated, two children who had been explanted for medical reasons and one who had died were not included in the study, leaving 138 children at the time of the analysis.

The child's local teachers also complete annual questionnaires about the child's chosen mode of communication. Communication choices include a wide range of options with varying emphases on oral or sign language, depending where the child lives in the UK, is educated, or their needs. For this study, the child's chosen communication mode as identified by their teachers was used; and the children were classified as using oral communication if they chose to use spoken language to communicate all the time at home and school, and as using signed communication if using signed support or sign language to whatever degree either at home or at school. It is recognised that this covers a wide variation in practice; it follows the descriptions used previously by Archbold et al. (2000).

The teachers' questionnaire also asked about educational placement: whether the child attends a school for the deaf, or a resource class (unit) based in a mainstream school or full-time placement in a mainstream school. These categories are used here in the knowledge that they also cover a wide range of provision with varying emphases; for example, children in mainstream schools have a large variety of support, ranging from full-time in-class support to none at all.

The demographic details of the 138 implanted children involved in the present study are shown in Table 1.

Table 1: Demographic details of all subjects included in the study

		No. of children (%)	
Aetiology			
Congenital (unknown)		68 children (49%)	
Meningitis		45 children (33%)	
CMV		8 children (6%)	
Usher's syndrome		4 children (3%)	
CHARGE syndrome		2 children (1%)	
Other causes		11 children (8%)	
Age at implantation (mean, median, range)		4.7 years	4.2 years 1.7-11.5 years
Number of electrodes			
>20		129 children (93%)	
10-20		8 children (6%)	
<10		1 child (1%)	
CMV, Cytomegalovirus; CHARGE, Coloboma, Heart defects, Atresia of the choanae, Retardation of growth and development, Genital and urinary abnormalities, Ear abnormalities and/or hearing loss.			

The usage rates for the whole group, as reported by parents, were analysed first according to the categories described above. The children were then assigned into two groups: the first group, group F, contained all those who used their implant systems all of the time and the second group, group N, contained those who were non-full-time users, who used their devices for most (M), some (S) or none (N) of the time.

The two groups, group F and group N, were then compared with regard to age at implantation, any additional difficulties, mode of communication, and educational placement in order to reveal any associations between each of these issues and cochlear implant use.

Statistical analysis included the Student T test, chi-square test and Mann Whitney U test. Statistical significance was accepted at p less or equal to the 0.05 level.

In order to look further at what issues in the children's lives may have influenced any fluctuations in use, and any trend towards any level of non-use, further investigation of the pattern of use of the children over the preceding years was undertaken.

Results

Seven years after implantation, as shown in Figure 1, 115 children (83%) were wearing their implant systems full-time, as reported by their parents. Sixteen (12%) were wearing their devices most of the time, three (2%) some of the time and four (3%) were non-users. When those children who had been implanted for seven years and were wearing their devices full-time (group F) were compared with those who were not full-time users (group N), the mean age at implantation was 4.4 years with a median of four in group F and in group N the mean age was 5.8 years with a median of 5.5 years. This difference was highly statistically significant ($p = 0.0009$).

To explore the effect of age at implantation further, those implanted under and over the age of five were compared, and then those implanted under and over the age of three were compared. Comparing first those implanted under and over the age of five, Figure 2 shows the numbers and percentages for each category.

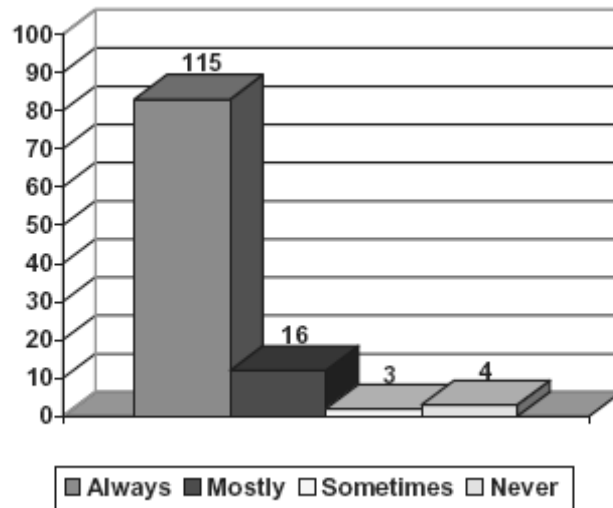


Figure 1. Device use by the whole group (N = 138) seven years after implantation (percentages on y axis and actual numbers given)

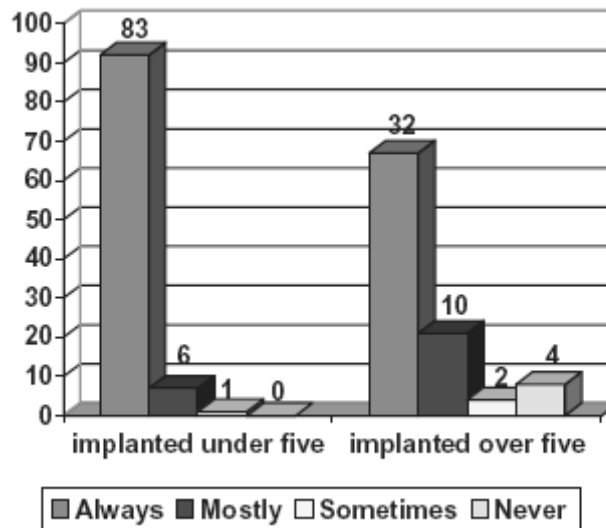


Figure 2. Device use seven years following implantation in children implanted under five and over five years old (percentages on y axis and actual numbers given).

Of those implanted under the age of five, 83 (92%) were full-time users compared with 32 (67%) of those implanted over the age of five. This difference is statistically significant ($p = 0.0003$). There were no children not using their devices who had been implanted below the age of five.

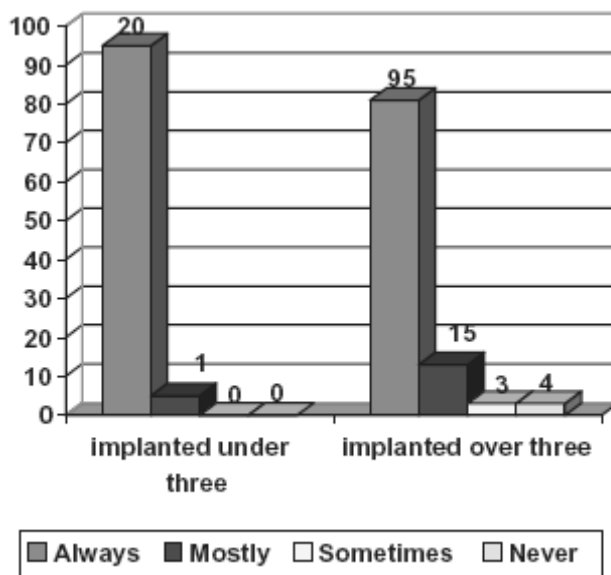


Figure 3. Device use seven years following implantation in children implanted under three and over three years old (percentages on y axis and actual numbers given).

To investigate the effect of age at implantation further, we looked at those implanted below the age of three and those implanted above the age of three. Figure 3 shows the numbers and percentages for each category.

Twenty children (95%) in the group implanted below the age of three were full-time users seven years after implantation; only one child (5%) was using the device most of the time. There were no children using their devices some or none of the time.

In the children implanted over the age of three, 22 (19%) of the children (out of 117) were not full-time users. Four (3.4%) were not using their devices at all, and three (2.5%) were using them some of the time; the others (12.8%) were using them most of the time. However, this difference was not statistically significant, due to the small numbers in the groups.

With regard to additional disorders, as classified on the programme's database, (cognitive, physical, visual, for example), among the 115 full-time users, 47 (41%) had additional disorders. Among the 23 non-full-time users, ten (43%) had additional disorders. There was no statistically significant difference, and it is in line with data on numbers of deaf children with additional disabilities (Fortnum et al., 1996; Stredler-Brown and Yoshinago-Itano, 1994).

Looking next at communication mode, the judgements of the teachers of the children as to whether the children were using oral communication or signed communication were analysed to investigate the relationship with continued usage

of the cochlear implant system. In group F (115 full-time users), 46 (40%) used signed communication to some degree seven years after implantation and 69 (60%) used oral communication. In group N, (23 non-full-time users), 17 (74%) used signed communication and six (26%) used oral communication. This difference is statistically significant. The predominant mode of communication was oral in the fulltime users and signed communication in the non-full-time users, as illustrated in Figure 4.

In the four children not using their implant systems at all, they were all using signed communication and had always done so.

Figure 5 illustrates educational placement: seven years after implantation. Of the children in group F (full-time users) 90 (78%) were in mainstream education, either mainstream school or a resource base in a mainstream school, whereas 23 (20%) were in schools for the deaf (and two in other special schools). In group N (non-full-time users), 13 (57%) were in mainstream education and nine (39%) in schools for the deaf (and one in another special school). This difference was statistically significant.

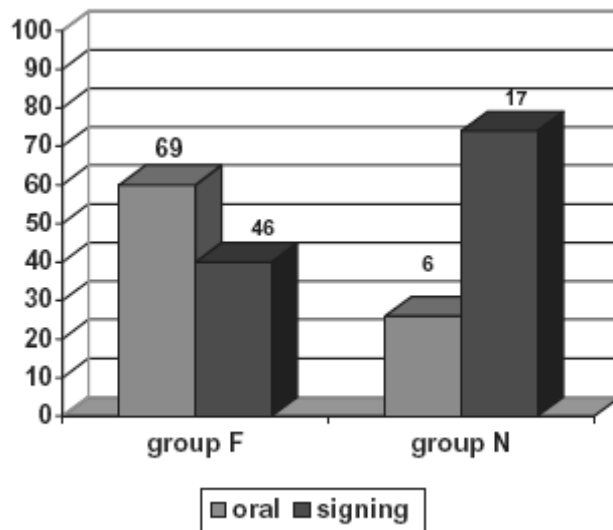


Figure 4. Communication mode of group F (full-time users) and group N (non-full-time users) at the data collection interval seven years after implantation (percentages on y axis and actual numbers given).

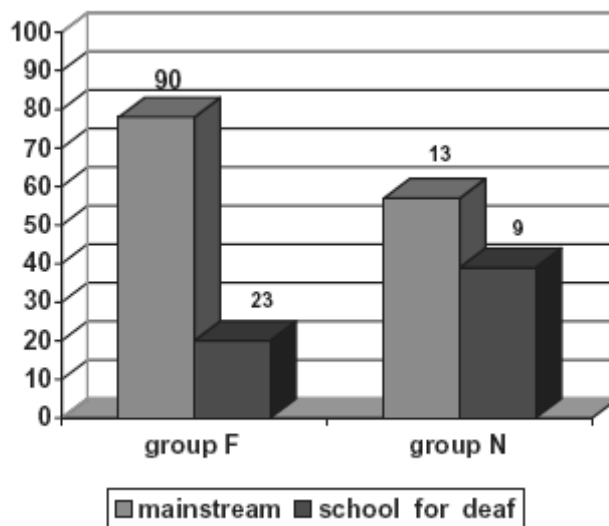


Figure 5. The educational placements of group F (full-time users) and group N (non-full-time users) seven years after implantation (percentages on y axis and actual numbers given).

As the numbers of children not using their implant systems were small, statistical analysis is limited in its value, and we looked next at the pattern of use of all of the children as individuals over time. Detailed examination of the pattern of use over time of both group F and group N showed consistent usage rates in group F over time and fluctuating patterns over time in group N. Only one child of the 115 in group F wore the device for 'some of the time' at several intervals over the years; one was rated as a non-user at the five year interval and became a full-time user at seven years after implantation, following the resolution of considerable educational difficulties and a change of educational placement.

Looking in more detail at those in group N, that is those using their devices most (M), some (S), or none (N) of the time showed that there was a fluctuating pattern of use over time in the majority of these children. Of the 16 children who were using their systems most of the time at seven years after implantation, three had at least one period of total non-use over the years. These three were all in schools for the deaf, with British Sign Language as the main means of communication; two had considerable difficulties at home and one experienced device failure. Thirteen of the group fluctuated between full-time use and using their implant systems most of the time, showing a different pattern to those in group F.

In the three children who were wearing their implants some of the time seven years after implantation all show a fluctuating pattern of use over the years, although none of this group had a period of non-use over the seven years.

Finally, investigating further the four children who were not using their devices at all, Table 2 shows their details.

Exploring these non-users further, all were implanted at five years of age, one became a non-user at the age of ten and the other three were 12 years of age when becoming non-users of their implant systems, having just entered secondary education. All were educated in educational settings using British Sign Language, three in schools for the deaf and one in a unit or resource base in a mainstream school. All the children have other issues: all have complex issues at home and two have significant other learning difficulties. For one child several changes of school took place in response to difficulties experienced at home and considerable behavioural difficulties. One child experienced physical pain on stimulation with the implant system when becoming a teenager, which was never completely resolved and which contributed to her not using the implant system at all.

Discussion

In this particular group of children, with long-term follow-up, there was a high usage rate; 83 per cent of the total group being full-time users seven years after implantation and a further 14 per cent part-time users, as reported by their parents. This was a non-selected group with none lost to follow-up, other than by death, emigration or removal of implant. It includes those with other disabilities and those from the full range of social backgrounds and educational systems found in the UK.

Age at implantation was a factor in ensuring long-term implant use; there were no non-users of their implant systems seven years after implantation who were implanted below the age of five.

Children today are being implanted at a younger age than this group and increasingly in the first year of life; based on the data of this group, one would expect a higher usage rate in the long term.

In the study of Watson and Gregory (2005), two of the non-users had been against having an implant prior to the operation and they emphasise the importance of careful preparation and of participation in the consent process by older children. In the study of Wiley et al. (2005) where the child had been unsupportive of proceeding with an implant, this had also led to non-use. At the Nottingham programme children are prepared for implantation by their parents, their local teachers and teachers of the deaf on the implant team with appropriate materials.

Table 2. Annual use of implant systems of children who are non-users seven years after implant with details about each child.

Age at implant	Notes on child	One year after implant	Two years after implant	Three years after implant	Four years after implant	Five years after implant	Six years after implant	Seven years after implant
5 y 2 m	No additional needs identified. Complex issues at home	A	A	S	A	N	S	N
		SFD	SFD	SFD	SFD	SFD	SFD	SFD
		Sign	Sign	Sign	Sign	Sign	Sign	Sign
5 y 6 m	Post-meningitis. Complex issues at home. Several changes of school. Behaviour problems	A	A	S	S	A	A	N
		SFD	SFD	SFD	SFD	SFD	SFD	SFD
		Sign	Sign	Sign	Sign	Sign	Sign	Sign
5 y 6 m	Additional language, communication and cognitive difficulties. Complex issues at home	A	A	A	A	A	S	N
		Unit	Unit	Unit	Unit	Unit	Unit	Unit
		Sign	Sign	Sign	Sign	Sign	Sign	Sign
5 y 9 m	Pain on stimulation five years after implant – no cause found. Additional language and communication difficulties identified. Complex issues at home	A	A	A	A	M	M	N
		Unit	Unit	Unit	Unit	Unit	SFD	SFD
		Sign	Sign	Sign	Sign	Sign	Sign	Sign

A = Always; M = most of the time; S = some of the time; N = never; SFD = School for the Deaf.

In this study, all the non-users were implanted at the age of five; at that age the children are old enough to participate in decision making, but it would be difficult to engage them meaningfully.

Educational placement and communication mode were both significant factors in whether a child was a full-time user of the implant system; in younger children, these decisions are likely to be more open to change and to be more flexible as a child's needs change, with or without implant. Watson et al. (2006) found that communication mode is less likely to change in children implanted over the age of five and once a child is settled in school there are many reasons, such as social and emotional issues, in addition to the practicalities of moving school, for the child to remain in the same placement (Archbold et al., 1998a).

Although mode of communication and educational placement were related to non-use or reduced rates of use of implant systems, care must be taken in linking correlation with causation. However, the four non-users were all using British Sign Language to access the curriculum and had always done so; they were also in educational settings where hearing was not emphasised, or the use of the implant system fully supported. It may be that hearing provided by the implant system was irrelevant to them for communication or learning in everyday life. In the study of Watson and Gregory (2005) all five non-users of their implants were also in educational settings using signed communication. Greater involvement in mainstream schooling was linked to greater full-time use of the implant system in this study, but again it is not clear as to whether children attend mainstream school because they are consistent users of their implants, or whether they are more fully supported in the use of their implants in mainstream schools. However, it is of note that all children who were non-users were implanted at the age of five and, seven years after implantation, when these data were collected, had recently made the transition to secondary (high) school with the challenges for deaf children of more demanding language and curriculum and often poor acoustic conditions and less attention to individual needs. These challenges may lead to non-use if consistent use has not already been well established or if a child is experiencing difficulties with the device. It may also be that at that age peer pressure becomes important; teenagers are reluctant to wear or do anything that makes them different to their peers, and cochlear implant systems are very noticeable and difficult to hide.

In this group family issues appeared to be related to non-use of implant systems; these are difficult to identify or measure their influence, but in all children who

became non-users there were complex issues at home noted by the implant team staff and local support staff. These young people were dealing with significant difficulties including death, divorce and other complex family issues. Such issues can make dealing with the technology more difficult or the young person's learning or behavioural difficulties more complex to deal with and of greater significance. Other psycho-social issues which appeared of note to the implant staff were difficulties experienced in school where children may feel unsupported in the use of the implant system, or in the handling of any difficulties in its use. On investigation, several of the children who showed fluctuating patterns of use were supported to become users once more after changes in the support provided by school, or change of educational placement or teacher. It is of note that only one of the nonusers had technical problems and none experienced device failure, and psychosocial issues seemed more important influences on the wearing of the system.

One way to support full-time use is to establish close liaison between the implant centre and school, and the training of teachers in the long-term management of implant systems. The Nottingham programme has established working relationships with educational services; reports from the implant centre routinely go to the teacher working with the child and direct contact is maintained by teachers of the deaf working with the implant programme. This level of continued long-term contact and dialogue with local educators and parents may well contribute to the high usage rates reported in this paper and in the paper by Beadle et al. (2005) giving high use rates ten years after implantation. However, this liaison may not always be sufficient, or possible, and there needs to be an informed infrastructure including those skilled in family counselling and social workers for the deaf, who can be involved if intermittent device use requires further exploration of the relevant issues. A significant finding from this study is that the pattern of use over time from this group is more complex and changing than has been reported earlier. Watson and Gregory (2005) in their study of five cases found signs of non-use becoming apparent early after implantation, in the first year, without consistent use becoming established, but this does not appear to be the case in our group. The two groups, group F, full-time users, and group N, non-full-time users, show differing patterns. Group F shows consistent use over time, and Group N shows some fluctuations in use over time. While the vast majority of children in our group became full-time users and remained so, some children showed changing use over time before becoming users or non-users. Of the four non-users in the group all were users two years after implantation, with one becoming a non-user after

five years of implant use, then using his device some of the time, before becoming a non-user again at seven years after implantation. The other three showed a changing pattern over time, until becoming non-users seven years after implantation at the age of 12. In addition, three other children in the group were non-users at the five year interval, but became users by the seven year interval studied in this paper. Looking at these three further, changes in educational support were significant factors in promoting use to become established once more.

For cochlear implant programmes and for those supporting children on a daily basis, monitoring use of implant systems and looking into the reasons for any reported non-use is important; it may be that the child will become a user once more if certain issues are addressed. It may also be that to wait to address the issue until a routine visit to the implant centre may be too late; a pattern of varied use leading to non-use may become established. This is consistent with the findings of Watson and Gregory (2005) where parents felt that closer cooperation between the implant centre and education could have promoted more effective use of the implant system, and where they requested more tuning appointments when the young people were reporting uncomfortable sensations. For example, during adolescence, a young person may experience discomfort due to hormonal changes, which can easily be corrected by a change in tuning levels, but which, if left unchanged can lead a young person to discontinue wearing their system. In their study, Watson and Gregory (2005) particularly found that the five children who were not using their device did not like the signal through the implant system and found it uncomfortable. In this study one of the non-users experienced significant problems and pain on stimulation which were never fully resolved. This has implications for implant teams in setting up systems comfortably and effectively; input from local educators can assist in ensuring the settings are comfortable in everyday life and not only in the clinic. These issues also have implications for implant manufacturers in ensuring that complex implant systems can be tuned effectively for children; particularly as increasing numbers of implants are being carried out on young children, and systems are being tuned by implant teams who may be inexperienced in both implant management and the management of young deaf children. Looking at other factors which may influence continued usage, Raine et al. (2005) reported that the majority of non-users were implanted early in the implant programme's development; in our group further analysis comparing year on year usage rates showed no evidence that this was the case. Raine et al. also identified age at implantation, educational setting and

parental support as alerting staff to potential non-use. Three years after implantation, they also identified a score on the Categories of Auditory Performance (CAP) (Archbold et al., 1998; Nikolopoulos et al., 1999b) of five or less as being an indication of potential non-use; children scoring five or less on CAP are not able to understand conversation without lipreading and hence are likely to have some difficulty in mainstream education. In this study, of the four children not wearing their implant systems, two have CAP scores of six, where they can understand conversation without lipreading, one a score of five, where she understands common phrases and one a score of one, only being aware of environmental sounds. There is no link between CAP scores and non-use; two children have good use of their implant system as measured by CAP. However, all of these children have poor speech intelligibility as measured by the Speech Intelligibility Rating (Allen et al., 1998, 2001); two are unintelligible and the other two intelligible only to those who know them and know the context. Speech intelligibility of this level, seven years after implant, does not make for ease of communication by spoken language for these children, and may not make the use of the implant system important in communication. Why might sustained implant use be considered important? Implantation is an invasive form of management for young deaf children which is costly in terms of money for society and parents, and in terms of emotional investment for the family (Watson and Gregory, 2005). Parents choose implantation to give useful hearing to their child for both access to environmental sounds for safety reasons and with the goal of spoken language development (Archbold et al., 2002b; Nikolopoulos et al., 2001). These children were all profoundly/totally deaf, and when not wearing their implants were not able to hear speech or to identify environmental sounds. Hence, the goal of implantation for their parents is unlikely to be met if device usage is discontinued. It may be that the decision to implant could be seen by the child as a lack of acceptance by the parents of their deafness, and a result of a search for a cure for their deafness (Luterman, 2005). For parents this rejection of the decision they made, and the lack of fulfilment of their goals may be difficult to accept and may become an area of contention between parent and child. In adolescence, young people need to develop their self-esteem in achieving their own goals, rather than those of their parents, and rejection of their parents' earlier emotional, time and financial commitment can cause tremendous difficulties in the family.

Cochlear implantation offers profoundly deaf children greater choices – it may be that those who choose not to wear their devices full-time, but wear them most or some of the time are exercising the choice that they have been given. As more of

these young people are able to articulate what an implant can and can't offer, then they must be consulted about the process of implantation and the support they require to ensure they are able to make genuine choices. If the decision to stop wearing an implant system is made because it has never functioned properly, or been tuned appropriately, and is giving an uncomfortable signal, then the young person does not have a real choice, but is making a decision as a result of poor service.

In addition to these potential difficulties within the family caused by a young person deciding not to wear the implant system, there are implications for society.

The financial investment in implantation has not been sound if the child chooses to discontinue wearing the system and thus rejects the financial investment too. Paediatric implantation commits a great deal of society's resources to the process of implantation itself and the life-time's support of the equipment which is necessary.

High levels of non-use compromise the cost-effectiveness of the investment and may deter funders from supporting the process of implantation in a world of competing resources for healthcare.

Conclusion

Cochlear implantation in children is a rapidly growing procedure with great acceptance as a choice of management for young deaf children. For parents making the decision about implantation on behalf of their children, the comparatively high usage rate reported here is encouraging. Significant levels of non-use would indicate high levels of dissatisfaction amongst the users themselves, the children and young people, and have financial implications for the funders of this procedure.

This study, of 138 children, showed very high levels of full-time use, reported by parents, seven years after implantation. Factors linked with full-time use seven years after implantation were early implantation, oral communication and mainstream educational placement. No children implanted below the age of five became total non-users in this study. Those who became non-users showed a pattern of fluctuating use before doing so. Continued follow-up and contact with parents, children and local educational services facilitated long-term continued use of devices and may contribute to helping those with intermittent use to become

established users once more and thus benefiting fully from the procedure. It is important to ensure as far as possible, that the likelihood of non-use is minimised by careful preparation and decision making before implantation and by careful long-term follow-up afterwards

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Chapter 3

Evaluating educational outcomes

This chapter includes papers which explore the educational outcomes from implantation in terms of its influence on educational placement, on communication mode used by the children following implantation, and of what we know of its influence of cochlear implantation on reading attainment. The first paper is an early one, looking at the trend towards mainstream placement which was already becoming apparent, and the second paper develops this further, looking at age-matched groups. The contentious area of communication choice is addressed in the following three papers, illustrating that choices of communication mode are complex and change over time, and the research reported emphasises once more the diversity of the group. The final paper in this chapter is the first from the data to look at educational attainments: it illustrates the positive influence of early implantation on the development of reading skills in deaf children, and looks forward to further improvements in reading achievements in this group with improved technology and earlier implantation.

Chapter 3.1

Educational placement of deaf children following cochlear implantation

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G.M. O'Donoghue
M.E. Lutman

Abstract

This study examined the educational placements, before cochlear implantation, of 121 deaf children, and the educational placements, two years after implantation, of the 48 children who had reached that stage, looking at the influence of age at implantation and duration of deafness on the placement of these children. In addition, it compared the educational placements of those given implants prior to schooling, and those given implants when already in an educational setting. Categories used were pre-school, school for the deaf, unit or resource base within a mainstream school and full-time mainstream provision. Age at implantation and duration of deafness were found to be significant predictors of placement two years after implantation. The duration of deafness of children in schools for the deaf or units was twice that of children in mainstream education. Fifty-three per cent of children who were in pre-school at the time of implantation were in mainstream schools two years after implantation, whereas only 6% of those who were already in educational placements at the time of implantation were in mainstream education. This difference was statistically significant. The results indicate that children who are given implants early, before an educational decision has been made, are more likely to go to mainstream schools than those given implants when already in an educational setting.

Introduction

Historically, deaf children have been placed in schools for the deaf, which led to a growth in the number of special schools world-wide, often in remote areas. In recent years, economic and political pressure from minority groups has influenced the trend towards the increasing placement of children with disabilities in mainstream schools. For deaf children, the improvement in the quality of amplification, including provision of FM systems, has given more effective use of audition, and facilitated access to mainstream education. Units or special classes for deaf children attached to mainstream schools have been established, and since the mid-1970s more and more deaf children have been placed in mainstream schools full time, with varying levels of support (Lynas et al., 1997). Integration was the term used widely in the 1970s and 1980s to describe this movement. The terms 'inclusive education' and 'least restrictive environment' are now used world-wide to describe the growing trend towards educating all children with disabilities with their peers and increasingly in their local school (Chute et al.,

1996; Powers, 1996a). However, although most deaf children are in mainstream schools and colleges, profoundly deaf (>95 dBHL) children in the UK are often placed in schools for the deaf (BATOD, 1995; 1996). Now that cochlear implantation is giving this group of children access to spoken language via audition, which was not previously possible using hearing aids (Tait and Lutman, 1994; Miyamoto et al., 1995), it seemed timely to investigate any trend in educational placement of children following implantation. In addition, there is a great deal of interest in looking at the cost-effectiveness of cochlear implantation, and much discussion centres around possible savings in the costs of educational support following implantation (Summerfield and Marshall, 1996; Cowan, 1997). It is, therefore, essential to look at existing data to monitor current trends.

This study looked at the educational placements of a group of deaf children before implantation and two years after implantation, and considered the influence of age at implantation and duration of deafness on the placements of these children. It also compared the educational placements two years after surgery of children given implants prior to schooling, and those given implants when already in an educational setting.

Method

The educational placements of the first 121 children implanted in a specialized paediatric implant programme were classified by their local teachers of the deaf prior to implantation, and annually after implantation. The categories used were: pre-school (P), school for the deaf (SFD), unit or resource base in a mainstream school (U), and full-time mainstream provision (M). Of the 121 children, 47 were classified as being pre-school prior to implantation; that is, no decision had been taken as to educational placement. There were 74 children who were already in educational settings: 27 in schools for the deaf (37%), 35 in units or special classes (47%) and 12 in mainstream (16%).

The children's implants were funded by the National Health Service in the UK, with the children coming from throughout the UK, and having a variety of social and educational backgrounds. There were 61 children with acquired deafness (49 as a result of meningitis) and 60 were born deaf. The average age at onset of deafness of the acquired group was 19 months (range 6-79 months). The most common age to be given an implant of the whole group was 44 months, the mean age at implant being 61.8 months (range 21-203 months). It was

considered important to include all the children, with a wide age range, although the group as a whole tended to be young when given implants. All the children fell into the profoundly deaf category (>95 dBHL) used by the British Association of Teachers of the Deaf (BATOD) and were implanted with the multi-channel Nucleus 22 device with the most appropriate speech-coding strategy. The processor was upgraded to the latest type whenever newer models became available. Following implantation, the rehabilitation of the children was carried out largely by their local teacher with the support of the cochlear implant teacher of the deaf. The rehabilitation of the children therefore varied widely according to the local philosophy and conditions.

Considering the 48 children who had been implanted for two years: 30 children had acquired deafness, and 18 were congenitally deaf. The average age of onset of deafness was 16.4 months (range 0-79 months) and the most common age to be implanted was 51 months, with an average of 65.8 months. Since we were looking at the educational placements of these children two years after implantation, it is of interest to note that 20 of these 48 children were in oral educational settings, and 28 of them were in total communication settings, where signed support was used to some degree.

The educational placements of the 48 children who had reached the two-year assessment interval after implantation were analysed. The children were categorized into two groups: (1) those who were at the pre-school stage prior to implantation, and (2) those already in an educational setting prior to implantation. The educational placements two years after implantation of those children who were at the pre-school stage when implanted (17) were compared with the educational placements of the children who were already in educational settings when implanted (31).

Chi-square analysis was used to determine if children who were in pre-school at the time of implantation had different educational placements two years after implantation in comparison with children who were already in educational settings at the time of implantation. One-way analysis of variance (ANOVA) was used to examine duration of deafness for the various educational placements at the two-year interval after implantation. The duration of deafness in the three groups (SFD, U, M) met the criteria for normal distribution and therefore ANOVA was applicable. We used the Mann-Whitney U test to compare the age at implantation in the three groups (SFD, U, M - two-year interval) as the distributions were not normal.

Results

Figure 1 compares the educational settings (two years after implantation) of the 17 children who were in pre-school when implanted compared with the 31 children who were in an educational setting when implanted. Two children who were in pre-school prior to implantation remained in pre-school two years after implantation. Fifty-three per cent (8) of the pre-school children were in mainstream schools two years after implantation, compared with 6% (2) of the children who had been in education prior to implantation. Thirteen per cent (2) of the pre-school children were in schools for the deaf, compared with 33% (10) who were in education prior to implantation. Finally, 33% (5) of the pre-school children were in units, compared with 61 % (19) who were in education prior to implantation. Chi-square analysis revealed that this difference in educational placement (two years after implantation) between the above-mentioned groups is statistically significant ($p=0.001$).

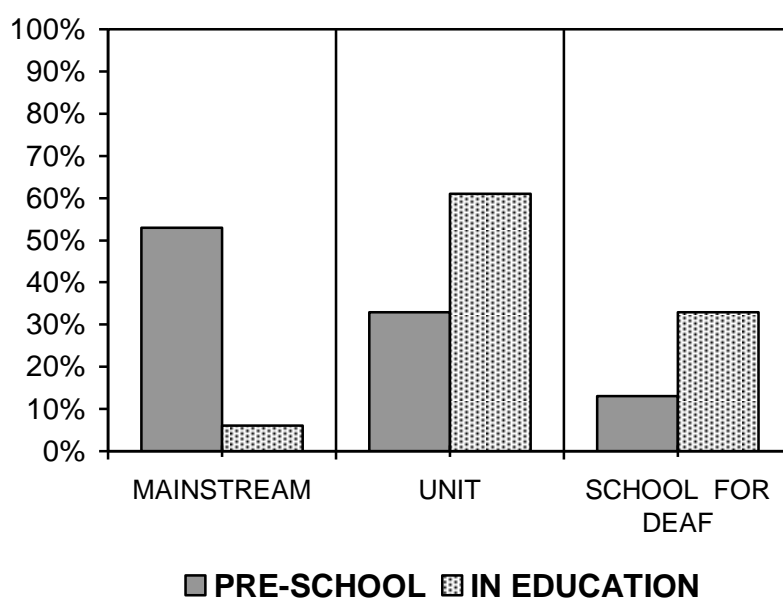


Figure 1. Educational placement of children two years after implantation: Comparison of those in pre-school (N=17) prior to implantation and those in education prior to implantation (N=31).

Considering the effect of age at implantation on educational placements two years after implantation, Table 1 shows the mean age at implantation for those children in a school for the deaf it was 72.2 months (12 children); for those in a unit it was 72.1 months (24 children); and for those in mainstream education it was 49.0 months (10 children). Age at implantation was statistically significantly lower in children in a mainstream setting compared with those in a unit ($p=0.002$) and

compared with those in a school for deaf ($p=0.004$).

The average duration of deafness (Table 2) of those in schools for the deaf was 58.3 months, for those in units it was 53.6 months and for those in mainstream education it was 24.7 months, indicating the shorter duration of deafness of those in mainstream education. *ANOVA* revealed that these differences were statistically significant ($p=0.004$) and discriminant analysis confirmed that children with shorter duration of deafness are more likely to be found in mainstream schools. ($p=0.004$).

Table 1. Mean age of children at implantation (educational placements two years after implantation) ($n=48$).

Educational placement	Mean age at implantation
School for the deaf	72.2 months
Unit	72.1 months
Mainstream	49.0 months

Table 2. Children's average duration of deafness (educational placements two years after implantation) ($n=48$).

Educational placement	Mean age at implantation
School for the deaf	58.3 months
Unit	53.6 months
Mainstream	24.7 months

Discussion

This study showed a trend towards mainstream provision of education following cochlear implantation in young children, as did the work of Nevins and Chute (1994) and Waltzman et al. (1995). These results show that age at implantation and duration of deafness are predictors of educational placement two years after implantation. The study also found a significant difference in the educational placements of children two years after implantation, depending on whether they were given implants prior to educational placement or after it. This may simply be the effect of age at implantation, with children given implants prior to educational placement being younger than those given implants afterwards; or it may be that children rarely change schools once a placement decision has been made - those in mainstream settings two years after implantation tended to have been implanted prior to that decision, compared with those in schools for the deaf or units.

In this study, children did not tend to change educational placement once the decision had been made: of the 74 children in educational placements before implantation, 31 had reached the two-year level, and of these, only two had changed educational setting. There may be several reasons for this stability of educational placement: there may be a recognition that the child may take some time to benefit from the implant system, in terms of spoken language; and it may be inappropriate to move the child in the first few years of implant use, particularly for older children and those who have been deaf for longer. However, it may equally be true that the educational placement that was considered appropriate for the child prior to implantation may not be the most effective in developing spoken language in a child with useful hearing following implantation, and the child may benefit from a change of management. The reason for an educational placement decision may not always be linked to the child's educational needs; the availability of provision or the influence of local policy may also be important (Archbold and Robinson, 1997). Additionally, in an educational system in the UK that is increasingly based on per capita funding, a school for the deaf may be reluctant to recommend a child's transfer elsewhere, with the consequent loss of income.

An additional factor to consider in the making of educational decisions for children with cochlear implants is the possible influence of the rehabilitation staff at the implant centre, who visit the educational setting. This influence exists for all children, at whatever age they are given implants; however, it may be that, with younger children, it is easier to influence the decision prior to it being made, rather than to argue for a change of placement for an older child, with the disruption that this may bring for the child. The effect of the influence of the implant team is not yet clear, and it may be worth investigating further.

There are, then, various factors that influence the decisions regarding educational placement of a deaf child, some of which, such as cognitive ability, linguistic ability and parental pressure, have not been discussed here, and are difficult to assess. Nevertheless, if mainstream placement is considered a desirable goal, these results argue for early implantation, where possible prior to an educational placement decision.

Educational placement, however, cannot be considered an end in itself; educational achievement and other issues may be more important. Powers (1996b) suggests that investigating educational outcomes is crucial in any discussion of the value, or otherwise, of educational placement. In addition, we

need to consider the psychosocial perspective of placing a deaf child in a mainstream school. Children remain deaf after implantation, and many consider that education with hearing children deprives them of their deaf peer group. Others would argue that mainstream education is part of the movement towards inclusive education, which includes education in the child's local school. Decisions about the appropriateness of an educational placement for a child should be based on objective assessments and observation, such as those attempted by Nevins and Chute (1996).

In order to compare the trend within this implanted group, we compared our results with the BATOD survey of 1994, which looked at the educational placements of all deaf children in the UK (BATOD, 1995; 1996). In the BATOD survey, 11 % of all profoundly deaf children were in mainstream schools, and 50% in schools for the deaf; whereas in our study, among those implanted prior to educational decisions being made, 53% were in mainstream schools two years after implantation, and 13% in schools for the deaf. It is apparent that a much greater proportion of children implanted when young attend mainstream school than is the overall pattern for deaf children in the UK. However, the numbers in our study are very small in comparison with the BATOD survey, and the children are younger on the whole; the BATOD study includes all school-aged deaf children. The transition to secondary schooling in particular is challenging for deaf children, and it is important that the educational placements of implanted children are monitored over much longer periods and in much larger groups, to consider if the effects on educational placements are sustained in the long term.

Summary and conclusion

In the present study, children implanted prior to educational placement were significantly more likely to go to mainstream schools than those implanted when already in educational placements. Children were unlikely to change educational placement in the first two years after implantation. Age at implantation and duration of deafness were significant predictors of placement two years after implantation, the duration of deafness of those in mainstream education being half that of those in units or schools for the deaf. Within this comparatively small group of children, those implanted before schooling may be more likely to go to mainstream schools than profoundly deaf children in the UK as a whole.

These results indicate that cochlear implantation may be influencing the

educational placement of profoundly deaf children in the UK. Further, larger, long-term studies are required to determine whether this trend continues as implanted children reach secondary education, to monitor the educational attainments of implanted children further, and the potential for cost savings in the educational system, should these apparent changes in educational placement prove to be sustained in long-term.

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Chapter 3.2

The educational settings of profoundly deaf children with cochlear implants compared with age-matched peers with hearing aids: implications for management.

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G.M. O'Donoghue

Abstract

The educational settings of 42 implanted profoundly deaf children 3 years after implantation were compared with the respective settings of 635 age-matched severely deaf and 511 profoundly deaf children with hearing aids. All implanted children received their implants before beginning school. The results revealed that 3 years after implantation, 38% (16 children) of the implanted profoundly deaf children attended mainstream schools, whereas 57% (24 children) were in a unit, or special class, in a mainstream school, and 5% (two children) were in schools for the deaf. With regard to the age-matched profoundly deaf children with hearing aids, 12% (63 children) attended mainstream schools, whereas 55% (281 children) were in a unit of a mainstream school, and 33% (167 children) were in schools for the deaf. In the group of age-matched severely deaf children, 38% (239 children) attended mainstream schools, whereas 51% (326 children) were in a unit of a mainstream school, and 11% (70 children) were in schools for the deaf. Statistical analysis revealed a highly significant difference between the educational placement of implanted children and hearing-aided profoundly deaf children ($p < 0.00001$), whereas there was no statistically significant difference between implanted children and hearing-aided severely deaf children. In conclusion, implanted profoundly deaf children who have received their implants before beginning school have the same profile of educational placement as aided severely deaf children rather than aided profoundly deaf children of the same age in the UK. This is likely to have significant implications for the future management of profoundly deaf children and to influence future planning of educational support services.

Introduction

The rapid development of cochlear implantation as an option for profoundly deaf children has brought together the medical and educational worlds in looking at the management of these children, and in examining outcomes from the procedure. Cochlear implantation has enabled some profoundly deaf children to access spoken language via audition more effectively than through hearing aids, and thus opened up new opportunities for them (Allen et al, 1998; Nikolopoulos and O'Donoghue, 1998; Nikolopoulos et al, 1999a; O'Donoghue et al, 1998a,b; Waltzman et al, 1997). Several studies have indeed illustrated a move towards mainstream education in profoundly deaf children after implantation (Nevins and

Chute, 1995; Archbold et al, 1998). This supports the worldwide trend towards the inclusion of all children with disabilities into mainstream education. In the UK, government policy is the placement of all children in mainstream schools, unless parents wish otherwise. In addition, there has been particular interest in looking at the educational placement of children following implantation with regard to the issue of cost-effectiveness (Francis et al, 1999; Niparko et al, 2000); if an implant provides a profoundly deaf child with enough auditory capacity to allow placement in the educational mainstream, then implant costs may be partially offset by a reduction in educational costs.

Although Hopwood and Gallaway (1999) suggested that hearing-impaired children are the most likely to be mainstreamed of all children with special educational needs, when looking at profound deafness the picture is not so clear-cut. In the UK, the most recent survey by the British Association of Teachers of the Deaf (BATOD, 2000) reveals that about 50% of profoundly deaf children are in schools for the deaf and less than 10% are in mainstream schools, when we consider children of all ages.

In a previous study, we found that children implanted prior to educational placement were significantly more likely to go to mainstream schools than those implanted when already in educational placement, and significantly more profoundly deaf children with cochlear implants were attending mainstream schools when compared with those with hearing aids (Archbold et al, 1998). Age at implantation, an important determinant of speech perception and production outcomes in implanted children (Nikolopoulos et al, 1999b, 2000; O'Donoghue et al, 2000), was found to be a significant predictor of educational placement. However, the study compared a small group of young children with cochlear implants with the entire age range (2-16 years) of children with hearing aids in the UK, and results were tentative. Other previous studies are limited by small sample size and a failure to match aided and implanted children on the basis of age. The present study seeks to address these problems.

The aim of the present paper is to compare the patterns of educational placements of implanted profoundly deaf children, hearing-aided profoundly deaf children, and hearing-aided severely deaf children, while controlling for the effect of age.

Materials and methods

Three categories of educational placement were used: school for the deaf, unit or special class within a mainstream school, and full-time mainstream provision.

The educational settings of a group of 42 profoundly deaf children were studied 3 years after implantation. The criteria for entry to the study were that children should have been implanted before beginning school, therefore before the age of 5, and have been implanted for at least 3 years. The children came from throughout the UK, having a variety of social and educational backgrounds, and were implanted at Nottingham Paediatric Cochlear Implant Programme. Their implants were funded by the National Health Service in the UK, so that the direct costs were not an issue for parents. There were no exclusions. The aetiology of deafness was meningitis for 25 children, congenital deafness for 14 children and other causes for three children. The 25 post-meningitic children were all pre-lingually deaf, with age of onset less than 3 years (mean 13 months). The children were all profoundly deaf, having average unaided hearing threshold levels of greater than 95 dBHL, across the speech frequency range 500 Hz to 4 kHz inclusive. The mean age at implantation was 3.3 years (range: 1.8-4.8 years). Three years after implantation, the age of the children ranged from 4.8 to 7.8 years; 24 were using oral communication, and 18 total communication. All children had been implanted with the Nucleus multichannel device.

The educational settings of these children were compared with the educational settings of severely (puretone hearing threshold levels between 71 and 95 dB) and profoundly (pure-tone hearing threshold levels greater than 95 dB). deaf children with hearing aids, using data from the most recent survey carried out by the British Association of Teachers of the Deaf in 1998. BATOD produces a summary report of this survey of deaf children from throughout the UK (BATOD, 2000). The detailed data necessary for this study were obtained directly from the BATOD database.

In order to have comparable groups of children with regard to age, the educational settings of all profoundly and severely deaf children with hearing aids who were born between September 1989 and September 1993 were obtained from the BATOD database. There were 511 profoundly deaf children and 635 severely deaf children. The mean age of the profoundly deaf children with hearing aids was 6.38 years; the mean age of the severely deaf with hearing aids was 6.40 years; and

the mean age of the profoundly deaf with cochlear implants, 3 years after surgery, was 6.3 years.

Chi-squared analysis was used for the statistical comparisons of the data, and statistical significance was accepted at the $p < 0.05$ level.

Results

Of the 42 implanted profoundly deaf children, 3 years after implantation, 16 children (38%) were in mainstream schools, 24 children (57%) were in a unit or special class in a mainstream school, and two children (5%) were in schools for the deaf. Corresponding figures for the 511 aided profoundly deaf were 63 (12%), 281 (55%) and 167 (33%). For the 635 aided severely deaf children, the figures were 239 (38%), 326 (51%), and 70 (11%), as shown in Figure 1. The statistical analysis revealed that there was a highly significant difference between the educational placement of children in the first two groups ($p < 0.00001$), whereas there was no statistical difference between implanted profoundly deaf children and aided severely deaf children.

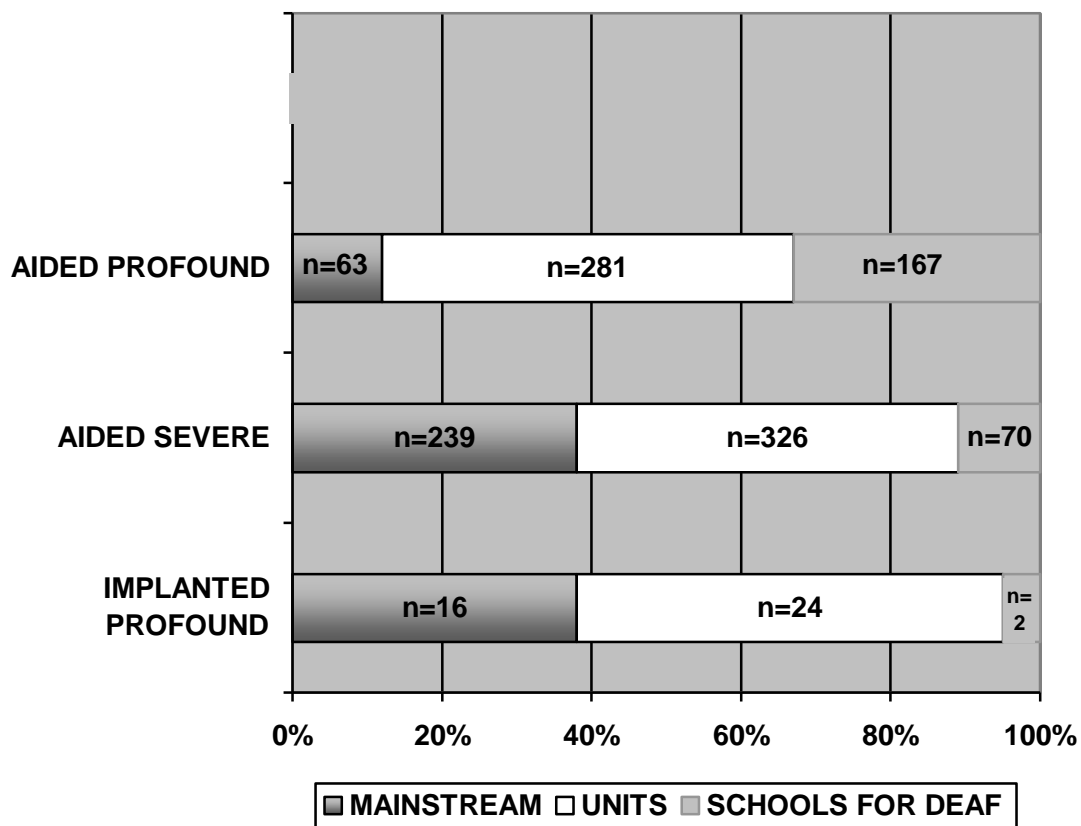


Figure 1. Distribution of educational placements among three age-matched groups of deaf children.

From Figure 1, it can be seen that an implanted profoundly deaf child is more likely to be placed in mainstream than an aided profoundly deaf child of the same age, and less likely to be placed in a school for the deaf. The percentages of children in special units or classes, however, are very similar for the three groups.

Discussion

The results of the present study suggest that implanted profoundly deaf children, who had received their implants before they started school, are in educational settings 3 years following implantation similar to those of age-matched severely deaf children with hearing aids. Summerfield et al's (1999) continuing study of support options for deaf and hearing-impaired children in the UK also reported that children with cochlear implants were showing a pattern similar to those with severe deafness rather than those with profound deafness who have not received an implant. However, they compared children with implants and hearing aids of all ages. Those with implants will tend to be much younger than the group with hearing aids. Francis et al (1999) found that children with more than 2 years of implant experience were in mainstream schools at twice the rate of age-matched children with profound hearing loss who did not have implants. Although they used age-matched groups, the sample size was small; there were 10 children with hearing aids and 10 children with more than 2 years of cochlear implant experience, and all the children were in total communication settings, not reflecting the full range of educational provision. In the present study, the smallest group assessed consisted of 42 children. In addition, the children were implanted prior to a decision being made about educational placement. This removes the likelihood of the child's educational setting remaining-fixed regardless of progress with the implant system, due to funding issues or local inflexibility in the educational system (Archbold et al, 1998).

Evidence from longitudinal studies suggests that implanted profoundly deaf children function, with regard to their auditory capacity and speech perception, at levels equivalent to aided severe and not profound deafness after 2 or 3 years of implant use (Boothroyd and Eran, 1994; Meyer et al, 1998; Vermeulen et al, 1997). The present study is in line with these results, showing that young implanted profoundly deaf children have the same or stronger trend towards mainstreaming as aided severely deaf children. This trend towards mainstreaming after cochlear implantation is of interest for two main reasons. The first is

concerned with the benefits perceived from higher educational attainments and natural language models of spoken language found within the mainstream (Robbins-McConkey, 2000). The second relates to the issue of cost-effectiveness of cochlear implantation and the balancing of the costs of cochlear implantation itself with the possible savings from reduced specialist educational support in the long term (Francis et al, 1999; Koch et al, 1997). The situation is not yet clear-cut on either issue. Data with regard to educational attainments of deaf children in mainstream as opposed to other settings are inconclusive (Powers and Gregory, 1998).

Furthermore, Niparko et al (2000) suggest that the move towards mainstream may in fact entail increased support services for deaf children, although the needs for these services appear to diminish with time. If children are placed in mainstream following cochlear implantation, their varying support needs requires careful monitoring. Koch et al (1997) developed the Educational Resource Matrix to illustrate the complex relationship between educational placement and use of support services. This enables the various complex scenarios to be illustrated on the matrix. For example, it is possible to illustrate that a child in a mainstream setting may, in fact, be receiving more support than a child in a special unit or resource centre. It is very complex to estimate the cost of these services in a range of educational settings, and across educational services, and assumptions that the trend towards mainstream saves money requires further investigation. However, one study in the UK (Coopers and Lybrand, 1998) has looked at the relative cost based on costings given by education authorities of educating severely deaf and profoundly deaf children. This illustrated that the mean difference in the educational cost for severely and profoundly deaf children is £26,000 over the compulsory school years. Therefore, if profoundly deaf children with cochlear implants were found to be following a similar pattern of educational provision as the severely deaf, the savings in educational costs following implantation could exceed 50% of the cost of providing and maintaining a cochlear implant for the compulsory school years (O'Neill et al, 2000). The present study did indeed find that profoundly deaf children with implants have the same educational placement as severely deaf children. If these changes in educational placement patterns were to be sustained in the long term, it would appear to have significant implications for the cost-effectiveness of cochlear implantation.

The present study compared the educational settings of implanted deaf children with those of aided deaf children at 3 years after implantation, while controlling for the effect of age. However, other factors, such as socioeconomic status, the

presence of other disabilities, and ethnicity, may be different in these groups and may have affected the educational settings of certain children. These factors are difficult to identify, especially in the large numbers of aided deaf children. This first attempt to compare age-matched groups of children must be continued with further studies to assess the educational settings of deaf children at later intervals while controlling for other possible confounding factors besides age.

While the present study has shown a significant trend towards a pattern of mainstreaming for young profoundly deaf children after early cochlear implantation similar to that of children who are severely deaf, other issues may be equally important to the child. A child remains deaf following cochlear implantation, although using the implant may give the functional performance of one less deaf. A child with a cochlear implant in mainstream school continues to need a range of support to ensure full access to the curriculum. This is particularly so as adolescence approaches, when the opportunity arises to discuss identity issues as a deaf teenager wearing a cochlear implant. Without a deaf peer group within the mainstream school, it may be that implanted deaf teenagers will need extra support and access to other deaf teenagers with cochlear implants. Some cochlear implant centres are already meeting this need with summer camps to provide support groups, as teenagers come to terms with the benefits and restrictions that cochlear implantation brings to their lives, and to the decision that others have made for them earlier in their lives.

Although the results of the present study are in line with current government initiatives towards the inclusion of all children with disabilities into mainstream schools, they do not imply that the mainstream is necessarily the most effective educational environment for a deaf child with a cochlear implant or a hearing aid. The goal is not to place deaf children in regular classrooms at all costs, but to choose the most appropriate environment that will help children to achieve their potential. The educational attainments of children with implants must be monitored over the years to come, to investigate the effects of the trend of more profoundly deaf children being placed in mainstream settings.

However, the results of the present study clearly illustrated this trend, which has implications for educators and healthcare providers. Schools for the deaf may have to consider their role with regard to children with cochlear implants; they are likely to have significantly fewer profoundly deaf children as more receive cochlear implants, at increasingly young ages. Some schools are already responding by providing early-years support centres, where young children and their families can

receive intensive specialist support, and later go on to mainstream school, if appropriate. Others are specializing in those children with complex needs who have received implants. In addition, there is an increasing group of children who have received implants early and who have done well in mainstream school at the primary stage. These children may find accessing the curriculum at the secondary stage very demanding and may require more specialist support than can be provided in the mainstream; some schools for the deaf are providing specialist secondary provision. Other deaf schools are providing specialist services to those children with implants who are in their local mainstream school.

It is clear that cochlear implants are enabling more deaf children to go to mainstream school. Educators of the deaf have a responsibility to ensure that they do so with appropriate support, and monitor their functioning there, so that changes of placement are made based on facts rather than philosophy or expectation.

Conclusion

The present study found that profoundly deaf children implanted before beginning school currently have the same pattern of educational settings as aided severely deaf children of the same age in the UK. That is, they are attending mainstream schools in the same proportions as the aided severely deaf rather than aided profoundly deaf. This may have significant implications for the cost-effectiveness of paediatric cochlear implantation and for the future management of profoundly deaf children.

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Chapter 3.3

Approach to communication, speech perception and intelligibility after paediatric cochlear implantation

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S. Gregory

Abstract

The aim of this study was to explore the relationship between approach to communication, speech perception and speech intelligibility after cochlear implantation of young children with profound early deafness. A prospective speech perception and speech intelligibility assessment was undertaken on a consecutive group of implanted children. There were 46 children at the three-year, 26 at the four-year and 20 at the five-year intervals. All had been born deaf or deafened before the age of three and received cochlear implants before the age of seven. Their speech perception ability and the intelligibility of their speech were measured before cochlear implantation and annually thereafter. The children's communication had been classified by their teachers of the deaf at each interval into one of two categories: those using an oral approach and those using a signing approach. Results revealed that at all intervals, those children classified as using oral communication significantly exceeded those using signed communication on measures of speech perception and intelligibility ($p < 0.05$). When those children who had changed from signed to oral communication were compared at the three-year interval with those who used oral communication throughout, there was no significant difference in their results. However, it remains to be explored whether children use oral communication after cochlear implantation because they are doing well, or whether they do well because they are using oral communication.

Introduction

A major aim of cochlear implantation in young children is to promote the development of spoken language. It is anticipated that children receiving implants will use spoken language as either their only or dominant means of communication, or as part of a bilingual system. There are many studies that show that this is possible (Waltzman et al., 1994; Miyamoto et al., 1995; Waltzman et al., 1997; Allen et al., 1998). However, there is still debate about the most effective means of facilitating spoken language after implantation. The choice of language and communication approach for deaf children has long been a matter of debate. A broad spectrum of opinion lies between two extremes: those who believe that all deaf children can communicate through speech, and those who hold that deaf children should have sign language, the language of deaf people, as a first language. Descriptions of communication approaches are inevitably contentious. However, three broad approaches can be distinguished and are currently being used:

- Oral/aural, where only spoken language is used.
- Bilingual, where spoken language and the sign language of deaf people are used.
- Bimodal, often called total or simultaneous communication, where spoken language is used in conjunction with signs.

Where a bilingual approach is used, spoken language cannot be used simultaneously with sign language, since both languages have their own different grammatical structures. In the UK, most educational provision for the deaf uses what is described as a 'total communication' approach, although practice varies widely and there is an increasing interest in the use of bilingualism in education. However, there is little evidence to support greater effectiveness of anyone approach in terms of educational or linguistic outcomes (Powers et al., 1998).

When evaluating outcomes from implantation, approach to communication is one of the factors that has been considered. Miyamoto et al. (1993) found that communication mode did not account for differences in speech perception performance in pre-lingually deaf children. On the other hand, Dowell et al. (1997) found that children in oral/aural settings outperformed those in total communication settings in tests of open-set speech perception. Similarly, Osberger et al. (1998) found that children in oral settings did better than those in total communication settings on auditory tests. Osberger et al. (1994) looked at the speech production of children after cochlear implantation and found that results were better in children from oral settings than those using total communication. Reports on the mode of communication used by children after implantation are inconclusive: Waltzman et al. (1997) found that all children in a group implanted below the age of five were using spoken language as their main means of communication, and were in oral educational settings. However, Tye-Murray et al. (1995) studied 28 young deaf children, who wore implants for at least two years and were in total communication settings, and concluded that children continue to use signing after implantation.

There is no clear picture of an association between available communication approach and functional outcomes from implantation. Moreover, the available studies illustrate the problems associated with most studies on groups of deaf children. These include accounting for the many variables involved, the small samples and comparatively short follow-up period. The present study examines the influence of communication approach on the progress of a large, unselected group of young deaf children. They were from a wide range of educational

settings, with a wide range of communication philosophies and practice. They did not receive intensive rehabilitation from the cochlear implant centre. The aim of the present study was to look at the association between communication approach and speech perception ability and intelligibility.

Method

The children in the study were an unselected consecutive group of children born deaf, or deafened before the age of three, and who received cochlear implants before the age of seven at a specialist paediatric programme. All received the Nucleus-22 cochlear implant. The children were followed prospectively three, four and five years after implantation. Forty-six children were available that had reached at least the three-year interval after implantation, of whom 26 had reached the four-year interval and 20 the five-year interval. No child had been lost to follow-up. The children came from the full range of social backgrounds in the UK, uninfluenced by ability to pay, as the programme is publicly funded. They were from the full range of education settings: mainstream schools, resource or special classes in mainstream school and special schools for deaf children. Some children had not yet started school and were still at home before implantation, receiving support from a visiting teacher of the deaf. Varying communication approaches available in the UK were found within the educational settings. No child was considered unsuitable for implantation due to the nature of local educational support or communication approach in use. Rehabilitation after implantation was primarily in the care of professionals local to the child, whereas use of the system was monitored by the implant centre staff. A naturalistic approach was encouraged as opposed to intensive training in auditory skills following implantation (Archbold and Tait, 1994).

Of the 46 children, 19 were congenitally deaf and 27 had acquired losses. Those deafened before the age of three were included in the study as the literature suggests that there is no significant difference in progress after implantation between these children and those born deaf (Osberger et al., 1991). Mean age at implantation was 53 months (range 30-82 months) and median age of onset of deafness was seven months (range 0-34 months). All children fulfilled the audiological criterion of having sound-field thresholds <60 dB across the speech frequency range, in the best conventionally aided condition. Children were assessed using a range of communication, speech perception and production and educational assessments (McCormick et al., 1994).

It was clear that no one classification would fully describe the diversity of communication approaches being used by the children, their parents and teachers. The authors decided to use the following two broad categories; accepting that they cover a wide diversity of practice.

- Oral/aural approaches; the child was communicating and being educated by means of spoken language.
- Sign communication approach: the child was communicating and being educated using sign for all or part of the day; this included use of spoken English with sign support (total or simultaneous communication).

Only one child in the study was in a bilingual setting, and she moved to a total communication setting soon after implantation. For the purposes of this study, this child was included in the total communication group.

Communication approaches used with each of the children were classified by their cochlear implant teachers of the deaf, in consultation with their own local teacher of the deaf, before implantation and annually after implantation. In this way any changes of communication approach over time were recorded. Children were classified as being in the oral/aural category, for example, if they were taught by use of spoken language and oral communication was used at home, even if signed support was available for other children in the same educational setting. Therefore, it was the communication approach used with, and by, the child that was classified, rather than that available in the school.

The speech perception ability of the children and the intelligibility of their speech were measured before implantation and annually thereafter. Speech perception was measured using three assessments; two of these were performance measures and one was a rating scale. Any child who could not complete a performance test, for whatever reason, scored zero. The rating scale was completed for all children. Closed set speech perception was assessed by use of the IOWA Closed-Set Sentence Test, levels A and B, (Tyler and Holstad, 1987). All children were tested on both levels; Level A has four 2 x 3 matrices and Level B has two 4 x 4 matrices. The sentences were presented without lip-reading cues and the children responded by repeating or pointing out the pictures. Open-set speech perception was assessed using connected discourse tracking (CDT). The children were required to repeat stories read to them phrase by phrase, without lip-reading. The number of words repeated correctly per minute was calculated; a more thorough description can be found elsewhere (De Filippo and Scott, 1978; Tait and Lutman, 1997; O'Donoghue et al., 1998). The rating scale used was

Categories of Auditory Performance (CAP) described by Archbold et al. (1995), which is as an eight-point rating scale developed to measure progress after implantation. Its descriptors range from response and identification of environmental sounds, through identification of speech sounds, phrases, conversation to being able to converse on the telephone. It has been found to have high inter-user reliability (Archbold et al., 1998). Speech intelligibility was rated by the implant centre speech and language therapist by use of the Speech Intelligibility Rating (SIR) measure (Dyar, 1994; Allen et al., 1998), which was developed to rate changes in speech intelligibility over time. The SIR includes five categories: intelligible to all, intelligible to a listener with little experience, intelligible to an experienced listener, unintelligible and pre-recognizable words in spoken language. It is scored by the child's speech and language therapist at each interval, according to specific criteria.

Student's *t* test was used for statistical comparison of variables that were continuous and normally distributed. When one of the distributions did not meet these criteria the Mann-Whitney U test was used. Statistical significance was accepted at the 0.05 level of probability.

Results

The outcomes on the five measures are compared in tables 1, 2 and 3. All the statistical comparisons were significant ($p < 0.05$) and in favour of children using oral communication at the assessment interval.

Table 1. Results of 36 months comparing those using signed communication (S) (N=24) with those using oral communication (O) (N=22)

Test measure	Mean results		Median results		P
	S	O	S	O	
SIR (1-5)	2.3	3.1	2	3	0.0004
Iowa A (%)	81	85	97	100	0.01
Iowa B (%)	30	61	0	90	0.02
CDT (wpm)	16	33	0	38	0.008
CAP (0-7)	5	5.8	5	6	0.0006
Age at implantation (months)	60	47	55	43	0.0004

P = level of statistical significance; SIR = Speech Intelligibility Rating (Allen et al., 1998); Iowa (A and B) = Iowa closed-set Sentence Test (Tyler and Holstad, 1987); CDT = connected discourse tracking; CAP = Categories of Auditory Performance (Archbold et al., 1998).

Table 2. Results at 48 months comparing those using signed communication (S) (N=10) with those using oral communication (O) (N=16)

Test measure	Mean results		Median results		P
	S	O	S	O	
SIR (1-5)	2.7	3.7	3	4	0.0006
Iowa A (%)	64	94	95	100	0.005
Iowa B (%)	35	92	0	98	0.002
CDT (wpm)	19	44	14	43	0.007
CAP (0-7)	5.2	6.1	5	6	0.006
Age at implantation (months)	63	45	62	43	0.0004

P = level of statistical significance; SIR = Speech Intelligibility Rating (Allen et al., 1998); Iowa (A and B) = Iowa closed-set Sentence Test (Tyler and Holstad, 1987); CDT = connected discourse tracking; CAP = Categories of Auditory Performance (Archbold et al., 1998).

Table 3. Results at 60 months comparing those using signed communication (S) (N=7) with those using oral communication (O) (N=13)

Test measure	Mean results		Median results		P
	S	O	S	O	
SIR (1-5)	2.5	4.3	3	4	0.001
Iowa A (%)	71	100	100	100	0.01
Iowa B (%)	41	92	0	100	0.005
CDT (wpm)	25	55	21	61	0.05
CAP (0-7)	5.3	6.4	5	6	0.02
Age at implantation (months)	56	44	52	42	0.03

P = level of statistical significance; SIR = Speech Intelligibility Rating (Allen et al., 1998); Iowa (A and B) = Iowa closed-set Sentence Test (Tyler and Holstad, 1987); CDT = connected discourse tracking; CAP = Categories of Auditory Performance (Archbold et al., 1998).

Iowa Closed-set Sentence Test

There is the problem with the IOWA Closed-set Sentence Test of floor and ceiling effects; however, the extent of completion of A and B tests reveals differences between the oral and signing groups. Before implantation all children could not perform the test and scored 0 in both groups. Three, four and five years after implantation, the scores on test A were statistically higher in the oral group (median 100% at all intervals) than in the signing group (median 95-100%), although the medians are only slightly different. However, the results of Test B reveal much greater differences between the two groups. The median was 90-100% in the oral groups and uniformly zero in the signing groups at all intervals. The more difficult (B) version of the test can be attempted by most children in the oral group at three years after implantation (median 90%) when the median score

of the signing group was zero. Of the children who have reached the five-year interval (N = 20), the median score of the oral group (N = 13) was 100%, whereas that for the signing group (N = 7) was zero.

Connected discourse tracking (CDT)

CDT is a demanding task for both groups. Before implantation all children could not perform the test and scored 0. For children using signed communication, it remained a difficult task at all intervals. At five years after implantation, the median score of the children using signed communication was 21 words per minute (wpm), a low score indicating difficulty in following connected speech without lip-reading. The median score of the oral group was significantly better ($p < 0.05$) at 61 wpm at the five-year interval.

Categories of Auditory Performance (CAP)

Before implantation all children were in category 0 except from one child in the total communication group who was in category 1. At the followup intervals the median score of the children using oral communication was one category higher than that of those children using signed communication. The median score of each group remained constant from three years after implantation: understanding common phrases without lip-reading (category 5) for the children in the signing group and understanding conversation without lip-reading (category 6) for the children in the oral group.

Speech Intelligibility Rating (SIR)

Before implantation all children in the total communication group were in category 1, except from one child who was in category 2. In the oral communication group all children were in category 1, except two children who were in category 2, and one child who was in category 3. This small difference was not statistically significant. At the follow-up intervals, the median SIR of the oral group was one category higher than those using signed communication and these differences were statistically significant. At five years after implantation, the median of the oral group was category 4 (intelligible to a listener with little experience), whereas that of the signing group was category 3 (intelligible to an experienced listener).

A simple analysis seems to indicate that children using oral communication do better on these measures than those using signed communication. However, the

children were categorized by the communication mode used by each child at each interval, with no regard to any change in communication approach over time by that child. From tables 1, 2 and 3 it may be seen that the proportion of children in the oral group increased over time, due to changes in the communication approach. Children may be changing communication approach as a consequence of changing performance, adding circularity to the analysis. Rather than performance being consequent on approach, the approach used could be an outcome of the child's performance. To investigate this further, the children using oral communication at the 36-month interval were each assigned to one of two groups; one group (N = 12) had been using oral communication throughout (oral group O), and the other group began using signed communication and had moved to using oral communication (changed group C) (N = 10). For the changed group, one child had changed in the first year after implantation, five in the second year and four in the third year. Table 4 shows these children at the 36-month interval (N = 22). Mean age at implantation of the two groups was not statistically different (50 months and 42 months in the oral and changed groups, respectively). When the two groups were compared on the five outcome measures, at 36 months after implantation, none of the comparisons between the two groups was statistically significant. Furthermore, any differences (Table 4) were very small and observable in both directions between mean values or medians.

Table 4. Results at 36 months in the oral communication group only; comparing those those using oral communication throughout (O) (N=12) and those changed from signing to oral communication (C) (N=10)

Test measure	Mean results		Median results		P
	O	C	O	C	
SIR (1-5)	3.2	3	3	3	NS
Iowa A (%)	81	89	100	100	NS
Iowa B (%)	66	56	90	84	Ns
CDT (wpm)	26	42	35	42	NS
CAP (0-7)	5.8	5.8	6	6	NS
Age at implantation (months)	50	42	44	42	NS

P = level of statistical significance; NS= Not Significant; SIR = Speech Intelligibility Rating (Allen et al., 1998); Iowa (A and B) = Iowa closed-set Sentence Test (Tyler and Holstad, 1987); CDT = connected discourse tracking; CAP = Categories of Auditory Performance (Archbold et al., 1998).

A small group (four children) transferred from using oral to use of signed communication during this period. The performance of these children was considerably poorer than children using oral communication, or children who started using a sign approach and changed to oral, although no statistical

comparison can be made in such a small group. All these children had known additional learning difficulties which would affect speech perception and intelligibility. However, it was also considered that two were moved partly due to changes in local educational philosophy.

Age at implantation is known to be a strong predictor of outcome (Dowell. et al., 1997; Fryauf-Bertschy et al., 1997; Nikolopoulos et al., 1999; Nikolopoulos et al., 2000). Average age at implantation of the children in the signing category at each interval, was significantly higher than that of the oral group, and it could be argued that this was the reason for the results. In order to minimize the effects of age at implantation, the group of children was limited by selecting only those children receiving cochlear implants at the age of four or less. In these young implanted children, regression analysis was used to find that better CDT and CAP results at 48 months were still significantly associated with the oral communication approach, whereas age at implantation and age of onset of deafness did not have any statistically significant association with the outcome. With regard to Iowa Sentence test, the distributions were not normal and, therefore, regression analysis was not applicable. Regression analysis of the SIR outcomes showed that the associations with the previously mentioned factors did not reach statistical significance, probably due to small numbers.

Discussion

At each yearly assessment interval, those children who were using oral communication outperformed those who were using signed communication, on the five measures of speech perception and intelligibility that were used and the differences were all statistically significant.

Although other studies (Dowell et al., 1997; Osberger et al., 1998) have shown improved scores for children in oral settings, no other study has investigated the changes in communication approach over time; other studies have tended to assume that oral and signing groups remain fixed. The present study underlined the fact that communication approach may change for some children over time. It also revealed that those children who begin using oral communication and continue to do so and those children who begin using signed communication and change to oral communication do equally well on the measures used.

Of the 46 children, 30 began using signed communication. Ten of these changed to oral communication in the first three years. We need to consider whether these children transfer from signed to oral communication on the basis of developing

spoken language, or whether they move on the expectation of it; whether the change was the cause, or result, of developing spoken language skills. These children may develop spoken language because of well-developed underlying communication skills before implantation, or because of educational and parental management and expectations. It could be argued that the communication approach changed for these children before they developed spoken language, because they had received an implant, and based on expectation of parents and professionals. However, looking at the ten children who changed from sign communication to oral communication, the majority (nine) had changed following progress with the implant in the development of spoken language, in the opinion of their teachers of the deaf. It would be worth exploring the educational settings of these children further, to investigate how they facilitated the development of spoken language and on what judgements change of communication approach was made. However, we do not know whether the children who have not changed had the opportunity to change approach to oral communication if appropriate, or whether local factors would not permit such a change. It may be difficult for local educators to provide flexibility of approach to meet the varied needs of their pupils in a low incidence disability such as deafness.

This study only used measures of speech perception and production and it may therefore seem unsurprising that those using oral communication do better than those using signed communication. However, these outcome measures are pertinent since the major aim of implantation is to provide access to spoken language which was not possible for that deaf child before implantation. The aim of all communication approaches is to develop English skills; whereas for oral approaches, speech intelligibility and spoken English will be a major goal, for signing approaches, English development remains a major aim and is not neglected. For all the children in this study, the signing approach used was that of Sign Supported English rather than bilingualism. Children receiving cochlear implants may be in signing or oral approaches, with or without the possibility of change. The issue arises as to whether either or both of these approaches do promote the development of spoken English, as assessed by these measures. The finding that those who changed communication approach do as well as those using an oral approach consistently could be taken to support the view that early (pre-implant) signing is not a disadvantage to developing later oral skills. The work of Tait et al. (2000) showing that the quality of pre-implant communication as measured on video analysis is a predictor of later speech perception and production, and is regardless of whether it is vocal or gestural communication, seems to support this view, as does the work of Yoshinaga-Itano (2000) where the age of

the intervention was the crucial factor in later language outcomes in young deaf children (with cochlear implants or hearing aids) rather than the communication approach chosen at that stage.

Attempts to relate communication approach and educational attainment have been inconclusive (Powers et al., 1998), and it would be useful to follow these and larger groups of children and their educational attainments over a longer period of time. Other measures of language and educational attainments need to be compared within these groups to ensure that the development of speech perception and intelligibility of spoken language has not been at the expense of linguistic and educational development.

The results of the present study imply that the communication needs of children may change after cochlear implantation; the influences on both choice of communication approach and educational placement need further investigation. It is not yet known what are the significant factors determining initial placement and influencing changes. Performance, local policy, parental expectations are worthy of investigation and further data continues to be collected in these areas.

Conclusion

The present study revealed that, on measures of speech perception and intelligibility obtained three, four and five years after implantation, children using oral communication outperformed those using signed communication. There was no significant difference between the performances of those children who had always used oral communication and those who changed from use of sign to oral communication over the time period. Thus, the question remains as to whether it is the oral approach that results in better performance, or whether children use oral approaches because of their better performance.

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Chapter 3.4

Children's communication mode five years after cochlear implantation: changes over time according to age at implant.

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Abstract

One hundred and seventy six children who had received cochlear implants at one centre in the UK were followed up for five years post-implant. The cohort was divided into three groups by age at implant. 1: Under three years of age; 2: Between three and five; 3: Over five. Their mode of communication was noted at four key intervals –pre-implant; 1, 3 and 5 years post-implant. It was classified as either oral or sign. By five years post-implant, 83% of group 1 were using oral communication, 63.5% of group 2 and 45. 1% of group 3. The results showed that the mode of communication five years post-implant is statistically related to age at implantation with more children implanted younger using an oral mode of communication ($p=0.001$). Children implanted younger are more likely to change communication mode over time from sign to oral, and do so more quickly than those implanted later.

Introduction

Cochlear implants provide deaf children with access to spoken language via hearing and hence facilitate the development of spoken language. Over the past 20 years, their use has become increasingly widespread and a cochlear implant is now an accepted option for profoundly deaf children. This means that there is now a sizeable cohort of children who have had a cochlear implant for several years and there have been many research studies assessing their progress.

A major focus of these studies into the efficacy of cochlear implantation has been the development of spoken language. It has been shown that deaf children with cochlear implants may develop spoken language at a faster rate than children with hearing aids (Svirsky et al. 2000). The single most important factor in determining successful development of spoken language after implantation seems to be age at implantation; the younger a child is implanted, the more likely they are to be able to understand spoken language and to use intelligible spoken language for every day communication (Nikolopoulos et al 1999,2000; McDonald Connor et al 2000.; O'Donoghue et al. 2000).

An ongoing debate exists as to whether children who have received cochlear implants perform better in an oral environment or one in which sign is used. A review of the research into outcomes from cochlear implantation in children (Thoutenhoofd et al. 2005) found that, in spite of the amount of research in this area, there was still a great deal of controversy as to whether implanted children

do better in an oral approach or an approach using sign. This may refer to sign used in conjunction with speech (total or simultaneous communication) or a sign language such as British Sign Language (BSL) being used as the child's first or primary language, with spoken or written English being introduced as a second language. Some studies report no difference in outcomes for oral settings or those using sign: McDonald Connor et al. (2000) found no difference in speech perception or production performance in 147 implanted children and McConkey Robbins et al. (1997) reported roughly equivalent outcomes for 23 cochlear implanted children.

Where a difference is reported it is in favour of oral settings. Osberger et al. (1998) observed that 19 cochlear implanted children in oral settings were significantly outperforming 11 cochlear implanted children in settings using sign (in this case total or simultaneous communication). Miyamoto et al. (1999) found significant effects of communication mode in favour of oral settings in results in speech perception and speech production assessments, and on the Reynell Developmental Language Scale (RDLs). Cullington et al. (2000) found that oral subjects demonstrated significantly less spoken language delay than did subjects using total communication, based on speech perception scores only; speech production scores were not significantly correlated with communication mode. Geers et al. (2000) concluded for 31 cochlear implanted children that those enrolled in programmes reliant on spoken language were better able to derive auditory benefit from their cochlear implant than those in settings that included the use of sign, although the oral and signing groups had different levels of support. Geers et al. (2002) reported a study including 136 8- to 9-year-olds, and concluded, following elaborate multivariate analysis, that an oral approach is the better option for children with cochlear implants. Kirk et al. (2002) reported that oral children made significantly more rapid gains in communication abilities than children who used total communication.

The assumption is generally made that the communication approach of the child is static and does not change over time after implantation, although Spencer (2004), in her study of individual differences in language performance after cochlear implantation at 1 to 3 years of age, found that three out of the 13 children considered changed from classrooms using one kind of language system to another. Of these three, one changed from Signed English to oral, one from oral to Signed English and the third from Signed English to bilingual. These changes presuppose a change in the child's communication use following cochlear implantation. Geers and Brenner (2003) reported changes in educational placement as children gained experience after implantation. The reported changes

were to settings with an increased emphasis on speech and audition. Although the paper did not investigate children's use of communication, it may be inferred from the change in educational placement towards an increased emphasis on speech that this change was accompanied by a change in the child's communication use. However, this was not made explicit. This paper investigates the issue of children's change in communication approach by considering the patterns of communication use during the first 5 years after implantation in children of different ages who have received a cochlear implant at the Nottingham Cochlear Implant Programme. Data on communication use are collected annually on children who have received a cochlear implant at this programme. Teachers of the deaf on the implant programme gather information from the child's teacher and parent, and from direct observation at home and school.

Method

Design and subjects

Data on all paediatric subjects in the Nottingham Cochlear Implant Programme who had been in receipt of a cochlear implant for at least 5 years were analysed to investigate two questions:

- Is there a correlation between age at implant and the child's communication mode 5 years post-implant?
- Do children change their communication mode during the 5 years post-implant, and if so what is the nature of the change and is it related to age at implant?

The Nottingham Cochlear Implant Programme is not selective with regard to intellectual ability or aetiology of deafness, accepting candidates with the full range of intellectual ability, including children with learning difficulties, and with a wide range of aetiologies. There are now also a number of deaf children of deaf parents. As the programme draws candidates from throughout the UK, it receives children from the full range of demographic areas and social and linguistic backgrounds. It also draws candidates from the range of educational settings and communication approaches used with deaf children in the UK. Thus some children are from educational services that advocate an oral approach to communication, others from services that advocate a combined oral and signing approach (frequently referred to as total communication) and some from services where a

sign bilingual approach is advocated, with BSL used as the child's first language and English taught as a second language. The children do not receive intensive habilitation from the implant centre, but support after implantation is largely carried out by the child's local professionals, and covers a range of philosophies and practices.

Longitudinal data in a range of domains and outcomes have routinely been collected on all children who have been implanted in the Nottingham Cochlear Implant Programme since the inception of the programme. At the time of data collection, 450 children had been implanted in Nottingham and the programme's rigorous follow-up and outreach programme mean that only a few children are lost to follow-up, for example if they have emigrated, and that there is now a sizeable cohort of children who have been implanted for a considerable period of time. These children and their data provide a unique resource to use in exploring their methods of communication and investigating the factors that facilitate the development of spoken language after implantation. At the time of data collection, there were 191 children who had had a cochlear implant for at least 5 years, and complete data were available for 176. Data for the other children were incomplete for different reasons: some of them emigrated or moved to be managed by another implant centre and were therefore no longer available for follow-up, others had device problems or failures and therefore data at the specific intervals could not be collected. The mean age at implantation was 4;8 years and the median 4;2 years. There were 90 female and 86 male children. Aetiology of deafness was meningitis for 54 (31%) children, cytomegalovirus (CMV) for nine (5%) children, syndromic for eight (4%) children, congenital deafness of unknown cause for 93 (53%) children and various other causes for 12 (7%) children. All children but one received the Nucleus multichannel cochlear implant system; one child received the Med-El extra-cochlear device. This child was excluded from further consideration since it was decided that the child's experience of sound would be likely to be very different from that of the other children. This left a cohort of 175 children for investigation.

The longitudinal data were interrogated to uncover the pattern of children's communication mode during the 5-year period immediately post-implant. Communication mode was classified by the child's cochlear implant teacher of the deaf, in consultation with the local teacher of the deaf. It was based on observations of the child's communication at home and school by the implant centre teacher of the deaf, local teachers and parents. Two broad categories were used to classify children's communication approach: oral communication and

signed communication. This follows the pattern established by Archbold et al. (2000), in which these are categorized as follows:

- Oral communication approach: the child was communicating at home and school and being educated by means of spoken language.
- Sign communication approach: the child was communicating and being educated using sign for all or part of the day and to whatever degree; this included use of spoken English with sign support (total or simultaneous communication) and the use of BSL (Archbold et al. 2000).

The information collected related to the communication approach used with, and by, the child. Thus, where a child was in an education setting where signed support was offered to other deaf children but not to the child in question, that child was classified as being in the oral group. A minority of the children (5/175) were using a sign bilingual approach (that is, BSL without the simultaneous use of spoken English). For the purposes of the study, they were included within the 'sign communication approach' group alongside those using spoken English with sign support. The authors accept that the two categories both cover a wide diversity of practice, but they are sufficiently precise to differentiate between those children who use spoken language and those who use sign, either as a language or in conjunction with spoken language. They also permit the possibility of identifying when a child changes from one broad category of communication approach to the other.

The data from all the subjects who had had a cochlear implant for at least 5 years were included. No subject was excluded from the study on grounds of intellectual ability or aetiology. The cohort of 175 children was divided into three groups, according to age at implant: Group 1, those implanted prior to their third birthday (n=29); Group 2, those implanted between their third birthday and their fifth birthday (n=85); and Group 3, those implanted after their fifth birthday (n=61). Different ages for discussing outcomes are to be found in the literature on paediatric cochlear implantation. Age five is commonly used, e.g. Geers et al. (2003) and Kirk et al. (2002). This corresponds with the age at which children in the UK commence school, thus dividing at this age distinguishes between those children who have entered full-time education and those who are preschool, so forms a natural divide. When the under-5 group is further divided, examples in the literature make the division at age 3 (e.g. Kirk et al. 2002). In the study by Kirk et al., it was found that children who were implanted prior to age 3 showed significantly faster rates of language development. Some studies, for example Hammes et al. (2002) have considered children implanted by 18 months, and as

earlier implantation becomes more widespread it is likely that more studies will consider children who are implanted at a very young age. For this study, it was decided to consider children implanted prior to their third birthday, in keeping with other studies as discussed above.

Communication approach used by and with each child was investigated before implantation and at 1, 3 and 5 years after implantation, and changes over time analysed. The Chi-squared test was used for the statistical analysis of the data. Statistical significance was accepted at $p < 0.05$ level.

Results

Communication approach 5 years after implantation

The mode of communication 5 years after implantation was investigated for the whole cohort of 175 children. For the whole cohort, 106 children (61%) were using oral communication 5 years post-implant. However, there was considerable variation over the three groups. In group 1 (those implanted prior to age 3) 24/29 subjects (83%) were using oral communication. Group 2 (those implanted between ages 3 and 5) 54/85 subjects (63.5%) were using oral communication; and in Group 3 (those implanted over 5) 28/61 subjects (46%) were using oral communication (figure 1).

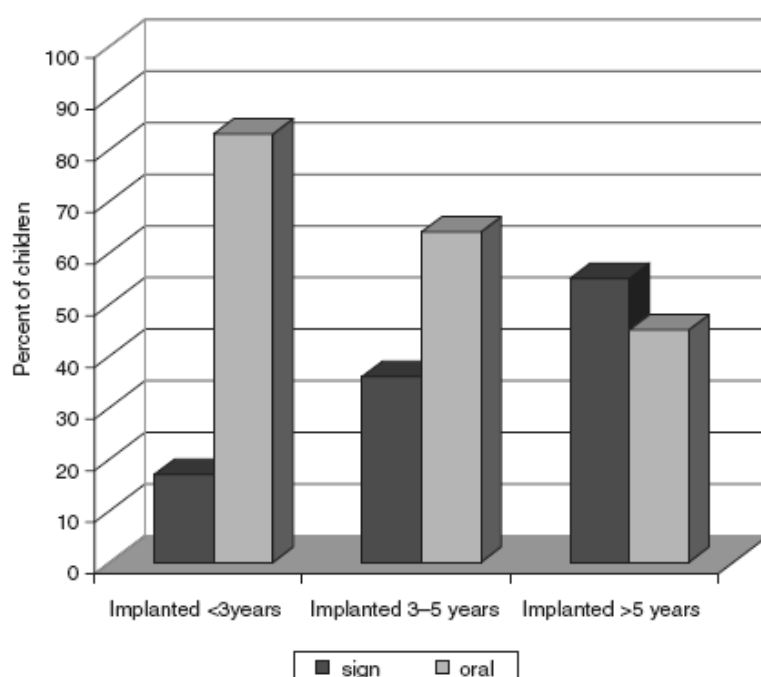


Figure 1. Mode of communication 5 years following implantation in percentages

The results for the whole cohort using the Chi-squared test showed that the mode of communication 5 years after implantation was statistically related to age at implantation, with more children implanted younger using an oral mode of communication ($p=0.001$). The difference between Groups 1 and 3 (those implanted under 3 and those implanted over 5) was statistically significant ($p=0.001$), as was the difference between Groups 2 and 3 (those implanted between 3 and 5 and over 5) ($p=0.04$), but the difference between Groups 1 and 2 was not significant.

Trends in communication approach during the 5 years after implantation

The data were also analysed to uncover trends in mode of communication during the 5 years after implantation (Figure 2). Many subjects changed their mode of communication from sign to oral during this time. Again there were found to be differences between the three groups. In the under-3 cohort ($n=29$), 26 children (90%) were using sign and three (10%) were using oral communication pre-implant, but by 5 years after implantation 24 (83%) were using oral communication and five (17%) were using sign. No child in this group changed from oral to sign, and 21/26 (81%) children who were using sign pre-implant switched communication mode from sign to oral during the 5-year period.

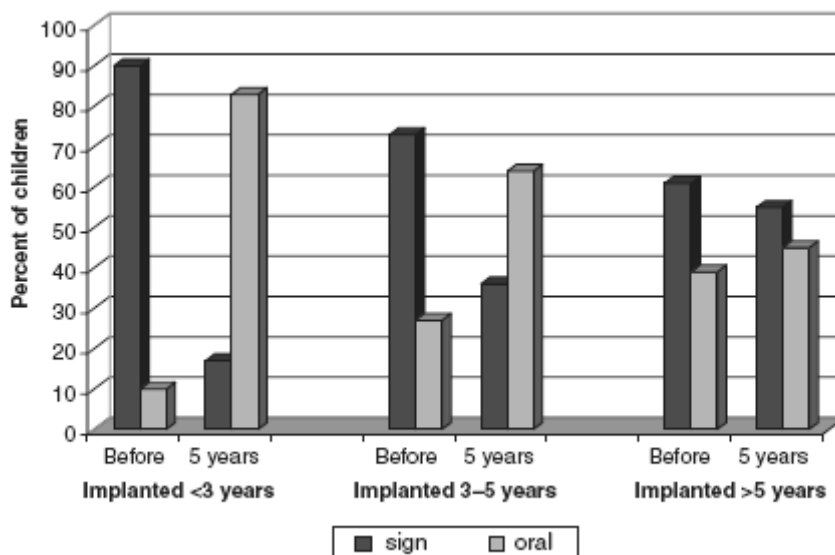


Figure 2. Mode of communication before and 5 years following implantation in the three groups of children: those implanted prior to their 3rd birthday; those implanted between the ages of 3 and 5; and those implanted after their 5th birthday.

A similar but less-marked trend was found in Group 2 (those implanted between ages 3 and 5). In this group (n=85), at the pre-implant stage 62 subjects (73%) were using sign and 23 subjects (27%) were using oral communication. By 5 years after implantation, 31 children (36%) were using sign and 54 children (64%) were using oral communication. There were 36/62 children (58%) who changed communication approach from sign to oral during the 5-year period. However, 5/23 children (22%) who were using oral communication pre-implant changed to using sign during the 5-year period.

The subjects in Group 3 (those implanted over age 5) did not show the same tendency to switch to oral communication. Pre-implant, 24 children (39%) were using oral communication and 37 (61%) were using sign. By 5-years post-implant, 28 children (46%) were using oral communication and 33 (54%) were using sign. Six children switched from sign to oral communication from this group and two children switched from oral to sign. Also included in the group were five children whose mode of communication changed more than once (for example sign to oral then back to sign) during the 5-year period after implantation.

Changes in communication approach over time

Table 1 gives the full data showing communication approach being used by the three groups before implantation, 1, 3 and 5 years after implantation. This illustrates that changes take place over time in communication mode.

Table 1. Percentages of children using oral or sign communication mode before implantation and 1, 3, and 5 years after implantation.

	Pre-implant		1 year		3 years		5 years	
	Oral	Sign	Oral	Sign	Oral	Sign	Oral	Sign
Group 1 (n =29)	10	90	31	69	72	28	83	17
Group 2 (n = 85)	27	73	29	71	51	49	64	36
Group 3 (n = 61)	39	61	44	56	47	53	46	54

Group 1: children implanted < 3 years old; Group 2: children implanted between 3 and 5 years old; Group 3: children implanted > 5 years old

In Group 1, children who changed communication approach were most likely to do so between 1 and 3 years after implantation. Very few children changed during the first year (4/21; 19%). The majority of children (14/21; 67%) changed between 1 and 3 years after implantation and a further three children (14%) changed between

3 and 5 years after implantation. Over time, all changes were from sign communication to an oral approach.

In Group 2, 36 children (58%) changed from sign communication to an oral approach. As with the younger children, only a minority changed during the first year (4/36; 11%), and the majority of those who changed did so between 1 and 3 years post-implant (21/36; 58%). However, a further 11/36 (31%) changed from sign to oral between 3 and 5 years after implantation, as compared with 14% for the younger children at this stage. There were five children in this group who changed their communication approach in the opposite direction, from oral to sign, during the 5 years post-implant. Looking at these five children, who constituted 22% of the oral children in Group two before implantation, two children changed during the first year, another two changed between 1 and 3 years, and one child changed between 3 and 5 years after implantation.

In Group 3, those implanted at over 5 years of age, only six children changed towards oral communication, one in year 1, three between 1 and 3 years after implantation and two children between 3 and 5 years after implantation. Two children changed from oral to sign; one changed during the first year and the other changed between 1 and 3 years after implantation.

Discussion

The aim of cochlear implantation is to provide children with access to spoken language through hearing. Where a child uses spoken language, then the cochlear implant must have fulfilled its aim of providing such access. These results demonstrate that children who receive a cochlear implant at the Nottingham Cochlear Implant Programme are likely to use oral communication by 5 years post-implantation, since this obtained for 60% of the whole cohort. The use of oral communication shows a correlation with age at implant, with those implanted younger more likely to change from using a sign approach to an oral approach.

Group 1 (those implanted under age 3) were most likely to use oral communication by 5 years after implantation (24/29; 83%). This was independent of communication mode pre-implant. Since 21/26 children (81%) changed from sign to oral, it could be argued that choice of communication mode pre-implant is not a significant factor in predicting communication approach 5 years after implantation. Only three children were using oral communication pre-implant and all three continued to use spoken language by 5 years after implantation.

Children in Group 1 who changed communication approach were most likely to do so between 1 and 3 years post-implant, rather than earlier. In this age group it may take a considerable length of time to tune the implant system, and then it is recognized that children require a period of time to use sounds meaningfully. Evidence of progress in the first year may not be readily apparent. Although it is anticipated that children will be able to recognize their name without lip-reading by 1 year after implantation (Nikolopoulos et al., 2000), this may not be sufficient access to spoken language for a child to switch communication mode in favour of using oral communication. The majority of children changed between 1 and 3 years after implantation, with a few others changing by 5 years after implantation. Thus, if a child receives a cochlear implant under the age of 3 and continues to use sign 3 years after implantation, then the likelihood is that they will continue to use a signed approach rather than changing to oral communication.

Parents of young deaf children are faced with many choices. One is the decision about assessment for cochlear implantation and another is the choice of communication approach for their child. These are difficult choices for parents and in order to make an informed choice they need details of likely outcomes. From these results parents could conclude that if they use speech and sign with their young deaf child, the majority will use oral communication later. This is in keeping with findings that it is the quality of communication pre-implant that predicts later progress, rather than the mode of communication (Tait et al. 2001). However, 19% of those children implanted younger continued to use sign, demonstrating that not all children will make this change. The small number of children in this group who were classified as oral prior to implant continued to use oral language afterwards.

The question of whether a child's communication approach changes during the first 5 years after implantation is an important one to investigate for several reasons. First, it is of relevance to parents who are considering implantation for their young deaf child and to educationalists/therapists involved in early intervention in families with a young deaf child. If a child's communication approach remains fixed and does not change following cochlear implantation, then parents who choose a cochlear implant for their deaf child in order to enhance the child's access to spoken language will need to use oral communication with their child prior to implantation. Professionals involved in advising families who have chosen to pursue a cochlear implant for their child will need to bear this in mind and counsel parents to use spoken language to their child. However, if following cochlear implantation, a child can change their communication approach then parents can be supported in choosing whether to use spoken language exclusively

with their deaf child or whether to introduce some sign in addition to spoken language. Archbold et al. (2002), in a small study of 46 children, showed that there was no significant difference in speech perception and production 3 years after cochlear implantation between those children who had oral provision before and after implantation, and those who began with a signed approach and changed to oral communication during the 3 years, although the numbers were relatively small. It appeared that it was possible for children to change communication approach successfully after implantation and to develop oral communication. This finding requires to be investigated on a larger scale as it clearly has implications regarding communication choice in families with young deaf children and expectations after implantation. The latter in turn has implications for educational placement of children with cochlear implants and the provision that will need to be made for them.

Children who are implanted between the ages of 3 and 5 years are also likely to use oral communication by 5 years after implantation (54/85 children, i.e. 63.5%). However, this percentage is not as high as for the younger age group. At implant, 62/85 (73%) children used sign. Of this group, 36 (58%) changed to oral communication during the 5 years after implantation. As with the younger children, only a minority changed during the first year and the majority of those who changed did so between 1 and 3 years after implantation. However, a considerable percentage (31%) did change between 3 and 5 years after implantation. Thus for children implanted between the ages of 3 and 5, it is less safe to assume that, if they have not changed their communication approach from sign to oral by 3 years after implantation, then they are unlikely to do so. There are several possible reasons why the change may take longer. First, there are the issues related to sensitivity of the central nervous system and neural plasticity. While the effects that deafness may have on neuronal connectivity within the auditory pathway have yet to be defined, neural plasticity of the brain in infants has been discussed when considering early implantation (Hehar et al. 2002). It seems that those implanted over the age of 3 may need more time to adjust to the new signal being received, and are less likely to change from a signed approach to an oral approach, and some who do change are likely to take longer in comparison with those implanted at an earlier age.

A second possible reason why these children could take longer to change is that their communication pattern will be more firmly established. Congenitally deaf children in this group will have spent at least 3 years with only very limited access

to sound, if any, and will have learnt to use vision as their primary or sole route to communication. In order to change from the use of a visual system, which utilizes a sense that for the majority is unimpaired, the auditory signal will need to become the more salient route for communication. The fact that for some children this is a process after implantation, which continues over years, rather than months (for example Tait et al. 2001).

A third factor that could have a bearing relates to the fact that these children would either have already started school prior to the implant or they would have entered school within approximately a year of the implant being tuned.

Communication approach and school placement

The question of the relationship between school placement and communication approach used with and by children with cochlear implants is not straightforward, and merits consideration. It has been found that cochlear implantation is affecting patterns of school placement (Archbold et al. 2002). Children who have received a cochlear implant prior to school entry are more likely to be placed in a mainstream setting or a unit or resource base than in a special school for the deaf. The child's communication approach would be considered as one factor in the decision regarding school placement. For children who were implanted between the ages of 3 and 5 who used sign when they started school, their placement would have made provision for this. Staff working with the child would have provided signed input in order to facilitate communication and might have continued to use sign at a stage when the child was able to process information auditorily and was in transition to showing a preference for oral communication. Once a child starts school, there is a pressure on educationalists to ensure that the child accesses the curriculum. The emphasis must be on teaching and ensuring that the child has grasped significant concepts and accessed information. If the child's language development is delayed compared to their hearing peers, then the pressure to ensure that the child can access the curriculum will be increased. Staff may have less time available to spend in promoting the child's listening skills, either in a global way by encouraging the child to listen and presenting auditory cues first, followed by visual cues as necessary, or by engaging the child in discrete listening activities. It is also possible that the expectations of staff, maybe born out of experience of profoundly deaf children with hearing aids, are that children who start to use sign do not change, whereas in reality cochlear implants differ from hearing aids in that they surgically alter the potential to hear spoken language, and over time this may change the child's communication use. The important finding

from this study is that, despite the fact that they were being educated in a setting where sign was used, children implanted between the ages of 3 and 5 still changed from sign to oral communication. The findings of this study challenge expectations regarding longer-term communication approach and therefore have implications for the need for flexibility in educational provision.

While it proved to be the case that 36/62 children (58%) who were implanted between the ages of 3 and 5 changed from sign communication to oral during the 5 year period, 26 children (42%) who used sign pre-implant, did not change. All children at the Nottingham Cochlear Implant Programme receive ongoing individual assessment of their progress following implantation. While their use of communication mode is monitored, they are not pressured to use oral communication. For many children, the implant may provide useful additional input or function as an aid to lip-reading, but it may not result in a change in their communication mode towards an oral approach. This fact is discussed with parents prior to implantation. In a minority of cases (5/23; 22%) the child changed communication approach from oral communication to sign communications. This illustrates the fact that, while access to spoken language is a primary aim of cochlear implantation, it is communication, regardless of mode, that is the main consideration in relation to the development of individual children and for a minority of children this will mean a change from oral to sign.

The third group, those implanted over the age of 5, showed a different pattern of communication approach after implantation. These children were likely to continue to use the same communication approach as pre-implant. Only six children changed towards oral communication: one in year one, three between 1 and 3 years after implantation and two further children between 3 and 5 years after implantation. Two children changed from oral communication to sign communication.

When a child is older at the time of implant, different considerations may be taken into account. Their communication mode will be well established and their educational placement will be settled and unlikely to change (Archbold et al. 2002) compared with younger children. Where these children have had very little access to audition, for a period of some years in cases of congenital deafness, the chances of the implant providing sufficient access to spoken language for them to change communication approach are remote, bearing in mind the comments made above in relation to neural plasticity. It could be seen as unusual that any children

of this age changed from sign communication to oral communication. In these cases, the auditory signal from the implant may have provided easier access to spoken language, although numbers are too small to draw firm conclusions.

A much higher percentage of this age group (24/62; 39%) used oral communication prior to implant. One reason for considering a cochlear implant for a child in this age group is in a case of a progressive hearing loss, where a child is using some residual hearing well and is already using an oral approach. In the case of a progressive hearing loss, a child may have well-established spoken communication, but as the hearing deteriorates their access to spoken language via hearing aids becomes increasingly compromised to the point where a cochlear implant may offer more benefit. Other children in this age group may have been assessed for a cochlear implant when they were younger and not met the criteria that pertained at the time, but changing criteria mean that they are now considered suitable cases for implant. Thus, the fact that a child was using oral communication could have been an important consideration in the referral and assessment process, and in the decision to proceed with implantation.

With respect to education, for children in this group (implanted over age 5) who used sign communication, the education setting would have been selected with this in mind. Children are likely to be settled into an educational placement in which they were accessing the curriculum through sign, and change would be regarded as a big risk for their educational progress, and therefore unlikely to occur.

The fact that some children in the study from Groups 2 and 3 changed their communication approach from oral to sign during the 5 years after implantation appears initially to be an unexpected finding, given the fact that a primary aim of cochlear implantation is to promote the development of spoken language. As already discussed, many children did change their communication approach from sign to oral, a change which is in keeping with the aim of implantation. The progress of all children in the Nottingham Cochlear Implant Programme is monitored at regular intervals. Where children who are using an oral approach are found to be making inadequate progress in the development of listening skills, speech reception or production, or are deemed to be struggling to access the curriculum, then discussions and further investigations are held and reasons for the lack of progress are sought. These investigations may result in changes being made to the child's map and ways of promoting use of the implant may be exploited. In a minority of cases, the conclusion may be that the child would benefit from the introduction of sign. This is not seen as a failure, but as a positive

response to the child's needs. For some children, the implant may provide access to speech sounds, but the child may not be able to translate that access to speech sounds into an ability to receive or use spoken language, at least to an extent to allow the child to communicate or to access the curriculum. There may be an underlying language difficulty in addition to deafness that was not apparent until the child had received a cochlear implant and it had not proved beneficial. While the use of the implant is promoted, children are not forced to use spoken language, rather the quality of communication, irrespective of mode, is viewed as the over-riding consideration.

Conclusion

The findings of this study demonstrate that the majority of younger children who receive a cochlear implant at the Nottingham Cochlear Implant Programme change their communication mode to oral communication during the 5 years after implantation. This has implications for members of implant teams who counsel parents prior to implantation. It also has implications for parents and educators, particularly in respect of expectations. The children who were most likely to use oral communication by 5 years after implantation were those who were implanted prior to 3 years of age. Children implanted at an older age are less likely to change communication mode, and to take longer about doing so. With the advent of newborn hearing screening in the UK, leading to earlier identification of deafness and therefore earlier referral for assessment for cochlear implantation, the proportion of children who receive their implant at a young age is likely to increase. The findings of this study suggest that this will result in a greater proportion of profoundly deaf children with cochlear implants whose mode of communication is oral, with the implications for provision that this requires to be made for them.

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Chapter 3.5

Children with cochlear implants: The communication journey

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Abstract

Cochlear implantation is now a well-established procedure for profoundly deaf children providing access to speech through hearing for many of them. Much attention has focused on which communication mode to adopt with this group of children but very little work has looked at the choices that parents make before and after cochlear implantation.

This study, following on from two earlier studies, looked in depth at the experiences of 12 families. It finds that parents choose the most effective way of communicating with their child but retain as their goal, the development of oral communication skills. For many this is a journey in which different approaches are utilised at various stages in the child's development.

Cochlear implantation, in giving access to useful hearing, has provided profoundly deaf children with new opportunities to develop intelligible speech effectively (Geers, 2006; Miyamoto et al., 1997). Research into paediatric implantation has focused on outcomes in terms of speech perception and production. Some studies have explored whether those children in oral educational settings do better than those in educational settings using signed communication (Connor et al., 2000; Geers et al., 2003; Tobey et al., 2004), with an interest in discovering whether some educational programmes are more effective in supporting children with implants than others. As outcomes from implantation show a wide variation in children (Miyamoto et al., 1997; Sarent et al., 2001; Wie et al., 2007), it is clearly of great interest to determine how children are best supported after implantation in order to maximise the benefits. However, these studies have largely regarded the use of signed communication or oral communication as static, rather than as a dimension which can change over time. A study by Watson et al. (2006) looked at communication mode over time in a large group of children, as judged by the staff of the implant centre, and found that, for those children implanted below the age of three, the majority changed communication mode from sign to oral over the first years after implant, suggesting that communication mode was more flexible than had been suggested.

Another study (Watson et al., 2006, 2008) used a questionnaire of parents to elicit information about communication choices pre- and post-cochlear implantation. They found that communication within an implanted child's family is not fixed, but changes over time with a shift towards greater use of oral communication skills in the child. A major goal of implantation in children is the development of spoken language (Geers, 2006) and it is therefore vitally important that the ways in which

this is best achieved are explored. There has been little reported work in this area, and so this study, using qualitative methods, examined in depth the reasons for this change over time. It explores the views of 12 families who responded to the original questionnaire, the views of the child's local teacher of the deaf (LTOD) and also the implant centre teacher of the deaf (ICTOD). Additionally the children themselves were interviewed to establish their perspective on communication and whether this was in agreement with their parents' views.

Method

Families were selected for interview from the group of 142 who had participated in returning the previously reported questionnaire (Watson et al., 2008) about changes in communication mode and who had indicated their willingness to participate in a further in-depth study.

The study passed through, and was approved by, the local medical ethics committee. All children had been implanted at Nottingham Cochlear Implant Programme.

The cohort was sorted into differing groups:

1. Those who had shown little or no change in communication mode.
2. Those who had shown a degree of change (e.g. from entirely sign to sign and speech).
3. Those who had shown great change.

These groups were subdivided into those who started from contrasting communication approaches (e.g. signed communication pre-implant or oral communication pre implant). Twelve families were recruited from the cohort in proportions which reflected the size of each group (group 1 = four; group 2 = six; group 3 = two). The selection of families from within each group was random. No child or family was excluded from the study. Families were sent a letter with accompanying information about the study for both parents and child and with consent forms for both parents and child.

The families were advised that their LTOD and ICTOD would also be contacted and interviewed for the study and asked to consent to this. Teachers were contacted, with information on the study and consent obtained. The same researcher undertook all the interviews. She is a teacher of the deaf with experience of working with families with cochlear implants but who had not worked with children on the Nottingham Cochlear Implant Programme.

The parent interview schedules were designed to elicit further information regarding communication choice pre- and post implant and how that choice was made. Children or young people were interviewed separately from their parent using a simple interview format designed to provide information on how they communicated at home and school and where their preferences lay. The teacher interview schedules were the same for both the LTOD and the ICTOD and were designed to provide additional information about the communication mode used by the child, particularly in the school environment and also to examine teachers' own views regarding cochlear implantation and communication choice. The interview schedules are attached in Appendix A.

One LTOD was unable to find time to take part in the study due to work commitments and therefore 47 out of 48 interviews were completed. In one case an interview with the implant centre speech and language therapist (ICSLT) was used as the ICTOD involved with the child had left employment at the centre.

The family interviews were recorded digitally with video used for the children. All interviews were transcribed into Nvivo1¹ software to facilitate further analysis.

Parental responses in the interviews were compared against their individual questionnaire results from Watson et al. (2008). In the questionnaire, parents were asked to describe their child's communication pre implant as: Entirely sign/mainly sign/equal sign and speech/mainly speech or entirely speech. The same five categories were also used to describe communication change post implant. Thus entirely sign pre-implant to entirely speech post-implant would represent a very dramatic change whilst equal sign and speech to mainly speech would represent a more moderate degree of change. Material from the parent and child interviews provided additional, detailed information on the use of single signs, British Sign Language (BSL), gestures and oral communication.

Interview responses were coded to elicit emerging themes (e.g. areas of conflict between parents and professionals).

Background data was imported from the Bawtry Computer Systems (BCS) database² used for data collection by Nottingham Cochlear Implant Programme. This covered attributes such as aetiology, onset of deafness, age at implant, and outcomes from speech production and perception assessments.

¹ QSR Nvivo Software. Version 2.0.163.

² Em for Cochlear Implant Centres Release 5.2 (2005) Info@bawtry.net.

Findings

Table 1 summarises the study group's pre-implant history and key outcomes in speech intelligibility (SIR)³ and listening skills (CAP)⁴ from data recorded on the BCS database. These scores represent the most recent assessments carried out. Current school placement results show that nine children are now being educated in mainstream schools, two of which are resourced for hearing impaired children. Two secondary aged young people (eight and 11) have recently moved to a special school with an oral/aural⁵ philosophy from mainstream primary schools.

Table 1. Study group attributes

Study No.	Age at implant (months)	Period implanted (months)	Aetiology	Onset of deafness	Sex	Speech intelligibility rating latest score (BSC) ¹	Categories of auditory performance ² latest score (BCS)	Current school placement (BCS) ³
1	32	181	Post MMR	Acquired	F	5	7	Mainstream
2	35	110	CMV	Congenital	F	3	7	Special school
3	64	91	Unknown	Congenital	F	4	7	Mainstream
4	37	71	CMV	Progressive	F	3	7	Mainstream
5	25	129	Meningitis	Acquired	M	5	7	Mainstream
6	47	60	Genetic	Congenital	M	4	6	Mainstream
7	43	131	Unknown	Congenital	M	4	7	Mainstream
8	37	104	Usher	Congenital	M	5	7	Special school
9	24	66	Unknown	Congenital	F	2	5	Resourced school
10	70	62	Unknown	Congenital	M	4	6	Resourced school
11	64	69	CMV	Progressive	F	5	7	Special school
12	60	64	Genetic	Congenital	F	5	7	Mainstream

¹Scores are the most recent recorded by ICSLTs on the BCS database system (see above). For a description of SIR categories see Appendix A. ²Score are the most recent recorded by ICTODs on the BCS database system (see above). For a description of CAP see Appendix A. ³Current school placement is recorded by ICTODs on the BCS database system (see above). 'Mainstream' indicates that pupils are fully included in a local school, usually with some advisory support from a local teacher of the deaf. 'Resourced' indicates that the mainstream school is resourced for hearing impaired children with a teacher of the deaf and other support staff on site and facilities for withdrawal teaching. 'Special school' indicates a school for the deaf. In two cases (8,11) this represented residential provision.

³ Speech intelligibility rating (Allen et al., 2001)

⁴ Categories of auditory performance (Archbold et al, 1998a)

⁵ Oral/Aural: Philosophy placing emphasis on listening and speaking without sign support.

All the children in the study had been implanted for five years or more, the average duration was seven years ten months with a range of five years to 15 years 11 months. The average age at implantation was three years eight months with a range of two years to five years ten months. The findings in this study will now be discussed under the themes which emerged from the analysis of the data. Quotations are also given from the interview responses.⁶

Pre implant communication in the family

Findings in this current study confirm those of this earlier work (Watson et al., 2007) based on questionnaire responses that parents are primarily interested in finding the most effective way of communicating with their profoundly deaf child. Within this study group all the parents agreed strongly that they wanted the most effective means of communication and this was borne out in the interviews.

We found out that she was deaf at four months and started signing then. I couldn't have gone through 3 or 4 years with no communication. (2P)

We muddled through using speech, sign and gesture. The most important thing was being able to communicate as a family. (4P)

Questionnaire results for the interview group were re-examined and compared with responses obtained in the interviews (Table 2).

Table 2. Parent and child communication mode before cochlear implantation.

Study no.	Age at Implant (months)	Child communication Mode (parent questionnaire)	Child communication Mode (parent interview)	Parent mode To child (parent interview)
1	32	Entirely sign	BSL	BSL
2	35	Entirely sign	Signed communication	BSL
3	64	Mainly sign	Signs and vocalisations	Sign and speech
4	37	Entirely sign	Single signs	Voice, gesture, sign
5	25	Entirely sign	Single signs/learnt phrases	Sign and gestures
6	47	Equal sign and speech	Speech-40 words approx	Sign and speech
7	43	Entirely sign	Pointing, vocalisation and some sign	Sign and speech
8	37	Equal sign and speech	Sign and some vocalisations	Voice, gesture, sign
9	24	Entirely sign	Single signs	Gesture and sign
10	70	Equal sign and speech	Pointing/gesture and 10-20 words	Voice, gesture, sign
11	64	Entirely speech	Speech	Voice, gesture, sign

⁶ Quotations are labelled with the child study number and the prefix P for parent interview, or number alone for the child interview.

12	60	Mainly speech	Pointing and vocalisations intelligible to mother	Voice and 'meaningful gesture'
BSL = British Sign Language				

When asked in the parent questionnaire how they communicated with their child pre-implant, ten families stated that they had used either entirely sign (six) or a combination of sign and speech (four). Two parents responded that they used speech pre-implant.

The parent interviews were used to examine these choices further. The parent who responded that their child used 'entirely speech' prior to implant did in fact attend sign language classes with the child's father. She described herself as using 'single, iconic signs' along with gesture and always spoke to her child. This child had a progressive hearing loss so there was a need to adapt over time. Access to greater levels of hearing initially is also the likely explanation for her use of speech as her primary communication mode.

The parent who responded 'mainly speech' did not use signs at all but did make use of:

Meaningful gesture which hadn't fully developed to sign. (12P)

Whilst two parents had had some experience of meeting a hearing impaired child before receiving a diagnosis of deafness for their own child, other parents had no experience of deafness and remained conscious that their child belonged within a hearing family:

We felt we were a hearing family. We found it very hard to go out into the deaf world. We wanted to bring him into our hearing family. (6P)

However this did not prevent this particular parent from wanting to use signed communication as a support.

Two sets of parents introduced signed communication specifically because the problems that they were experiencing with communication either led to or compounded behaviour problems. In one case this was not as successful as had been hoped.

He was really diffi cult and unco-operative re communication. He wouldn't look or sign just made noises and pointed. Very reluctant to use sign – he would turn his back and away from conversation, making an effort to get attention. (7P)

Other parents introduced signed communication in the context of a total communication approach:

Gesture, pointing, sign language and talking. I (Dad) went to sign language classes. (10P)

Overall the interview results suggested that most of the parents, with the exception of the two BSL users, were generally using a mixture of strings of single signs and speech rather than formal sign language structures prior to cochlear implantation.

Communication after cochlear implantation

Inceselu et al. (2003) have reported that parents' main concern in choosing cochlear implantation was to facilitate the development of their child's speech and language skills. A questionnaire study by Archbold et al. (2006) supports this view and found that 63 per cent of parents agreed with the statement that learning to talk was an important expectation from cochlear implantation. This is consistent with other studies which suggest that parents' primary motive in choosing cochlear implantation is to enable their child to develop oral communication skills. Kluwin and Stewart (2000) interviewed 35 parents and found that 13 of these wanted their child to function like a hearing person and nine parents felt frustrated with their child's communication skills and hoped that a cochlear implant would make a difference.

Most parents in this study saw a strong association between having a cochlear implant and developing speech but their attitudes varied towards the relative importance of speech over sign.

We were hoping that she would be more oral- if she hadn't been we would have been disappointed but we always wanted her to be bi-lingual. (3P)

Some parents hoped that spoken language skills would make their child's life easier:

We just hoped that he would hear speech and would be able to speak. A lot easier than trying to lip-read. (8P)

For the majority of families, this goal was achieved.

The results shown in Table 3 are taken from the questionnaire used in the earlier study (Watson et al., 2008) which record the parents' classification of their child's communication mode following implantation and are compared with the information given in the interviews with the parent and child.

Table 3. Communication mode used by the child after implantation

Study no.	Age at implant (months)	Child mode post implant (parent questionnaire)	Child mode post implant (parent interview)	Child mode post implant (child interview)
1	32	Entirely speech	Exclusively spoken language	Speech
2	35	Entirely sign and speech	BSL/SSE	Bi-lingual
3	64	Entirely speech	Speech	Speech and sign to deaf friends
4	37	Mainly speech	Speech and some sign	Sign and speech
5	25	Entirely speech	Totally oral	Speech
6	47	Entirely speech	Speech	Speech
7	43	Entirely speech	Speech	Speech
8	37	Entirely speech	Speech only	Speech
9	24	Mainly sign	Own way of responding	(Sign)
10	70	Mainly speech	Speech only	Speech
11	64	Mainly speech	Speech and sign	Sign and speech
12	60	Entirely speech	Speech only	Speech

BSL = British Sign Language; SSE = Sign Supported English.

Three children were reported on the questionnaire results to have made the complete switch from using entirely sign to entirely speech, and this was supported by information provided in the parent and teacher interviews. The children themselves also agreed with this description of their communication in their own interviews. Of the other three children who were reported to be using entirely sign pre-implant, one was now using a mixture of BSL, spoken language and sign supported English (SSE, sign used with speech in English word order) in a true bilingual sense, varying language use to situation. She was attending a special school which places strong emphasis on the development of BSL. This young person was reported to have a range of additional difficulties including behavioural and attention problems and it was this, rather than her communication needs which influenced school placement.

Another child had been educated initially in a total communication environment post-implant and then her parents chose to transfer her to her local school where she would rely totally on listening and speaking. Her mother stated that she felt that her child needed to learn one language really well and that she now needed to concentrate on spoken English. However at the time of interview, although the child remained in this placement and had intelligible oral communication skills, a

decision had been made to re-introduce sign as a second language, as her mother wanted her to be bi-lingual.

I want her to feel confident in using sign in her mid to late teens. (4P)

When the child herself was asked which she preferred she responded that she liked 'both best' (4.)

The final child who was described as using entirely sign pre-implant was reported to be using mainly sign post-implant. Interview results suggested that this child uses very little in the way of vocalisation, although it is thought that she may understand some spoken words and key phrases when using her implant. This child only uses her cochlear implant at school and has also been assessed as having an additional communication disorder (this diagnosis was made only after implantation).

If she can hear what is being asked of her she will find a way of responding. Simple sentences with familiar vocabulary she can hear and respond appropriately. It is very rare for her to wear it (cochlear implant) out of school. All we can do is hope that as she gets older she will see a reason to wear it. <NAME> is on the autistic spectrum. She is totally dependent on sign, gesture and lip-reading – but we don't know how much she is picking up. (9P)

One young person, deafened by a progressive hearing loss, who was described as using entirely speech pre-implant, was recorded as using mainly speech post implant in the questionnaire, suggesting a decrement in her oral communication skills. On further investigation during the interview it transpired that she had indeed developed intelligible oral communication skills but was now wanting to use sign as well. It was apparent from the interviews with the LTOD that she had been expressing an interest in sign language for some time:

At junior school she communicated with hearing peers orally. She wanted to learn to sign – asked for help with sign language lessons but none were available through social services – only for siblings. She has always expressed a desire to sign to use when she took her cochlear implant off – she saw herself as a deaf child. (LTOD)

This young person now attends a secondary school for deaf pupils expressly because she wanted to have a deaf peer group and the opportunity to develop signed communication although the school philosophy is itself, oral/aural.

I sign to all my friends. Saw a lot of people signing so I picked it up.

Interviewer: Do you use sign only or sign and voice?

If someone is a good signer I sign without my voice.

Interviewer: Which do you like to do best? Do you like to sign or talk or do both?

Do both because if I sign it makes me feel kind of good when you do two languages. Sometimes I miss talking but when I am talking with my family I miss signing. (11)

When she was asked what communication mode she expected to use after leaving school she replied:

Talk but I will still keep in touch with deaf friends. (11)

Three children who had been described as using a mixture of sign and speech prior to implantation were described as entirely oral post-implant. In one case, results from the interviews suggested that the child was still using sign support at school. His parents were most anxious that he should develop speech as neither sign nor English was routinely used at home. However his teacher of the deaf found that she needed to use sign support in the classroom to enable him to access some aspects of the curriculum. It was interesting that when the young person was asked about his communication mode he stated that he used speech and sign at school and speech only at home. When asked why he responded:

because sign language is for babies, speaking is adult that's why. (10)

In practice, parents and their children did not make an immediate switch from one mode to another; the process was gradual and followed the child's lead:

Within a couple of years he stopped signing totally. If he met deaf people in town he had the ability to sign with them but he wouldn't sign at home. As he got more confident with speech the sign stopped. If there was any sign language going on it was more as a reinforcement for a word. (7P)

Marschark and Spencer (2003) have drawn attention to the need for a prompt response and flexibility in supporting young deaf children and their families:

One thing we do know is that no single method of communication is going to be appropriate for all deaf children. The goal, therefore, must be to identify hearing losses as early as possible and begin interventions that match the strengths and needs of each child and the child's family. (Marschark and Spencer, 2003, p. 492)

The children in this study were all from hearing families, and they and their parents were strongly supportive of cochlear implantation and of the choice it has given them for the development of oral communication skills. The only change that they would have made would have been to have the implant earlier. This supports the findings of Perold (2001) who reports that some mothers expressed anger that their child had not been referred earlier for cochlear implantation.

The influence of professionals

A number of parents were critical of the advice that they received regarding the management of their child's hearing and communication skills.

The issue of the advice parents were given in some cases, including the appropriateness of cochlear implantation, became a recurring theme within this study. Ben-Itzhak et al. (2005) have discussed the effect that professionals' beliefs and expectations can have on families and the results of cochlear implantation. They comment that a professional's previous experience can affect their expectations of what can be achieved through cochlear implantation and perhaps their attitude towards communication mode.

Parents were asked specifically about the support and advice that they received from local professionals and implant centre staff. Some parents were very unhappy about what they perceived as lack of support from local professionals. Nine of the families interviewed reported some conflict over communication strategy, usually with local teachers of the deaf. In two cases parents moved house and then received the support to implement their chosen communication mode that they failed to find in their original location. Only three families had always felt supported by local professionals. One parent reported some initial difficulties with the ICTOD over continued use of sign after cochlear implantation. All other comments (6) regarding implant centre staff were either neutral or positive in relation to communication choice. Parents consistently stated that implant centre staff supported them in their choice of communication mode, whilst the conflict with local teachers arose from offering of specific direction regarding this.

In one case the parents already had another child with a less severe hearing loss who was functioning successfully with hearing aids and developing speech. They therefore hoped that their second child would follow the same pattern. However they were frustrated by the unwillingness of professionals to provide them with clear advice as to how their child might progress with oral communication skills in the future, on the basis of the audiological information available to them. This parent received strong advice from proponents of both a strongly 'oral' and strongly signed communication based approach (not necessarily professionals) and felt that neither should be didactic. Additionally, they were initially turned down for cochlear implantation and had to transfer to another cochlear implant centre.

In another family there was a strong 'steer' from local professionals within a context of a local education authority (LEA) which had a strongly oral/aural philosophy at the time. This parent stated that had she known at the outset that her child's progressive hearing loss would deteriorate to the degree that it did, then she might have chosen to reject the advice that she was given and adopt signed communication formally within the family (she did make use of some single signs).

At the beginning it was very strongly skewed to oral – philosophy of LEA which I don't think is right now. I don't think that signing as well as talking is going to prevent speech – if you can't talk you won't develop – you run the risk of depriving them of communication. I don't think we would have followed oral if it hadn't worked.

Interviewer: So what you are saying is that if you had wanted to use sign you would have been advised against it?

Yes but if we had felt we needed to use sign we would have. (11P)

One parent had to introduce sign in secret, before moving to another part of the country where a total communication approach was more readily available.

Another parent reported that although sign had been introduced, he was not really comfortable with it but he did see it as a bridge towards eventual spoken communication:

Basically everyone would say that it was better to use sign language and speech. We didn't agree with sign. We would agree (to use sign) for the transitional period until his speech developed. (10P)

One parent discussed how she felt pressurised into adopting signed communication because the family was living in an area which had a strong commitment to a sign bi-lingual approach.

The speech therapist was always trying to teach <NAME> signs – it makes you feel that your deaf child has not succeeded and needs signs as a back up – she was saying that we could be bi-lingual. (8P)

Despite this she was not opposed to using sign support for communication in the early years: Parents find it very difficult when they receive conflicting advice which clearly reveals the personal opinion of the professional concerned:

Also I received conflicting advice pre-implant with a teacher of the deaf who said 'I wouldn't let them experiment on my child'. 'Just continue signing with her'. (1P)

At the time <NAME> was the only child that the LTOD knew had who had been implanted. Prior to cochlear implant, the teacher of the deaf's view on sign was that it was the last route you wanted to go down. She has Stage 1 signing skills but wasn't prepared to use them. 'Well let's see if he gets on with the cochlear implant first'. 'You want him to go the oral route because you want him to speak'. 'No placements for signing children in county, if he was to sign he would have to go out of county'. She had never had a child who had acquired a hearing loss or who was profoundly deaf before so the children she had supported had some residual hearing. (5P)

Overall, parents seemed much more positive about the support and advice that they received from ICTODs and speech therapists (ICSLTs) working on their child's cochlear implant programme.

ICTOD and ICSLT were a great support to us in any decision that we made. They have just been fantastic. ICTOD has been honest with us and very supportive. ICSLT was very supportive in saying 'if you want to, drop the signs when he knows the word' didn't advise us either way. Their advice was very much appreciated and honest. (3P)

It seems that what they appreciate most was being supported in the decisions that they made rather than being steered in a particular direction.

Professional perspectives

Given the stated influence of professionals in the development of deaf children's communication we were interested to know more about their perceptions of the children they worked with and their own beliefs with respect to cochlear implantation. Archbold et al. (1998b) surveyed opinions of teachers of the deaf and found that 38 per cent believed that the most effective communication environment for children with implants was one that had the potential to vary according to the child and that 23 per cent felt that the communication strategy used with the child should also vary over time.

Implant centre teachers of the deaf were very clear in their views:

I think it should be a careful balance between the way in which you use sign and auditory input but I am a strong believer in following the route in which the child is being taught, the mode of communication in which they feel comfortable and in following the child's lead in their interaction with you. (ICTOD)

One implant centre teacher, who works mainly with adolescents, commented on the trend for young people to move between communication modes:

I think the idea is that they should become code switchers by that I mean they should be able to speak with the hearing and sign with those deaf people who need sign. However oral these kids are, they sign with their deaf friends. The code switching shows they are comfortable with deaf identity and hearing identity that is why they have an implant. (ICTOD)

One local teacher articulated an approach which mirrors that followed by many of the parents in this study.

At first I used sign and speech. Now I have dropped a lot of sign. In a one:one situation I wouldn't sign to him. I support him in class at the moment. I would use sign to give him access to curriculum where he needs it. (LTOD)

Of the two children who were the strongest signed communication users, one local teacher did not respond to the invitation to be interviewed. For the second child,

who has been described previously as having Autistic Spectrum Disorder (ASD), she described her approach for this child as using mostly BSL. However when she was asked to outline her views generally she made the following response:

I think they should be given the choice to develop their preferred method of communication – sign, speech or both. Should still be down to child's preference. If they have been a signer beforehand, shouldn't stop when implanted. Very much dependent on what has happened pre-implant. Also child needs to be closely monitored. (LTOD)

This was very much the prevailing view amongst local teachers of the deaf. Five teachers stated that if signed communication had been introduced prior to implantation then it should not be dropped immediately but continue until the child is ready. Three teachers stated that using signed communication would not inhibit speech development and two teachers expressed the view that the use of sign was very positive in terms of developing understanding of communication rules (e.g. turn-taking) and comprehension. Four teachers talked about following the child's lead. However they were also clear that giving a cochlear implant to a child carries with it an expectation that the child will learn to hear and use speech.

There's no point in having a cochlear implant if you are not going to access speech. If sign is in place pre-implant then continue with SSE. If child naturally starts to use speech then start to drop the sign – switch your approach – use the sandwich approach – speech, then support with sign then speech again. Signed communication enables comprehension. Develop speech along with small classes and good acoustics. (LTOD)

Three teachers who had quite strong auditory/oral beliefs also showed a willingness to enable the child to access signed communication in certain situations or in response to parental request. In one case the teacher suggested that signed communication should be introduced for a child whom she perceived as being complex. In another instance the teacher stated that she would transfer the family to the caseload of another teacher who could sign, if this was their choice.

Although most local teachers seemed to be advocating an approach which varied with the needs of the child and which had the potential to change as the child developed, this was at variance with the parents' views on the readiness of professionals to be flexible in meeting their needs. This may be accounted for in

part by the passage of time. Some of these parents are talking about events which are five or more years in the past whilst teachers are probably reflecting on their current views and attitudes. Another factor may be that local teachers were subject to restrictions which affected the advice they were able to offer. This became most apparent in discussions around school placement.

Education

Not only do parents have to address the difficult issue of deciding on the right communication approach to use with their child, together with the advantages and disadvantages of cochlear implantation, but several parents found that this decision in turn led to further conflicts with LEAs with regard to school placement. Sach and Whynes (2005) in their study of the views of parents on cochlear implantation report that 15 per cent of parents stated that they had to fight for services which they believed their child was entitled to. The authors draw attention to the lack of flexibility in the system to meet individual needs. This became a particular difficulty when the provision offered did not provide for the changing communication and listening needs following implantation.

<NAME> dropped the sign unconsciously which may also be due to school setting. A new teacher came to the school who did not agree with sign and had unrealistic expectations of how she would cope with a cochlear implant in a mainstream classroom. She was implanted when she was 5½ and by Year 4 she was refusing to go to school – it all went pear shaped. So we moved her to <SCHOOL> nobody signed there which accelerated the process also she was being taught in small classes with good acoustic conditions. (3P)

One young person in the study who had acquired a hearing loss at a young age and had been introduced to BSL, developed good oral communication skills after implantation. She was being educated in a resourced school with a total communication philosophy. However as her spoken language developed she began to reject the signed communication support:

I would have liked the whole education system to be different. As a mother I felt I had failed her – (the family reported immense difficulties re: school placement at secondary level and conflict with LEA). We wanted an oral placement – <NAME> would not go anywhere with sign support. We wanted her to be able to access

the curriculum but she couldn't without support; she ended up going to an independent girls' school. (2P)

However one parent at least acknowledged that local teachers can find themselves in a difficult position. It may be that it is local education policy that results in local teachers appearing to be less flexible in their approach and advice.

Teacher of the deaf – I got fantastic support, very good quality but I don't like the political thing around schooling. She is so limited in what she is allowed to advise. They (LEA) didn't like the school I chose.....(details of this) (6P)

Some parents felt that they were the ones who had to drive change locally to ensure that their child's changing needs were met:

Some reluctance at the hearing impaired unit to let her go when we talked about moving her. They felt that she should stay until Key Stage 2 and that she needed the sign support to access the curriculum. Another professional (speech therapist) supported our desire to focus on English. The unit staff didn't put us under undue pressure but they didn't agree with us. (4P)

These comments suggest that there may sometimes be an underlying tension between teachers and parents regarding the level of support needed by the child in question. Whilst teachers were reluctant to comment 'on the record' during interviews on issues around school placement, more information was given in private discussion with the interviewer which suggested in three cases that parents were driving forward change at a faster rate than the teacher concerned felt comfortable with.

Parental reflections

Parents were asked about their hopes and expectations in going forward for cochlear implantation for their child and if they had any regrets. Many parents were immensely grateful for the difference the cochlear implant had made for their child:

We are very happy. We were warned to have realistic expectations but this is 100% more than we could have hoped for – couldn't hope for more. He has local friends, goes to local school, catches the bus home with his friends, goes to local

discos. I never worry about <NAME>. It is very easy to forget that he is hearing-impaired. Although his speech might not be perfect, people generally understand what he is saying. (5P)

This is consistent with outcomes reported by Nicholas and Geers (2003) and Perold (2001) who found that parents' satisfaction with their child's cochlear implant was significantly related to their child's speech and language achievements.

Whilst the outcomes from cochlear implantation can be beneficial it can have unexpected results as was clearly outlined by one parent in the study:

No regrets about my decision making process but now I have a young woman who...will not acknowledge her identity which has created issues of itself. I hadn't expected this. Support in school – she won't have it but she needs it...Had she stayed deaf none of this would have happened. At her new school it was six months before she told anybody. If she doesn't hear/mishears, her friends think she is being arrogant. I really don't think it has come from my attitude

– I wasn't determined to make her speak, she went to deaf club, she had deaf adults as role models

– we did it all but are still left with a young woman who is so anti-deaf. She thinks that in order to succeed in the world you have to be perfect....The cochlear implant has accentuated this. (1P)

Only one parent stated that she was not unduly concerned re audition/cochlear implant for her child; she used sign (BSL) from the outset after diagnosis and was confident that she and her daughter would always be able to communicate. However she wanted to give her child that choice to help her with communication in the outside world where not everyone signs.

When she had her implant I always said 'keep the sign'. If there had only been me and <NAME> and not the world I would not have had cochlear implant. (2P)

However, most parents saw a strong association between having a cochlear implant and developing speech but their attitudes varied towards the relative importance of oral communication over sign communication.

*Everyone hopes that a cochlear implant will improve access to spoken language.
(4P)*

For a family where their child had gone deaf through meningitis the cochlear implant was seen as a means of reinstating what had been lost.

No I don't think I would have done anything differently. At the end of the day the cochlear implant was his only hope of being able to learn to listen and speak again – for us that was our goal. If it had not been possible we would have gone headlong into sign but we wanted to give him every opportunity to listen and speak again. (5P)

For another family, where their child had been diagnosed with a communication disorder, things had not turned out as they had hoped:

We hoped that she would want to wear her cochlear implant all the time, that she would learn to talk in such a way that someone who did not know her would understand. But we understood that it might not be the case. We said that if it gave her access to environmental sound it would be worth it. (9P)

Four parents referred to the current move to implant children at an increasingly young age and wished that this had been done for their child:

I would have liked him to have a cochlear implant sooner. If he was a baby now and deaf we would want an implant straight away – other than that, nothing. (7P)

Comment – a communication journey (Figure 1)

The findings of this study confirmed, on further exploration of individual cases, the move towards greater use of oral communication after implantation which had been found in the previous large questionnaire study. Moreover, it confirmed that the perceptions of the children were in agreement with those of their parents at the present time, although they were unable to comment on what had happened before implantation. Eleven of the 12 children were using spoken language for communication: the child for whom there had been no change towards spoken language had significant additional difficulties. Three of the young people are actively using sign in addition to intelligible speech and a fourth makes use of sign support in school (this child was implanted relatively late).

Prior to implantation, effective communication of whatever kind is chosen. Timely cochlear implantation appears to facilitate a change in communication mode from sign/gesture supported English pre-implant to oral communication postimplant. This change is gradual and mostly follows the child as they develop spoken language and drop the signs which they no longer need. Both parents and teachers agree with this, and concur that where signed communication is used before implantation it should not be suddenly dropped but there should be a gradual change in emphasis over time. Parents ensure that there is a consistent focus on developing spoken language. Nevertheless, they and many of the children and young people remain flexible in their attitude towards communication and the use of sign as a second language.

One of the main reasons we went for a cochlear implant was to give her a choice – there are two sides to this – recognise the fact that she is deaf but give her the option of spoken language. (4P)

This is consistent with the findings of Perold (2001) who reports that mothers of deaf children felt that cochlear implantation offered the chance of improved hearing and ability to speak which would enable them to integrate into mainstream society.

How the change to greater use of oral communication is achieved appeared to be an area of tension between parents and local teachers – parents seemed to be driving the educational changes they saw were needed in response to this change in emphasis on greater use of audition, rather than the teachers. This is in line with the findings of Sorkin and Zwolan (2004) where parents had difficulty in seeking out the services they felt their child needed after implantation. Implant centre teachers were often supportive but cannot influence school placement. While parents appear to be pragmatic about communication choice, local teachers' decisions may be driven by political and policy views rather than the changing needs of the child. Teachers are naturally concerned that the child has full access to the curriculum, and many see the value of sign for these children. However, several parents felt that their children would benefit from greater access to oral communication in the classroom and some had pushed for mainstream placement with support. In three cases this involved paying for private education.

The views of the parents describe a communication 'journey' in which they want the most effective means of communication before implantation, then, following implantation, there is a consistent focus on the development of oral communication skills as cochlear implantation drives the change. For parents,

where communication mode did not change significantly to spoken language there were specific reasons: the child had been implanted later, or had additional difficulties.

For a number of parents, the 'communication journey' appeared to move again, once effective oral communication had been achieved. Some parents, and their children, were then considering once more the use of signed communication, SSE or BSL. This was for reasons of thinking about deaf identity and the issues to do with this. Other parents, whilst not planning to introduce signed communication again themselves, were aware that their child might want to use this at a later date and were not opposed to the idea. The young people also appear open to the use of signed communication later and see it as having a role in their future; seven stated that they would use sign as well as speech to communicate with deaf friends or relatives and only three were clear that they only wanted to use oral communication in the future. Thus, cochlear implantation is offering real choices of communication for these children.

Although parents' ultimate goal is the traditional one of spoken language, the process by which this is achieved is pragmatic and involves the choice of whichever communication option is the most effective at a particular time. This in turn is influenced by the child's evolving use of audition which results from cochlear implantation. Parents respond to their child's changing needs, seeking always to encourage oral communication skills but not at the expense of poor or ineffective communication. However this is not always supported by local professionals who may be limited in their response to changing needs by organisational or bureaucratic restrictions. How to support parents and children in their communication journey is the challenge for all those who work with these children and their families.

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Chapter 3.5

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Appendix A

Speech intelligibility rating

A five point scale which is assessed by a speech and language therapist and is summarised as follows:

1. No spoken language
2. Unintelligible speech
3. Speech which is intelligible to a familiar listener in context
4. Speech which is intelligible to a listener with little experience of deaf children
5. Speech which is intelligible to all.

Categories of auditory performance

A seven point scale which is assessed by a teacher of the deaf and is summarised as follows:

0. No awareness of environmental sound
1. Awareness of environmental sound
2. Responds to speech sounds
3. Identifies environmental sounds
4. Discriminates speech sounds
5. Understands common phrases (audition alone)
6. Understands conversation (without lip reading)
7. Uses the telephone.

Appendix B

Interview schedule for parents/guardians

1. How would you describe N (child's name) to someone who did not know him/her?
1. How did you communicate with N before the cochlear implant?
2. How did N communicate with you before the cochlear implant?
3. What about the rest of the family – how did they communicate with N? How did N communicate with them?
4. How did you expect/hope that N would communicate after the cochlear implant?
5. Please tell me about how N communicates now. Has it changed since the implant?
6. What do you think are the reasons for this (i.e. if it has changed or if it has stayed the same)?
7. How do you feel about this?
8. Do you know how most of the other deaf children in your area communicate?
9. Please tell me about the advice/support that you received from your local professionals (e.g. teacher of the deaf, speech and language therapist).
10. Please tell me about the advice/support that you received from the cochlear implant team.
11. What, if anything, would you have liked to have happened differently?
12. Do you have any other comments you would like to make about your child's communication since the cochlear implant?

Interview schedule for children

1. Please tell me who is at home? (Get child to list Mummy, Daddy, names of siblings, etc.)
2. When you want to tell Mummy or Daddy something do you:
Sign?
Talk?
Sign and talk at the same time?
3. What about when you want to tell (name(s) of sibling(s))?
4. What about Nanny and Grandad?
5. Your friends at home?
6. Your friends at school?
7. Your teacher?
8. Which do you like to do best? Do you like to sign or talk or do both?
9. Have you always liked to sign/talk/sign and talk? (Ask question to fit with child's answer to previous question.)
10. Do you like other people to talk to you? Or sign? Or sign and talk?

11. Have you always liked other people to sign/talk/sign and talk? (Ask the question to fit with child's answer to previous question.)
12. Which will you use when you leave school/college?

Interview schedule for teachers

1. How would you describe N to someone who did not know him/her? {thumbnail}
2. How do you communicate with N?
3. How does N communicate with you?
4. How does N communicate with other pupils?
5. How do other pupils communicate with N?
6. Have there been changes to N's communication mode since the cochlear
7. implant? (Are you able to comment?)
8. What do you think are the reasons for this (either the changes or the fact that there have not been changes)?
9. What are your views on deaf children's communication after receiving a cochlear implant?
10. Are there any other comments that you would like to make regarding N's communication?

Chapter 3.6

Reading abilities after cochlear implantation: The effect of age at implantation on outcomes at five and seven years after implantation

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Summary

Objectives:

The reading skills of deaf children have typically been delayed and this delay has been found to increase with age. This study explored the reading ability of a large group of children who had received cochlear implants 7 years earlier and investigated the relationship between reading ability and age at implantation.

Methods:

The reading ages of 105 children, with age at implantation less than 7 years and onset of deafness below the age of three, were assessed 5 and 7 years after implantation using the Edinburgh reading test. Net reading age was calculated by using the difference between chronological age and reading age. Non-verbal intelligence was measured for a subset of 71 children, using Raven's coloured progressive matrices. Further investigation of this subset looked at the association of nonverbal intelligence, age at implantation and reading ability.

Results:

There was a strong negative correlation at both 5 and 7 years after implant between net reading score and age at implantation. In the subset of 71 children who had an IQ score within normal range, those implanted at or before 42 months had age-appropriate reading both 5 and 7 years post-implant. This was not the case for children implanted after 42 months. Reading progress at the two post-implant assessment intervals were found to be highly related.

Conclusions:

Age at implantation was a significant factor in the development of reading skills in this group. In children implanted below the age of 42 months, reading progress was in line with chronological age, which has not been the case previously with profoundly deaf children. With earlier implantation more common in present groups, and improved technology, there is every reason to be optimistic about the influence of cochlear implantation on the development of reading skills in deaf children.

Introduction

Attaining fluency in reading in childhood is essential for later educational attainments and later employment prospects, in addition to providing a means of participating fully in society. Many studies have shown that the great majority of deaf children find reading difficult, achieving significantly lower levels of reading attainment than their hearing peers throughout their years at school (Allen, 1986; Conrad, 1979); DiFrancesca, 1972; Lane & Baker, 1974; Lewis, 1996; Moog & Geers, 1985; Trybus & Karchmer, 1977). The gap between deaf children and hearing peers tends to widen with age (Marschark & Harris, 1996). Yoshinaga-Itano and Downey (1996) assessed 33 deaf children aged between 10 and 12 years and found them reading three grade levels below their hearing peers. Harris and Moreno (2004) assessed a similar group of children at 14 years of age and found that the average reading lag was over 4 years. Several decades of research and many debates about educational methods appear to have done little to change this picture (Marschark & Harris, 1996; Musselman, 2000).

A number of different factors have been identified as playing a specific role in deaf children's difficulties with literacy. One major problem is that many deaf children have a poor knowledge of the spoken language that is represented in a written text. For typically developing hearing children, the process of learning to read draws upon an extensive knowledge of both the vocabulary and grammar that they will encounter in their reading. By contrast, many deaf children come to reading with an impoverished knowledge of spoken vocabulary and grammar. Knowledge of spoken English has been shown to be an important concurrent predictor of reading ability for deaf children (Kyle & Harris, 2006) and it is also an important longitudinal predictor of reading ability between the ages of 7 and 10 years (Kyle & Harris, 2005). Reading at higher levels also involves world knowledge in addition to linguistic knowledge, an area in which profoundly deaf children traditionally have had difficulty, unable to hear conversational comments, television and radio news for example.

Another important contributor to reading success for deaf children is their phonological awareness. The ability to identify and manipulate phonemes within words has been shown to be at the core of early reading success for hearing children learning to read English (Muter et al., 2004) but there has been considerable debate about whether similar skills are important for literacy attainment in deaf children. Part of the difficulty in evaluating the importance of phonological skills for deaf children lies in the problem of providing assessments that are appropriate both for children who communicate orally and those who sign.

However, two recent studies (Kyle & Harris, 2006; Harris & Moreno, 2006) suggest that deaf children's ability to decode spoken sounds through speechreading may be a key skill even in children who are native users of British sign language.

The increasing availability of cochlear implants has held out the prospect of higher levels of literacy for profoundly deaf children. There is now a substantial body of evidence showing that cochlear implantation improves speech perception and production and facilitates the development of spoken language (Pisoni & Geers, 1998; Cleary et al., 2001; Geers, 2002; O'Donoghue et al., 2000; Archbold et al., 2000; Tait et al., 2001; Thoutenhoofd et al., 2005; Watson et al., 2008; Watson et al., 2006). Following from this, there are now claims that children with implants find the process of learning to read more straightforward as a result of their enhanced language skills (Geers, 2002). Reading in deaf children after implantation has been associated with greater use of phonological decoding strategies and linguistic competence and hence it has been claimed that cochlear implantation, in providing greater access to the phonology of the language, facilitates the development of literacy skills (Geers, 2003).

The findings about the literacy attainment of children with cochlear implants have not, however, been consistent. A study of eight children with implants (Boothroyd & Boothroyd-Turner, 2002) found continued delays in reading ability 4 years after implantation, although it should be noted that the average age at implantation was high at 5.8 years. In another study, 16 implanted children had reading comprehension scores within 1 S.D. of hearing peers and again that there was a strong correlation between spoken language and reading performances (Spencer, 2004). In a more extensive study of 181 children, over half were reading at an age-appropriate level (Geers, 2003). There was, however, considerable variability within the group with reading competence being linked to mainstream educational placement, wide dynamic range using recent technology, longer memory span and use of phonological coding. Reading attainment was predicted by linguistic competence, and by speech production skills, which may reflect phonological abilities (Tobey et al., 2003).

Two recent European studies both report higher literacy attainment in deaf children with cochlear implants in comparison to peers with traditional hearing aids. A study of the achievements of deaf pupils in Scotland showed that those with implants scored comparatively higher on reading, writing and maths assessments (Thoutenhoofd et al., 2005) and a similar pattern emerged from a recent study of pupils in the Netherlands (Vermeulen et al., 2007). It is important to note, however, that both studies found children with implants to be delayed when compared with hearing children.

The evidence to date suggests that the provision of a cochlear implant can, at least for some children, have a significant effect on the language and literacy abilities of in the years immediately following implant. What is less clear is whether this early advantage persists and whether reading levels can match those of hearing peers. Previous research into the literacy attainment of deaf children has indicated that the lag between deaf children and hearing tends to increase with age as reading demands an increasingly complex set of skills to integrate ideas across a text and to deal with more abstract material (Marshark & Harris, 1996; Harris & Moreno, 2004). It is therefore important to ask whether the improvement in reading ability, shown by deaf children in the years immediately following implantation, is maintained. To date there have been few large scale studies to investigate whether early gains hold up over a longer time. It is also important to ask whether literacy is affected by age at implantation since data on language outcomes (Richter et al., 2002) indicate that children who are implanted early show the greatest effects. It is therefore likely that similar effects of age at implantation will be evident in reading ability.

This study investigated the reading ability of a large group of children who had received cochlear implants 7 years earlier. It addressed two main questions: what is the relationship between chronological age and reading ability at 5 years after implantation and at 7 years; and is reading ability at each point related to age at implantation?

Methods

1. Participants

Participants were all children implanted at the publicly funded Nottingham Cochlear Implant Programme. The initial criteria for selection were that implantation occurred before the age of seven, onset of deafness was below the age of three and that reading data were available. There were a total of 105 children (55 boys and 50 girls) for whom age at implantation ranged from 16 months to 83 months with a mean of 50 months and a median of 48 months. For 60 children, aetiology was unknown, 27 had suffered from meningitis, 6 from CMV and the remaining 10 had other diagnoses (including Ushers and Charge Syndrome). Pre-implant hearing thresholds were greater than 105 dB in the better ear, and all children received the Nucleus™ cochlear implant, and were fitted with the most appropriate processing strategy. Mean chronological age at the time of

the 7 years post-implant assessment was 11 years 1 month with a range from 8 years 4 months to 13 years 11 months. Children came from a range of social backgrounds, and educational provision from throughout the UK. Details about their preferred communication strategy before and after implantation can be found in an earlier paper (Watson et al., 2006).

2. Assessment of reading ability

As part of their scheduled 7 years post-implant assessment, all 105 children completed the Edinburgh reading test (Educational Assessment Unit UoE, 2002), which gives normative data for hearing children, and enables a reading age to be calculated for each child. As the test can be used from the age of 7 years, all children were old enough to complete the test; some children in the sample ($n = 77$) were old enough to complete it 2 years earlier, at 5 years post-implant, and these data are also reported. The Edinburgh reading test includes a range of subtests which assess vocabulary, sequencing and sentence comprehension; for the purposes of this study the child's overall reading age was used as it had been used successfully to track the reading attainment of children with otitis media with effusion into adolescence (Bennett et al., 2001). The reading assessment was carried out by teachers of the deaf from the Nottingham Cochlear Implant Programme, in cooperation with the child's local teachers.

In view of the wide age range of the children assessed, net reading age was calculated using the difference between chronological age and reading age. For example, a child with the same reading age as chronological age would have a net reading age of zero, a child with a delay of 1 year, a net reading age of -1 and, with a reading age 2 years greater than their chronological age, a net reading age of $+2$.

2.3. Assessment of intelligence

Given that reading level attained by deaf children with cochlear implants has been shown to be related to nonverbal intelligence (Geers, 2003), a sub-group of 71 children was identified for whom a percentile score from Raven's coloured progressive matrices of 35 or more had been recorded as part of their routine post-implant assessment. Raven's coloured progressive matrices provide a measure of nonverbal intelligence, commonly used with deaf children. It has the advantage of being a paper and pencil test that can be administered by teachers of the deaf who do not have extensive training in psychometric testing. These

children were considered to have IQ within normal range and are comparable with samples used in earlier studies of deaf children's reading (Harris & Moreno, 2001; 2004; 2006; Kyle & Harris, 2006; Beech & Harris, 1997).

Results

1. Effect of age at implantation

The first analyses looked at the association between net reading score and age at implantation using a Pearson correlation. This showed that there was a strong negative association at both 5 years post-implant ($r = -0.80$, $N = 77$ and $p < 0.001$) and 7 years post-implant ($r = -0.74$, $N = 105$ and $p < 0.001$), indicating that children who were implanted earlier tended to have higher net reading scores. Figure 1 shows the association between net reading age at 7 years after implantation and age at implantation for all 105 children.

In light of this preliminary finding, children were subdivided into two groups according to age at implantation, children implanted at or before 42 months were assigned to the early group and those implanted later than 42 months to the late group.

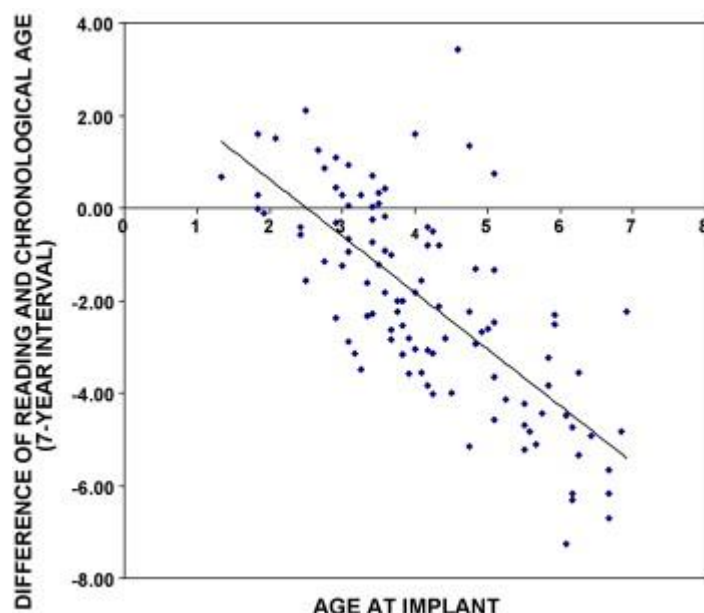


Figure 1. Seven years after implantation: age at implantation versus “net” reading age ($N = 105$).

Table 1. Net reading age (in years) at 5 and 7 years post-implant for children implanted early and late

	5 Years post-implant (<i>N</i> = 77)		7 years post-implant (<i>N</i> = 105)	
	Early (<i>N</i> = 27)	Late (<i>N</i> = 50)	Early (<i>N</i> = 37)	Late (<i>N</i> = 68)
Mean	+0.40	-1.79	-0.41	-2.94
S.D.	1.05	1.27	1.37	2.06

The decision to divide the sample at this point was determined by the distribution of the age at implantation within the sample. At 5 and 7 years post-implant, the 42 months cut off placed 27 children and 37 children in the early group. Dividing the sample at a younger age reduced the size of the early group to the point where statistical reliability was compromised.

Table 1 shows the mean net reading scores 5 and 7 years post-implant for the two groups. It can be seen that the children who received an implant at or before 42 months were reading close to chronological age whereas this was not the case for the children implanted later.

2. Analysis of sub-sample

Using net reading age at 7 years post-outcome as the dependent variable, a stepwise regression was carried out, entering Raven's percentile score at step one and age at implantation at step two. The results are summarised in Table 2. These show that nonverbal intelligence, when entered on its own, accounted for only 5% of the variance.

Table 2. Regression analysis on sub-sample of children with percentile Raven's scores of 35 or more

Variable	<i>B</i>	S.E. <i>B</i>	β	<i>p</i>	<i>R</i> ²
7 Years post-implant					
Step 1					0.05
Nonverbal IQ	0.03	0.02	0.23	0.05	
Step 2					0.57
Nonverbal IQ	<0.01	0.01	0.06	0.478	
Age at implant	-0.11	0.01	-0.74	<0.001	
5 Years post-implant					
Step 1					0.18
Nonverbal IQ	0.04	0.12	0.43	0.001	
Step 2					0.77
Nonverbal IQ	0.15	0.01	0.16	0.028	
Age at implant	-0.09	0.01	-0.81	<0.001	

When both variables were entered, 57% of the variance was accounted for, showing that age at implantation was a powerful and independent predictor of reading outcome 7 years post-implant. The regression analysis was repeated for net reading gain at 5 months post-implant. A similar pattern emerged with nonverbal intelligence alone accounting for 18% of the variance and the addition of age at implantation increasing this to 77%.

As in the analysis of the whole sample, the effect of age at implantation was also investigated by comparing net reading scores for children implanted before 42 months with those for children implanted later. At 5 years post-implant, the mean net reading age for early-implanted children ($n = 18$) was +8 months (S.D. = 1 year 4 months) and for late-implanted children ($n = 37$) it was -1 year 9 months (S.D. = 1 year 4 months). A t -test showed a highly significant effect of age at implantation ($t = 6.66$, $d.f. = 53$ and $p < 0.001$). At 7 years post-implant, mean net reading age was -0.4 month (S.D. = 1 year) for early-implanted children ($n = 23$) and -2 years 11 months (S.D. = 2 years 2 months) for late-implanted children ($n = 49$). This difference was also highly significant ($t = 7.58$, $d.f. = 70$ and $p > 0.001$). The data for the two post-implant points are depicted graphically in Figure 2. It should be noted that there was no difference between children who were implanted following meningitis and other children in the sample with both showing a strong effect of age at implantation on reading ability.

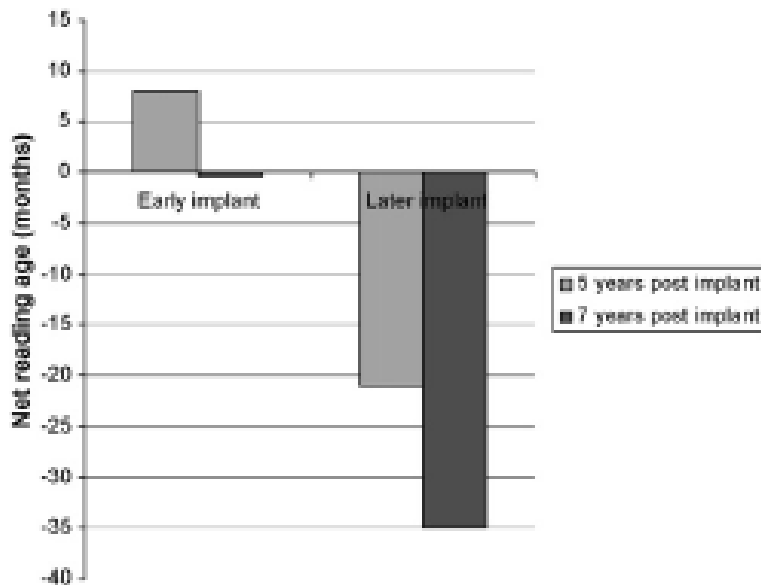


Figure 2. Net reading ages for children implanted at or before 42 months and later.

Finally, a partial correlation (controlling for nonverbal intelligence) between net reading ages at 5 and 7 years post-implant was carried out. This revealed a very

strong positive relationship ($r = 0.82$ and $p < 0.001$) showing that reading progress at the two post-implant assessments was highly related.

Discussion

As noted in the introduction, previous research has documented the generally poor literacy attainment of deaf children and the increasing lag between reading age and chronological age as children get older (Yoshinaga-Itano, 1996; Harris & Moreno, 2004). The results of the present study support recent findings of better literacy outcomes in children who receive a cochlear implant (Thoutenhoofd et al., 2005; Geers, 2003; Vermeulen et al., 2007). They also provide evidence that early achievements in reading are maintained at 5 and 7 years post-implant. Strikingly, for children who were implanted before the age of 42 months, average reading progress was in line with chronological age at both assessment points. This was not, however, the case for children who were implanted later. They showed a significant reading lag at both 5 and 7 years post-implant.

The effect of age at implantation on reading ability was very marked in the study. The regression analysis showed that age at implantation had a highly significant effect, accounting for just over 50% of the variance after the entry of nonverbal IQ. Similar effects were evident in the comparisons between the net reading scores of children in the early- and late-implanted groups where there were significantly better scores for the children implanted at or before 42 months. Only five children in the sample were implanted at or before 24 months so it was not possible to analyse them as a specific group. However, it is tantalising to note that their net reading scores at 7 years post-implant ranged from +1.6 years to -0.12 years. If they are representative of what might be expected from implants under the age of 24 months, then it may be that the outcomes of children implanted more recently will be even better than those reported here.

At 7 years post-implant, when the children were aged around 10 years, the mean reading lag was less than 7 months for early-implanted children who had a nonverbal IQ score within normal range. It is important to stress that the inclusion of IQ scores in the analysis was an important control because children with a low score, which is likely to reflect significant additional difficulties, are unlikely to have age-appropriate reading scores especially in a language like English where a deep orthography places a high demand on memory. It is also worth noting that the standard deviation of the net reading score was around 1 year for the young-implanted children at 7 years post-implant. This shows that by no means all

children were reading at an age-appropriate level but the pattern of the distribution was not dissimilar from that for hearing children of the same age.

Although the reading ability of the early-implanted children at 7 years post-implant exceeded that of children who were implanted later, there is an important issue to consider before drawing firm conclusions about the significance of this finding. Children who were implanted after 42 months were older at the time of the 7 years post-implant assessment than those implanted at or before 42 months. It could therefore be argued that the reading skills being assessed for late-implanted children were more complex than those being assessed in early-implanted children, especially in relation to text-level skills where deaf children may have additional difficulties (Marschark & Harris, 1996). Given that the reading skills of many deaf children tend to fall further and further behind hearing peers as they get older, this is an important concern. In a recent follow-up of an earlier study, many children continued to develop their reading skills into adolescence in line with chronological age. However there was wide variation and some children did not move beyond the scores they had achieved at the age of 8 and 9 years (Geers et al.).

One way of addressing this concern is to compare the early-implanted group at the 7 years follow-up with the late-implanted group at 5 years post-implant. At this point they were much more similar in age. Figure 1 shows that, on this comparison, there was still a large difference between the groups. Whereas the early-implanted children had a mean net reading score of -0.4 months the late-implanted children had a score of -1 year 9 months (using the figures for the children for whom there were valid nonverbal IQ scores). It would appear from this comparison that the difference between the two groups cannot be explained by the difference in age at the time of the 7 years post-implant assessment.

It does, however, remain a possibility that the reading levels that were evident at the 7 years post-implant assessment for the early-implanted group will not be sustained as children progress through the later years of school. As noted Section 1, the process of reading becomes increasingly complex as the demands of infrequent vocabulary, complex syntax and text integration increase every year. It is therefore important to carry out longitudinal studies well into adolescence to show whether the reading attainment of children implanted early is sustained. It will also be important in future research to investigate the kind of reading strategies that are used by deaf children who receive a cochlear implant early in life. Previous research on deaf children's literacy has shown that working memory span is strongly associated with reading level and this suggests that the ability to make use of phonological coding is a key to reading success for deaf children

(Harris & Morno 2004; MacSweeney et al., 1996). We would predict that successful early implantation enables deaf children to develop robust phonological coding skills and, if this is the case, these should be evident in their reading strategies.

Another issue for further research is the extent of the sensitive period for plasticity in development of the central auditory system in relation to literacy. As noted above, in our study, the cut off point for dividing children according to age at implant was mainly taken on statistical grounds. Research into cortical auditory evoked potentials (CEAPs) has found that children implanted before 42 months show a fundamentally different pattern of response to children implanted later (Sharma et al., 2005). The suggestion is that there is considerable plasticity in central auditory development up until 42 months but that the sensitive period ends around this age. However, other research suggests that there are differences in outcomes for children implanted before and after 24 months (Geers, 2004; Nicholas & Geers, 2008) and even before and after 12 months (Dettman et al., 2007). It thus remains an open question as to the maximum age at which successful implantation will lead to age-appropriate reading.

Finally, it should be noted that the average age of implantation of children in the present study was a great deal higher than that achieved today and, in addition, there has been considerable development of implant technology. Earlier implantation and the provision of state-of-the-art implants would be expected to have an additional positive effect on literacy and there is every reason to suppose that increasing numbers of children who are born deaf will leave school with age-appropriate literacy skills.

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Chapter 4

The parental and young people's perspectives

The papers in this chapter include the views of the users of cochlear implant services: parents and the young people themselves. They were included in the Nottingham protocol from the outset, and involved in the design of the research questionnaires and interviews used to obtain their views. In spite of the controversy surrounding the introduction of cochlear implantation, these parents and young people paint a largely positive picture of life after cochlear implantation with major changes in confidence and communication abilities in these deaf children. However, they are pragmatic and the picture is a realistic one. These children and young people remain deaf after implantation, and their comments and insights reflect this: they are also a diverse group and again the research reported in these papers reveals this. The analyses of the data provided by these families and young people with implants bring together research and practice, with implications for cochlear implant services and for educational services made clear.

Chapter 4.1

Parents and their deaf child: Their perceptions three years after cochlear implantation.

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Abstract

Parents of 30 consecutively implanted children who were born deaf or deafened under the age of three years completed an open-format schedule under 17 headings used as prompts. Their responses took the form of free text scripts of unrestricted length, completed three years after implantation. Rigorous content analysis of the scripts using illuminative research methods led to a framework which underpins this report. The areas covered include: child's functioning, parental implications, family implications, educational liaison, influences on progress, the process of implantation, future needs, and advice given by parents to others. This report describes the content of the scripts supported by quotations in an attempt to convey the richness of the text responses and to describe the experience of cochlear implantation from the family perspective. It covers the issues of the child's functioning, the implications for parents and wider family, and parental views on the process of implantation itself. The three most common issues raised by parents to arise from the analysis were those of increased confidence linked with developing communication abilities, the value of liaison between the cochlear implant centre and local educational services and the importance of continuing specialist support from the cochlear implant centre, particularly to manage any technical difficulties.

Introduction

Introduced to the UK amidst much controversy in 1989, paediatric cochlear implantation has gradually gained increased acceptance. Much research has addressed the surgical safety of the procedure and the functional achievements of children with cochlear implants (Hoffman and Cohen, 1995; Summerfield and Marshall, 1995; O'Donoghue et al., 1998; Allen et al., 1998). However, little attention has been paid to understanding patients' (or parents') perception of the outcomes from cochlear implantation or of the process itself. Healthcare systems are encouraging patients to have greater involvement in their own management and there is the demand to consult with them regularly (Richards, 1999).

A crucial element in paediatric cochlear implantation is the role that parents play in deciding to proceed with cochlear implantation for their child. Deafness is not a life-threatening condition and parents, in thinking about a cochlear implant for their child, are making a decision which is likely to alter communication and educational options for the child (Archbold et al., 2000; Archbold et al., 1998) and one with

which the child will have to live. It is essential that parents have appropriate information on which to base this decision, and the experiences of other parents will be highly relevant. Tapping this experience, considering what is important to parents rather than professionals, is therefore vital in order to make that information available.

However, cochlear implantation remains a controversial intervention. There is still considerable opposition from some parts of the deaf community that questions the whole procedure and the final outcome of cochlear implantation (Balkany and Hodges, 1995; Lane and Bahan, 1998). Mixed information is likely to increase parental anxiety when making a decision about proceeding with cochlear implantation, and the experiences of other parents may be helpful. The parental role does not end in the decision stage, as they are also asked systematically and continuously to play a major role in postoperative rehabilitation (Evans, 1989; Lloyd, 1994). Despite the many professionals involved in the follow-up care of these children, parents are from the beginning the strongest source of support for their children (Evans, 1989) and remain so, even if outcomes do not meet expectations. Additionally, as parents are the critical observers of any intervention to their children, they are uniquely able to assess outcomes in real-life rather than clinical situations.

The few previous studies based on parental experience have used closed format questionnaires devised by professionals to investigate perceptions of parents regarding outcomes for their child (Robbins et al., 1991; Kelsay and Tyler, 1996; Nikolopoulos et al., 2001), although these may have been completed in interview style. Such questionnaires can limit the responses that can be made, and hence may influence the measured outcomes. Little systematic published information has been based on the unrestricted reports of parents on the process of implantation and its outcomes.

This study set out to explore the perceptions of parents without limiting them to prescribed issues. They were asked to describe their child and their family using an open-format schedule (Appendix 1) and were also asked about their own reaction to the process of cochlear implantation, their concerns and future needs. They were asked to respond in the form of free text, without any limitation on the length of each response. Hence the responses were a series of scripts from each parent. A major aim of the investigation was to guide the authors in the construction of a subsequent closed-format questionnaire based on the issues considered important by parents, which is reported in detail separately (O'Neill et al., submitted). That report used rigorous content analysis of the scripts, following

the methods of illuminative evaluation to arrive at a framework for the closed-format questionnaire that was grounded in the original data (Glaser and Strauss, 1967). It also involved cross-checks to minimize bias in the classification of the scripts and in the development of emergent themes.

The above process of obtaining common themes from diverse scripts is a prerequisite for the construction of a closed-format questionnaire; however, it necessarily loses much of the richness and evident face validity of the original scripts. This report was compiled in order to convey the content of the scripts without undue data reduction. Extracts from the scripts are presented with only minimal quantitative analysis in order to allow the richness of the material to show through. The purpose is to allow the parents to speak for themselves, conveying their thoughts and feelings in a number of areas. Care has been taken to represent a range of parents and perspectives and not to over-represent or under-represent particular views.

Methods

The study sample consisted of children implanted at a specialist paediatric cochlear implant centre funded by the UK National Health Service free of charge to the family. They were the first 30 consecutive children to fulfil the criterion of being born deaf or deafened under the age of three years. Children came from all social strata and were educated in a wide range of schools with a variety of educational provision and communication approaches. Nine were born deaf and 21 had acquired hearing losses. Their ages at implantation ranged from 30 to 131 months (mean 50 months). Sixteen were boys and 14 were girls. They may not be representative of those now receiving implants; for example, more congenitally deaf children rather than deafened children are now implanted, as are those with greater levels of residual hearing and those who are younger. However, they do cover a wide range of those children currently being considered for implantation.

The open-format schedule consisted of 17 prompts each followed by white space in which parents were asked to respond in free text. The list of prompts is given in Appendix 1. Schedules were given to parents three years after implantation for self-completion at home. They were asked to return them to the implant centre, but many wished to discuss the questions and some needed help to write their responses. If the latter occurred, every attempt was made not to direct responses but only to act as scribe. The return rate was 100 per cent and most respondents

use the pronoun ‘we’, suggesting that the responses were on behalf of the family rather than one parent.

The order of prompts in the schedule was deliberately non-systematic to encourage independent answers to each prompt. However, in order to achieve a more logical framework for this report, they are grouped in a thematic order below under the headings shown in Table 1.

The following section illustrates the responses of parents using the above framework, incorporating numerous direct quotations. In each case the quotations are represented in italics followed by a figure in parentheses. The figure identifies each family anonymously and allows the reader to identify quotations relating to the same child. At the beginning of each section the major factors mentioned by at least 30 per cent of respondents are given in order, with the number of respondents in brackets.

Table 1. Framework for reporting parental responses

Child and family	
Child functioning	Before implantation Now, 3 years after implantation Greatest area of change Reliance on device What has it enabled child to achieve?
Parental implications	Decision making Concerns or worries Difficult periods Supporting the child Most encouraging moment
Family implications	
Process of implantation	
Educational liaison	
Most useful influences on progress	
How intrusive?	
Future needs	
Advice for others	

Results: implications for child, parents and family

Child's functioning before implantation

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Isolated/withdrawn/introverted	(15)
2. Quiet	(9)
3. Frustrated	(9)
4. Happy/good fun/contented	(9)

Note: Other factors mentioned: Insecure/lacking confidence, lack communication, deaf/no benefit from aid, unco-operative, unhappy, dependent, confused.

In looking at the child's functioning before implantation the most common constructs used to describe children before implantation by parents, in order of frequency of response, are given above. The most common adjectives used to describe children were 'isolated', 'withdrawn' or 'introverted':

'Quiet, withdrawn and confused as to what was going on in the world around him'
(4)

'... would play for hours on end in her own little world' (10)

The words withdrawn and isolated occurred in nine instances along with quiet and frustrated. A number of parents described their children as frustrated:

'She was very frustrated at her inability to communicate easily, especially when her Mummy and Daddy were unable to understand her' (6).

Even those children who had become good communicators using sign language, which had eased communication within the family, could become frustrated:

'... had limited ability to communicate outside the family (meeting so few signers) that he would become frustrated or withdrew from an activity and observed only'
(39)

Lack of communication was mentioned as a difficulty by seven parents: one parent put it strongly:

'... completely cut off with no communication. No confidence, unhappy and often unapproachable. She was out of touch with the world' (21).

Five parents commented that their child was unco-operative, often linked with difficulties in communication, and three other parents commented that their child was unhappy.

However, the picture was far from negative for a significant proportion (about one-third) of parents. For these parents, their child was described as happy, or contented, and fun to be with prior to implantation:

'Contented but quiet' (12).

'She coped amazingly well. Always extremely happy ...' (21).

The parental responses in this section, describing their children prior to implantation, describe the complexity of the situation, bringing up a child with no useful hearing; the majority view is of children who are withdrawn, having difficulties in communication (even in those who have developed good sign language skills), although for one-third of parents, their children were happy and contented.

In response to being asked about their child prior to implantation, five parents gave a description which related to the hearing loss, describing their child as:

'DEAF!!' (6).

'No benefit from powerful hearing aids' (2).

The question asking parents to describe their child after implantation was deliberately not placed adjacent to the question asking about their children before implantation. However, the responses are juxtaposed here to contrast the two intervals.

Child's functioning 3 years after implantation

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Happy/good fun	(16)
2. Gregarious/socially active	(15)
3. More confident/assertive	(15)
4. Communicates effectively	(14)
5. Well adjusted/not frustrated	(9)

Note: Other factors mentioned: Doing well at school/mainstream, independent, talkative, deaf/hearing impaired, monitors environment, socially isolated in new situations, argumentative, better behaved.

The majority of parents, three years after implantation, described the child in positive terms. Inevitably, we would expect a child three years older to be more confident and more socially active; however, it seems likely that parents were not making absolute comparisons, but comparing their child with previous expectations. All parents used at least one of the following constructs: happy, good fun, socially active, gregarious, well adjusted, not frustrated. Half of parents described their child as more confident and assertive:

'Very assertive, confident and kind' (23).

'The frustrations and tantrums of the past have gone' (13).

The increased confidence was not always positive:

'Confident – almost overpowering' (72).

'Strongwilled – fearless!' (14).

'Has learnt to argue!' (12).

The increased confidence and lack of frustration was seen as largely due to increased ability to communicate; it was seen as important to communicate with deaf and hearing people.

'He now talks to less familiar people where he is confident he will be understood' (11).

'Able to communicate with hearing children and adults' (5).

'... likes to be independent by trying to communicate with total strangers' (61).

'She can now mix well with hearing and deaf children at school' (10).

There was, in several cases, a realistic view of the ability to communicate:

'Always seeking to communicate, albeit not always successfully, even now' (27).

Four parents spontaneously commented that it was important to remember the child remains deaf:

'She knows she's deaf, which I think is important for her to remember' (21).

For parents who have decided to proceed with implantation for their child, one would expect a positive picture following implantation. This may be particularly so for this early group, who may not be representative of later parents. The picture was largely positive but at this stage three years after implantation limitations were recognized. Three parents commented on social difficulties:

'... still a little reserved with new people/situations' (20).

'Still somewhat socially isolated, but can work in a bigger group. Inclined to depend on family for interpretation in unfamiliar surroundings, but will try elsewhere' (41).

Eight parents spontaneously commented on improved educational functioning, in several cases linked with attendance at mainstream school. Although several parents commented that a cochlear implant had facilitated local provision rather than attendance at a school for the deaf, there was recognition of the support needed:

'She still needs additional support in school but can now communicate with hearing peers as well as deaf peers' (6).

'He enjoys school immensely ... his favourite subject is maths and he is doing well in all other aspects of his school work' (2).

Only a minority of parents (3) commented on the ability to monitor the environment, which is often quoted by professionals as a reason for implantation.

Child's functioning: greatest area of change

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. More confidence	(23)
2. Easier communication	(19)
3. Speech development	(18)
4. Language development	(15)
5. Greater independence	(12)
6. Improved behaviour	(12)

Note: Other factors mentioned: greater happiness.

When parents were asked about the greatest area of change, ten parents commented that it affected all areas.

'I can't answer this ... all areas!' (27).

'He has improved in every aspect!' (14).

Increased confidence was mentioned by 77 per cent and greater independence by 40 per cent, supporting the descriptions given by them of their children. Only two parents did not mention increased confidence or independence. The comments were frequently linked with the positive changes in communication commented on by 63 per cent of parents:

'The implant has given him a second language that has enabled him to communicate with a larger group of people, and therefore access more activities independently and confidently' (39).

'She is more confident and doesn't need Mum ...' (34).

Positive changes in speech and language development are mentioned in the majority of scripts; to some extent one would expect this as children grow up. However, parents seem again to be connecting what had actually happened, compared with what might have been expected, without an implant:

'SPEECH, without a doubt!' (6).

'Spoken language has developed from almost non-existent to using words and short phrases he hasn't been taught, e.g. move over ...' (41).

Only three parents do not mention positive changes in speech and language and for them there is a recognition that this is not due to the implant, Archbold et al. and that there are other areas of difficulty. For 12 parents, improved behaviour merits comment, often linked with greater ease of communication and fewer tantrums. Only two parents commented that a great area of change was happiness.

Child's functioning: reliance on device

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. All/most of time	(11)
2. At school	(10)

3. Listening/understanding communication (9)

Note: Other factors mentioned: playing outside/traffic, getting attention, entertainment (TV, music), converse in car/in the dark, in bed (radio), unfamiliar situations.

Parents were asked where they felt the child was reliant on the implant system. The three most common responses were: all of the time, at school and for listening, understanding and communication.

Eleven parents spontaneously commented 'everywhere', or 'all the time':

'This is difficult to answer. He puts on his processor first thing every morning; it is the last thing he takes off at night' (39).

'He is totally reliant on it. He wears it all the time and gets upset if not working' (12).

'He wears it all the time so really it's part of him ...' (2).

The implant system was needed at school, on visits, for listening and understanding; the majority of parents commented on its importance in these situations:

'All aspects of daily communication and schooling' (11).

'At home, school, basically all the time' (3).

Specific situations mentioned by parents included in traffic, playing outside (six parents), getting attention (five). These were linked to safety; for example:

'Hearing the traffic – he's safer now' (73).

Five parents mentioned the activities for pleasure which are facilitated by the implant: playing party games, learning a musical instrument, enjoying pop music.

'... is a Take That and Michael Jackson fan!' (49).

'Watching the television – he enjoys music' (73).

Four parents mentioned that it is now possible to have conversations in the dark, or in the car, which would be impossible without the implant system.

Child's functioning: what enabled to achieve

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. More integrated schooling	(19)
2. Greater social activities	(16)

Note: Other factors mentioned: spoken language, relationship with grandparents, participate in hearing world.

When parents were asked specifically what they felt the implant enabled their child to do which was impossible without it, the majority of parents (19) spontaneously commented on what they considered to be the influence of the implant system on educational placement and achievement. This was always in the direction of mainstream education and oral education. Where a child was in a unit or resource-base placement, it was compared with a school for the deaf; where the child was in mainstream, it was compared with a unit, or resource base.

'She is in a mainstream school and doing well ... with appropriate support keeping up' (34).

'Her schooling would have had to have been of a more sign based education' (20).

'I'm sure she would have had to be sent away to school which I dreaded. Now she can go to school locally and live at home' (10).

'It allowed her to attend mainstream school, which, without the implant, I think would have been very difficult to cope with' (21).

Greater possibility of social activities was mentioned by 16 parents; the fact that the child could be more independent in play, and participate more easily in a variety of activities, was mentioned once more. They mentioned making friends with children nearby and being able to attend Brownies, ballet classes and so on independently. It was felt that the implant had made socialization easier:

'Her social environment would have been more limited, relying on family to act as interpreters for her' (20).

'Play outside without supervision' (73).

Parents recognized the importance of having both deaf and hearing friends, and three commented that the implant had facilitated this:

'She's more independent within friendships due to being more confident than perhaps without a C.I.' (36).

'She has made friends herself, something which has never happened before' (5).

Within the family, four parents in this section specifically mentioned grandparents; this will be covered again later, but spontaneously occurred here; for example, children had been enabled by the implant to speak to grandparents on the telephone and thus have relationships otherwise impossible.

'She can talk to her grandparents, who are overseas, on the telephone' (34).

Results: parental issues

Having given the parents' views about their child, and implantation, what of the implications for themselves?

Parental issues: Decision making

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Nothing to lose/no benefit from aids	(14)
2. Chance to hear	(13)
3. Part of hearing world	(9)

Note: Other factors mentioned: chance to talk, wider options/fuller life, environmental sounds.

The table above reveals the constructs most commonly used by parents when asked about their reasons for choosing an implant for their child. Bearing in mind that the children in this study were implanted when only the most profoundly deaf children were considered suitable, half of parents stated clearly that they felt their child had nothing to lose, as there was no benefit from conventional hearing aids.

'She had nothing to lose and everything to gain' (27).

'He was getting no benefit from conventional hearing aids and we felt he had nothing to lose and everything to gain by going for an implant' (4).

'Due to her profound loss she had absolutely nothing to lose if it didn't work ...' (36).

The chance to hear was also mentioned by half of parents; only two parents didn't mention either notion:

'The best chance of giving her some sort of hearing ...' (32).

'It is the only possibility of hearing sounds of the world ...' (72).

For many parents making the decision today, with more relaxed guidelines on suitability, the decision may not be so clear cut. For the parents of the present study, the opportunity to hear sounds was an opportunity only an implant seemed to offer. A third of parents commented that they wanted their child to be part of the hearing world, many feeling this would offer their child a choice later:

'We felt this gave him a CHOICE for his future using both or either British Sign Language or spoken language' (39).

'We felt it offered her a chance to become part of the hearing world' (27).

'... in order to make the best of himself in a hearing world, for whether we like it or not, that is what it is' (25).

The chance to talk was felt to be an important part of this, spontaneously mentioned by one quarter of parents. For example:

'... the opportunity to acquire speech, a better chance of communicating effectively with the hearing world...' (103).

For the few children in the study who had some speech and lost it, this was particularly important:

'We had watched him lose his speech and after trials with hearing aids realized that we had nothing to lose if we tried the implant' (3).

For one-quarter of parents, the cochlear implant was seen to offer wider options through the possibility of developing spoken language and communicating more easily in the hearing world. Parents used the phrase 'a fuller life' or similar wording on several occasions:

'To achieve a more independent and fulfilling lifestyle. The ability to communicate with the majority of her peers' (34).

'We wanted her to have wider options with friends, education and eventually jobs' (23).

'We felt that this was the best opportunity of offering him a better quality of life ...'
(43).

Environmental sounds and their importance for safety reasons were mentioned by one-fifth of parents. For example:

'... even if the implant had not been hugely successful, we felt that some ability to be aware of environmental sounds would at least help her when dealing with, say traffic' (27).

Parental issues: Decision making – advice for others

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. 'Go for it!'	(18)
2. Gain information	(10)

Note: Other factors mentioned: prepare for hard work/long time/disruption/patience, strong oral/aural input, look at my child, do not compare child, choose centre.

Parents were asked what advice they would give to others considering cochlear implantation for their child. Although 18 used the phrase 'Go for it!', or something similar, this was tempered with advice about decision making, and about the period after implantation.

'It's wonderful and you must give your child this chance, BUT be prepared for a long haul and to work hard on persevering. I couldn't help thinking despite being told otherwise that after a couple of years there would be a roller coaster effect and his speech would just take off' (13).

'Do it. Whatever the outcome, you have to say you did what you could' (4).

'To remember that the wonderful achievements which are possible, only become apparent very gradually' (27).

'I would not give any advice apart from "do not hesitate!"' (14).

'Our experience has shown that implantation can have amazing benefits for profoundly deaf children' (2).

The advice in the majority of cases was to be patient and to be prepared for a long haul. Twenty-three per cent of parents directly mentioned the need for patience:

'Go ahead, being prepared for a lengthy period of tuning/learning etc.' (49).

'Have a lot of patience, it doesn't give children a sudden hearing capability' (49).

'We have no regrets – it was the best thing that could have happened for him, only don't expect too much too quickly' (12).

In addition, advice was given to parents to do homework prior to making the decision.

'Research – read all you can and meet as many implanted children and their parents as you can ... Ask questions, never feel they are silly or irrelevant' (6).

'Talk to other parents ... try not to have too high an expectation. Be as patient as possible'

(103).

Assessment was considered important:

'Go with it, providing the child is suitable' (17).

Three parents specifically advised choosing the Centre carefully. Four parents directly mentioned the need for a strong oral/aural input; this is not a substantial number, but no parents gave the advice to maintain signing in this section.

While four parents said, 'Look at my child and see the benefits', another three warned strongly against comparing children:

'Don't compare your child with other implanted children – it's what benefits your child is getting that matter' (16).

Although over half directly advised to proceed, the over-riding advice seemed to be to consider the decision carefully and proceed advisedly:

'It has to be a decision only you can make, don't let others influence you. I just feel we all have to try anything we can. Unfortunately it is still a very hearing orientated world so we have to give our children all the help we can' (16).

Parental issues: Concerns/worries

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Device failure/problems	(13)
2. Schooling	(11)
3. Speech (clarity/need for therapy)	(9)

Note: Other factors mentioned: constant underlying stress, employment, lacking belonging hearing/deaf world, child will blame parent, deaf culture pressure, longterm electrical stimulation.

The most commonly mentioned concern by nearly half of parents was device failure or technical difficulties and the effect this could have on their child.

'That for some reason the implant fails and she loses everything she has fought so hard to achieve' (34).

'What happens now if something mechanical fails, what happens if something internal fails?' (4).

'For the implant to remain functioning lifelong' (11).

With young children, parents were aware of possible physical restrictions:

'I am very concerned about him banging his head and damaging his implant' (14).

For parents who have experienced one device failure, this is clearly a priority.

'Our worst fears are of a more mechanical nature' (20).

The second most commonly appearing concern was education, appearing spontaneously in about one-third of replies. Typical concerns were:

'Educationally, will she be able to cope in mainstream?' (17).

'Education – we are concerned that he gets the right sort of input. Many schools in our area are going down the signing route and we don't want that' (12).

'Her schooling – whether the right amount of support will be available ... whether we've made the right decision' (21).

Thirty per cent of parents were concerned that the child's speech was not wholly intelligible and recognized that this may be a problem at school:

'His speech at times is unclear ... In the classroom situation I worry about what he is missing ...' (3).

'Whether she will continue to improve her speech' (23)

'There is still a long way to go to converse with her beyond short simple statements' (72).

For many parents, they believed that more speech therapy would be helpful:

'I believe the clarity of her speech would improve with adequate speech therapy' (6).

'Speech therapy – I feel that she is now ready for it and it is a must to clarify her speech' (36).

Two parents clearly felt that they were constantly under stress, two mentioned future employment and four parents discussed the decision related to the deaf/hearing worlds; one feeling concerned that their child might blame them in future:

'Him not fully belonging to the deaf and hearing community' (43).

'That he will actually be able to feel part of the hearing and/or deaf worlds and could be caught in the middle' (103).

Interestingly, no parent mentioned concern about the consequences of long-term electrical stimulation.

Parental issues: difficult periods

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Operation and anticipation	(10)
2. First few months	(9)

Note: Other factors mentioned: assessment, switch-on, decision, technical problems/re-implant, dislike of aid, expectations of others, Deaf culture pressure.

Parents were asked what the most difficult part of the implantation process had been. The operation itself and the lead-up to it were the most commonly named difficult period; for parents to decide to proceed with elective surgery for their child, the operation period obviously remains a difficult time they remember, even three years after.

'I hated the operation ... it seemed an awful thing to do to an unsuspecting child' (10).

'Making the decision and going through with the operation' (32).

'Most difficult period was on operation day waiting for him to come back and know he was OK' (25).

Having decided to proceed with this elective operation, parents were obviously anxious to see benefits and the next most commonly mentioned difficult time was the first few months after initial tuning, as parents waited to see the progress:

'The first three months after implantation – it seemed like three years. Doing all we were asked and nothing seemed to be happening. With hindsight our concerns were not justified!' (6).

'The first six months after the implant – getting him to wear it and long tuning sessions' (43).

'Probably the first six months after "switch-on" when he often pulled his device into pieces and flung them all over the house' (13).

Twenty-three per cent of parents mentioned the assessment period, when they did not know whether their child would be appropriate for implantation and another 23 per cent mentioned the 'switch-on' period as being particularly difficult.

'... after her traumatic reaction to switch-on waiting to see if she would accept and wear the implant (she did!)' (34).

'... switch-on and a couple of weeks afterwards were trying when she did not want to wear her processor' (6).

The decision itself was mentioned as the most difficult time by three parents particularly, but it underlay many responses:

'Always the question of are we doing the right thing' (16).

For the parents who had experienced re-implantation, this had clearly been the most stressful time of all:

'Re-implantation! ... they (siblings) were all very upset about the re-implantation' (17).

The impact of expectations was vividly described by one set of parents:

'The most difficult aspect throughout of all our time in the implant programme has been the continual over-expectations of family and friends and continuous under-expectation of Health and Education Professionals on a local level' (39).

Parental issues: supporting the child

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Reduced help	(13)

Note: Other factors mentioned: same quantity: different, more short term – less overall, no change, less signing, more rewards.

Parents were asked whether the implant had changed the amount of help needed by their child. The most common response by nearly one-half of parents was that the child needed less help, although this was often qualified with realism:

'... she does not need so much help to communicate. She still needs a vast amount of help to make progress' (72).

'The amount of help is less ... he becomes more independent' (11).

For 23 per cent of parents, the quantity of help was the same, but the focus different:

'The type of help needed has changed – not the amount' (49).

'He has always needed and will continue to need help. The type of help has changed. He no longer seems to need the systematic "formal" teaching from us.' (24).

For some parents (16 per cent) the amount of help was greater in the short term, with the hope of it being less in the long term:

'In the short term I would say she has more help, but of course we are hoping that in the long term she will need us less' (10).

Three parents commented on the need for less signing with their child, and two that there were more rewards. The parents were committed, on the whole, to supporting their child in any way possible, but one relaxed mum commented:

'I don't know, I don't really think about it' (36).

Parental issues: encouraging moment

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. First response	(9)

Note: Other factors mentioned: first response to name, converse without looking, joined in conversation, communicate with hearing child, attempt 'mummy', tells me about school, singing/choir, phone, first phrase learnt by hearing, go to events alone, every time call name, first word, hearing birds sing.

Having been asked about the most difficult period and their worries and concerns, parents were also asked about their most encouraging moment. Thirty per cent of parents spontaneously mentioned their child's first response to sound:

'Switch-on – seeing her respond to the first sounds' (32).

'When she first heard something – her reaction' (49).

There was a range of other moments: four parents mentioned the first response to name:

'When she turned to her name' (6).

When communication, using audition, is meaningful is clearly important. Parents commented on a variety of situations: When their child could converse without looking, when they could join in conversations, communicate with a hearing child, had acquired a phrase by hearing alone and when they could talk to their parents about school. Examples include:

'Seeing her in the playground (unaware you are watching) interacting with her friends. They are talking to her and she answers and is understood ... also when she comes home from school and you have understood before you open the home/school book ...' (34).

'When he answers a question and you know he isn't looking at you or was even in another room or upstairs' (2).

'He joined in a private conversation his Dad and I were having about his younger brothers – we couldn't believe it!' (43).

Two parents mentioned going to events alone:

'Being able to go to a Brownie weekend ...' (23).

'Leaving her at a party not really knowing any one there and having a good time' (20).

Using singing and talking for pleasure:

'When he was watering the plants by himself and singing to himself at the same time' (14).

One child showed her parents that she appreciated her own skills:

'She recently told a member of the family: "Don't sign – it's too difficult for you – talk. I can understand."' (28).

Family issues

Major factors mentioned

No. of respondents

1. Siblings relationships changed

(13)

Note: Other factors mentioned: improvement in grandparent relationships, share family situations more fully, more independent in family, no longer deaf/equal.

Relationships with siblings were the most common issue arising from implantation for the family, mentioned by parents. The effect was equally likely to be negative, as positive; seven parents commented on the difficulties experienced by brothers and sisters:

'His older brother, now eight years old, has found this whole period difficult to understand and cope with' (39).

'We think that the younger sister has suffered due to all the time and attention we have focused on her' (28).

The difficulties were not always due to implantation:

'Not specifically from implantation, his brother finds it hard going having a deaf brother and all the attention he gets' (2).

However, many siblings shared in the process:

'Possibly some slight jealousy from brother and sister due to extra attention for her, but mostly just delight at the improved communication' (10).

Half of the parents commented that there had been no effect on siblings, and six commented that it had been positive:

'Her brother and sister feel that all the effort of making her understand them is worthwhile, because it is becoming easier to communicate now' (72).

When asked about the implant's effect on the child's relationships with other members of the family, eight parents mentioned an improvement in grandparent relationships, generally because of ease of communication, particularly where grandparents hadn't learned to sign:

'Grandparents in particular feel more able to cope with him and he has been able to stay with them and make himself understood. They were too nervous before' (12).

'Grandparents especially feel more able to treat her as a grandchild and not someone to be feared if they are unable to understand her or make themselves understood' (6).

Sharing family situations more fully was commented on by seven parents; for example:

'More involved with the family and day to day conversations around dinner table where before he was possibly left out as it was extremely difficult to make him aware of what the conversation was about' (61).

The acquisition of spoken language skills, however slowly, had led to children becoming more independent in the family in several cases:

'He can now communicate with members of the family who bother to try and understand him rather than ask me what he is saying' (43).

This may lead to the possibility of arguing on more equal terms than previously:

'He argues with his brother and also plays and talks with him more' (2).

Three parents considered that within the family the child was no longer considered deaf:

'She is no longer "deaf" to them' (72).

'As time goes by his brother is forgetting he is deaf' (3).

The effect seems to arise from easier communication mentioned by well over half of the families, which is summed up by:

'The implant has improved, beyond measure, the family's willingness to interact with him' (39).

All parents, except three, commented on a positive development in family relationships, a fuller participation in family events. While one would expect improved relationships and communication over time as the child matured, parents related it directly to the acquisition of spoken language via the implant:

'Close relationships with family, especially grandparents and aunts and uncles. Just easier twoway communication' (6).

Results: Process of implantation

At several points in the questionnaire, parents were asked to comment on the process of implantation itself: its effects on them and the family, the vital parts of the process, and what they had learnt from it to advise others.

One of the strongest constructs to emerge from the questionnaire was the need for educational liaison between Centre and school.

Process of implantation: educational issues

(n = 29, as one family was abroad)

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Liaison necessary/very helpful/essential	(24)
2. Liaison – to work with local Teacher of the Deaf	(16)

Educational issues have already arisen as an important issue in other contexts: the perceived influence of the implant system on educational placement and achievement. However, parents were also asked directly about the implant programme's link with the educational service. Eighty-three per cent of parents commented that the liaison between school and implant centre had been very important; words such as 'necessary', 'essential' or 'invaluable' were used – it was most common for parents to comment on the need to advise and work with the teachers, rather than with the child:

'It's been helpful that you have been there to help the teachers and give advice' (73).

'Yes, your trained staff have been able to help and discuss his educational needs with his teacher of the deaf and staff at his primary school, all of whom we feel have worked extremely well together' (61).

Their teamwork is represented in many responses, with several parents commenting that advice came better from another professional, than from parents:

'... I think most teachers will only take advice from a professional' (36).

'Extremely helpful – invaluable to have these links. Everyone seems to work as a team on his behalf' (24).

'Excellent! Making them aware of what an implant does and raising their expectation levels. Giving them new ideas and encouraging them generally' (103).

Many of these children were the first to have implants in their areas and the advice and support was particularly welcome:

'No one had any previous experience of cochlear implants so some help with how to deal with a child with an implant was essential' (10).

Where there had been problems with the implant system, the support had been particularly useful:

'Invaluable, without your support we are confident she would not be wearing her implant at all' (28).

There could be the conflict between the interests of the cochlear implant children and those with hearing aids, but more than one parent commented that the liaison influenced the school with all deaf children:

'... is helping the school to become more aware of the needs of deaf children' (43).

The educational outreach programme, whereby implant centre teachers of the deaf visit local schools regularly, is an accepted means of providing support in the UK, with the aim of empowering local professionals to support children with cochlear implants. The comments that parents make in these scripts appear to reinforce its usefulness to them in terms of developing local confidence and skills, but also in maintaining levels of support.

Process of implantation: most useful influences

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Wearing it	(12)
2. Quality of team support	(11)

Note: Other factors mentioned: teaching to listen, regular tuning/assessments, links school/teacher of the deaf, Mum and Dad, positive attitude, everything, reliability, signing support.

Parents were also asked what were the most useful influences on promoting the use of the device. The most common spontaneous comment was one which may appear obvious: wearing it!

'Encouraging him to keep it on' (43).

'He's never needed encouragement to wear his device – it's on all waking hours' (2).

Factors in promoting the child's consistent wearing of the device included the quality of input by all aspects of the implant team, with regular tuning and assessments to ensure that the system was working optimally:

'Support from the implant team ...' (25).

'The implant centre teacher of the deaf explaining the potential at school' (103).

'Good tuning – continuous support' (23).

While parents recognized the importance of input from the team, four parents commented directly on their own involvement, and a further three on the need for a positive attitude:

'Mum and Dad, but the work we did (and are doing) would not have been possible without the implant centre teacher of the deaf's support/advice and information' (6).

Through the responses comes a sense that parents felt it important to make things fun, using everyday situations:

'... an enjoyment of wearing the processor' (39).

'Trying to make listening fun' (103).

'Making sure, foremost, she enjoys the benefits' (21).

One parent commented on the reliability of the system and one parent on the signed support which they felt had been useful in helping their child interpret the signals.

Process of implantation: how intrusive was it?

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Not at all/as expected	(17)
2. For siblings	(9)

Note: Other factors mentioned: travelling/time away, yes, financial, benefits outweigh disadvantages, operation.

Parents were asked to comment on the intrusiveness of the period of implantation for themselves and their family. While parents picked up on this notion, just over one-half of parents commented that the experience hadn't been intrusive, or at least, only as expected:

'Not really ... took it in our stride' (23).

'I feel, on the whole, it caused far less disruption than I envisaged' (16).

Nine parents specifically mentioned brothers and sisters once more in this section:

'Not intrusive, obviously siblings get a bit cheesed off, for want of a better word' (25).

'Brother has probably been affected the most being passed from one person to the other in order to attend appointments with her and not have him as well' (34).

For some parents the travel and appointments had clearly been very disruptive and difficult to organize:

'Appointment days in particular have been very long and stressful ...' (39).

'It was a very disruptive period, but the worst part was organization of the care of the family during trips to Nottingham – it was certainly worth it' (2).

'Considerably intrusive by the number of visits necessary, but these are realized as essential and the family adapted accordingly' (49).

Where difficulties have been experienced, for example re-implantation, then the effect on the family can be disruptive:

'You try and bring the other children into it, but it's bound to affect the family group – they were all very upset about the re-implantation' (17).

For parents of a child who was not happy wearing the device at first:

'With no doubt it has completely taken over all our lives – due to the pressure of getting her to wear the coil continuously followed by the problems regarding her educational placement' (28).

Process of implantation: future needs

<u>Major factors mentioned</u>	<u>No. of respondents</u>
1. Contact for queries/problems	(24)

Note: Other factors mentioned: information on new developments, monitor progress, happy with plans, concerned re reduction, parents/family meetings/ newsletter, as much as possible.

When parents were asked about their needs for the future from the cochlear implant team, all parents emphasized the need for continued contact:

'Continued advice/help when needed' (43).

'... it is nice to know that someone is at the end of the phone' (36).

Parents were well aware of the need for on-going technical support, as their children were becoming reliant on their implant systems:

'... have you all there for breakdowns' (3).

Parents remain aware of the responsibility they have taken for their child, and appear to want to continue to share it:

'... our children are walking round with a foreign body in their heads, hopefully for the rest of their lives and that will always be a concern' (25).

Six parents mentioned specifically that they wished to be kept up to date with new developments and technology and five specifically mentioned monitoring progress. These questionnaires were completed three years after implantation, and at that stage the educational support changes from a bi-monthly basis to an annual one; some parents (five) were concerned about the reduction, while another five said they were happy with the plans, although they would like more if available.

'As now, we understand that this is not possible, but we are glad that you can be available to help as and when it should be necessary' (24).

There emerges the possible problem of dependency on the implant team which needs to be addressed; for example:

'It's the problem of "once a year" – that we've got to separate from you. If you weren't seeing N I'd be worried about the lack of contact' (73).

'As much as possible, I can't imagine ever coping solely without you' (21).

While most parents recognized the time for change, four specifically mentioned the importance of family contacts via newsletters and family meetings.

'We thoroughly enjoy the meeting with all the other families, we would come more often if it wasn't such a trek for us' (13).

The impression is that these families had shared the responsibility and decision with the team and wished to continue the link and shared responsibility. With their experiences of implantation, what had these parents learnt which was useful advice for others?

Discussion

The present study was designed to allow parents to express their feelings as freely as they wished, rather than responding to professionally derived closed-set questionnaires. As can be seen from the quotes, parents were very forthcoming

about their experiences of paediatric cochlear implantation, and provided a great deal of information that needed little further discussion and interpretation.

When considering the views presented by this group of parents, it may well be that they are not a representative group of those whose children are referred for cochlear implantation today. They were the first 30 families at one specialist paediatric programme. Currently there are likely to be more congenitally deaf children than those with acquired losses, for example. In addition, this group of children comprises those whose aided thresholds were greater than 80 dB(A) using conventional hearing aids; children are now being considered for implantation with much greater levels of residual hearing, and at much younger ages. However, this group does cover the majority of the range of ages, of social strata, of educational settings and of communication approaches that would be currently represented.

A major difficulty in interpreting parental comments three years after surgery is the caution that must be used separating cause and effect. One would naturally expect changes in behaviour to take place due to maturation, for example. However, with these qualifications, there are some consistent threads through the responses which are worth noting.

The major one to appear was changes in the child's confidence and communication abilities. Parents attributed the development of and increase in confidence and communication abilities not to developing maturity, but to increased ability to hear – particularly to hear spoken language. This was reflected in many areas of the child's development: relationships with other members of the family, ability to participate socially and in educational settings. Alongside this developing confidence and communication was the emerging dependency on the technology, the need for long-term support, liaison with the cochlear implant centre and education liaison. This was particularly true in parents' awareness of the effects on their child of any technical problems and the need for the cochlear implant centre to manage these speedily to enable continued effective functioning of the device. There are significant implications for cochlear implant centres and manufacturers to provide the necessary infrastructure for long-term support as numbers of implantees continue to grow.

Deafness in a child has long been seen to affect the whole family (Luterman, 1987) and the parents' responses recognized the effect that the process of cochlear implantation had had on the whole family. Although there was this recognition, there was also evidence from the scripts that the process of cochlear implantation need not be intrusive for the family. There was an emphasis on

careful preparation, on obtaining as much information as possible prior to implantation and on the need for patience in many of the scripts.

This would appear to be sensible advice to parents considering cochlear implantation. It may be that the process of cochlear implantation appears intrusive to those for whom a decision must be made quickly, for example following meningitis, when there has been no period of adjustment to the diagnosis of deafness. Additionally, in the few cases requiring re-implantation following device failure, the effect on the whole family was mentioned in each case. The need for accurate, up-to-date information and careful preparation evident in these parental scripts has implications for those supporting parents in making such decisions following early identification of deafness, likely with the introduction of universal neonatal hearing screening.

With regard to the wider family, the effect on siblings was mentioned but was seen as equally likely to be positive as negative. It could be related to the deafness itself, rather than implantation. The other family members who were particularly mentioned were grandparents, with whom communication was seen to be easier as the children became more able to speak and more readily understood by them. It may be that cochlear implant teams should consider including the wider family in the preparation period more fully so that siblings can be more fully involved in the process and grandparents understand the long-term nature of outcomes from implantation.

Cochlear implantation has been criticized for requiring intensive rehabilitation and support: there has been extensive debate on whether this is necessary. Profoundly deaf children require specialist support with or without cochlear implantation; following cochlear implantation, the focus of support and management is likely to be different when there is greatly increased access to an auditory signal (Archbold, 2000). These parents commented that their children may need more support in the short term but less in the long term and this was supported by a survey of teachers of the deaf (Archbold and Robinson, 1997). Children following cochlear implantation have new auditory potential; the parental role in helping utilize this fully is considerable.

Parents were clearly aware of the importance of educational support for their children and also of the influence that cochlear implantation may have on the educational decisions of placement and communication mode. For these parents, implantation was seen to have had an effect on educational decisions and this was generally in the direction of mainstream provision and oral education. Recent studies confirm that this is likely to be a realistic outcome for children implanted early, without any other difficulties. Archbold et al. (submitted) showed that

children implanted below the age of five are significantly more likely than those profoundly deaf of the same age with hearing aids to go to mainstream schools.

A major issue of concern to parents was that there should be long-term liaison between cochlear implant centre and local educational services: at the time these children were receiving their implants, many teachers of the deaf had little experience of managing children with cochlear implants. During the ensuing period this may have changed; most implant centres provide continuous update courses in managing the technology and courses are available for those who wish to specialize in the management of children with cochlear implants. However, the implementation of the technology of cochlear implantation continues to develop rapidly and candidature and expectations continue to change. Direct contact between implant centre and local professionals is vital to ensure the most effective on-going care; this is particularly vital at several significant times. For example, at times of change of the child's school or teacher, when a change in the technology is provided, and particularly if there is a device problem. This problem may be medical, or technical; if technical it may be an intermittent problem, rather than device failure. This may be more difficult to determine and will require close liaison between those who know the child well at home and school, and those who are specialist in cochlear implant management at the implant centre.

These parents also had major concerns, three years after implantation, about levels of speech intelligibility and had hopes for further improvement. Long-term experience of children with implants informs us that, following implantation, speech intelligibility continues to develop over many years, where there are no other problems. It is not until the three-year interval, on average, that speech becomes intelligible provided the listener concentrates and lip-reads. Further improvement in speech intelligibility is generally observed at the four-year interval and has not reached a plateau even in the five-year interval (Allen et al., 1998). This information must be made available for parents in an accessible form while they are making decisions about proceeding with implantation in order to set realistic expectations.

Many of the issues in these scripts are common to those raised by the parents of any deaf child. However, for these parents, a crucial difference is the difficulty of making the decision to proceed with a major elective operation for their child. There was no evidence here that parents made the decision lightly – although supportive of cochlear implantation, their advice to other parents was to find out as much information as possible, and to be prepared to be patient.

Conclusion

Three issues particular to this group emerged from the scripts:

- 1) the change in confidence and communication abilities seen in their children following implantation
- 2) their reliance on the functioning of the technology and on the expertise of the cochlear implant centre to maintain it and therefore the need for continued ready contact
- 3) the necessity for close liaison between implant centre and educational services.

These were spontaneously mentioned by three-quarters of all parents and were clearly important to them. The free responses from these parents make these issues all the more worthy of note. The issues raised have implications for cochlear implant teams in terms of providing the infrastructure for effective long-term technical support, for accurate information and for liaison between cochlear implant centre and local educational support services.

The views reported here are of immense interest and value. They also make it possible to create a questionnaire instrument that can be used with larger samples, where statistical data are required. The need for such an instrument to evaluate the impact of cochlear implantation on large groups of deaf children and their families led us to develop a closed-format questionnaire based on these parental responses. This questionnaire (O'Neill et al., submitted) has the benefit of being derived from the parental rather than the professional perspective. It will enable us to explore these issues systematically with a larger group of parents and across cochlear implant centres.

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Appendix 1

The Open-format schedule used to elicit responses:

1. How would you describe your child before implantation?
2. Why did you decide to go ahead with the implant?
3. What has been the most difficult period for you and why?
4. How intrusive has the period of implantation and/or follow up been to you, your child, and other members of the family?
5. What area of development has shown the most changes? e.g. communication, behaviour, confidence, independence, language, speech
6. How would you describe your child now?
7. What do you feel the implant has enabled your child to do that would have been impossible without it? (Thinking of schooling, independence, family relationships, friendships etc.)
8. Can you give examples of situations in which your child is reliant on the implant?
9. What has been your most encouraging moment?
10. What areas of concern do you have now for the future?
11. Do you feel that having the implant has changed your child's relationship with other members of the family? If so, in what ways?
12. Do you feel that having the implant has changed the amount of help you need to give your child? If so, in what ways?
13. Has there been any effect on other members of the family from the implantation?
14. Have you found our links with your child's educational service helpful? If so, how?
15. What contact would you like from us in the future?
16. What do you feel has been the most important element in ensuring your child made as full use of the implant system as possible?
17. What advice would you give to other parents thinking about implantation?

Chapter 4.2

Deciding to have a cochlear implant and subsequent after-care: parental perspectives

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Abstract

Cochlear implantation provides a means of hearing to profoundly deaf children. As it is an elective procedure, parents must make the decision to proceed with this option if their child is suitable. The processes involved are complex and stressful, involving hope and expectation on the one hand, and doubts and caution on the other. This study explored parental perspectives on the process of implantation via an established questionnaire completed by parents three years after implantation.

The parents of 101 consecutively implanted children completed the questionnaire: Children with cochlear implants: parental perspectives. Average age of implantation was 4.7 years (range 1.3–12.4 years), with 86% congenitally deaf and 14% acquired deafness. Parents responded to 74 statements on a Likert scale; the responses exploring the experience of the process of implantation, including decision making, were analysed for this paper.

The study revealed a substantial consensus on parents' expectations, but there was also interesting diversity. Parents generally agreed that there was a need for regular checking and tuning of the device, that only experienced teams should carry out implantation and that reliability was a major factor in device choice. Need for as much information as possible prior to implantation and for long-term support with annual visits from the implant team on a regular basis was endorsed. Parents also valued their own role: a positive attitude was considered vital.

Areas of diversity included how stressful the decision making and the process were considered. Parents' needs may also differ from the traditional implant team view; in this study, while the main goal was spoken language, sign language was also valued.

In times of increasing accountability and demands on healthcare services, how the varied needs of families can be met in the long term to maximise successful implant use remains a major challenge. Copyright © 2006 John Wiley & Sons, Ltd.

Introduction

Cochlear implantation is an elective operation, stimulating the auditory nerve for those who are profoundly deaf and is an accepted option for young deaf children,

with over 45,000 children implanted world-wide. The cochlear implant system consists of a surgically implanted internal device and externally worn equipment. In children, the process of implantation itself, involving detailed assessment, surgery and a lifetime's ongoing technical support, involves a great deal of personal investment by parents, who usually make the decision on their child's behalf.

This decision about cochlear implantation is particularly challenging for parents, given the variation in outcomes which exists between children for reasons that are not yet fully understood (Thoutenhoofd et al., 2005) and the paucity of studies giving long term outcomes on large groups. Additionally, following the introduction of newborn hearing screening, parents are being confronted with the decision to implant earlier than ever, when they may be feeling uncertain and vulnerable, and looking for a cure for the deafness (Luterman, 2005). Making this decision is inevitably a combination of previous experience, knowledge and information and their hopes for their child (Li et al., 2004). Some query whether parents can judge on behalf of their deaf child. Parents may have differing priorities and some argue that the decision about implantation should wait until children are old enough to take it for themselves. However, this is no longer a realistic option, given the research evidence that early implantation gives better results (Nikolopoulos et al., 1999; O'Donoghue et al., 2000; Miyamoto et al., 2005). The small amount of research that has been conducted investigating parents' decision making processes highlights the variety in the attitudes of parents and the importance of personal

characteristics (Steinberg et al., 2000; Li et al., 2004). It is thus important to obtain information from a range of parents who have undergone the decision making and implantation processes themselves. These parents can provide insights for others considering the process which are unavailable to those professionals who are advising them (Nunes et al., 2005). This information is also important for clinical implant teams planning their practice.

Previous research has explored implantation from a professional perspective, but comparatively little work has examined the process of implantation from the perspective of family and parent (Thoutenhoofd et al., 2005). While it would be valuable to access the views of the children themselves, in practice waiting until there are significant numbers old enough to report is unrealistic (Nunes et al., 2005). Some questionnaires have looked at parental views (Robbins et al., 1991; Kelsay and Tyler, 1996; Nikolopoulos et al., 2001; Spahn, 2003). These questionnaires were usually designed by the professionals associated with implantation and this may restrict the responses from parents to those anticipated

by the professionals, rather than including those considered important by the families. Other studies have used qualitative research approaches which provide fresh insights into parental views (Perold, 2001; Steinberg et al., 2000), but investigated only small groups which may not be representative of larger groups. The study of Sach and Whynes (2005) interviewed over 200 parents, giving rise to rich data, but such interview data are complex and time-consuming to manage for clinical or educational teams.

The present study investigated the perspectives of a large number of parents three years after implantation using responses to the questionnaire, Children with cochlear implants: parental perspectives, developed by Archbold and Lutman (Archbold et al., 2002), thus providing data more readily analysable than those from interviews. The questionnaire arose from parental experiences of implantation expressed in open format written responses which were subject to content analysis. The questionnaire is therefore based on the issues considered important by parents rather than those considered worth exploring by the professionals working with them, and the data are a reflection of the views of the parents themselves. It has been shown to be robust (O'Neill et al., 2004) and was externally validated by questionnaire and interview (Nunes et al., 2005). The present study, in reviewing the responses of a large unselected group of families, three years after implantation, using a validated and reliable questionnaire which arose from the experiences of parents themselves, provides views of parents on the process of implantation, including the decision making, and the outcomes for their child and family. The study is reported in two papers; this first reports the views of parents on the decision making and their experiences of the process, and the second reports the parents' perceptions of the outcomes for their child and family.

Method

The questionnaire, Children with cochlear implants: parental perspectives, is routinely used with parents of children at Nottingham Cochlear Implant Programme at the three year assessment interval after cochlear implantation. It consists of 74 statements covering the two following areas:

The process of implantation including decision making.

The outcomes from implantation including:

- Communication
- General functioning

- Well-being
- Self reliance
- Social relations
- Education
- Effects of implantation
- Supporting the child

This paper reports the data collected from this group of parents about the process of implantation, including the decision to implant.

The development of the questionnaire has been fully described (Archbold et al., 2002; O'Neill, 2004) and has been used in other studies, for example, Nicholas and Geers (2003), and Huttunen et al. (2005). The statements are balanced for negativity and positivity, and are not grouped according to theme in the questionnaire itself. Statements are numbered consecutively as they appear in the questionnaire — S1 being the first statement, S2 the second and so on (See Tables 1 and 2). Teachers of the deaf at Nottingham Cochlear Implant Programme distributed the questionnaire to parents three years after implantation. It is likely that parents' perceptions change over time, as reported by Perold (2001) and therefore it was decided to collect data at one specific interval. At three years after implantation it was felt that parents were sufficiently distant from the operation itself to reflect in an objective manner, and by this time both the benefits and the challenges were likely to have become clear. It was self-administered and returned to the Programme by post. Data were entered onto the Programme's database. This paper used the responses of the parents of the first 104 children implanted consecutively, following completion of the questionnaire, excluding a further two explanted children and two who had emigrated. The programme is funded by the UK's National Health Service, and therefore free at the point of delivery. The families came from throughout the UK and from a wide range of social backgrounds.

Parents ticked responses to the statements on a Likert scale, ranging from strongly agree to strongly disagree. Strongly agreed (SA) took the value 1, agree (A) the value 2, neutral (N) 3, disagree (D) 4 and strongly disagree (SD) 5. Of the 104 entries on the database three cases were excluded from analysis, two because of missing data and one due to problems with data entry. Data were analysed in SPSS version 11.5 and explored using two approaches. First the distribution of responses across the five response categories was analysed for each statement to identify the strength of feeling and the variability in responses across parents measured by the standard deviation.

Second, correlations between responses to statements were examined using Spearman's to explore the relationships between parental responses.

A correlation coefficient indicates the nature of the relationship between statements, such that the value gives an indication of the strength of the relationship and the sign indicates the direction of the relationship. Although a statistically significant correlation (here defined as at either the 0.05 or 0.01 level) indicates that there is an association between two variables it does not imply causation.

Results

For the 101 completed questionnaires, 51% of the children were female and 49% male. Average age at implantation was 4.7 years with a range of 1.3 to 12.4 years. The majority (86%) were congenitally deaf whilst the remaining 14% had acquired or progressive deafness. Three years after implantation 59% of the children used an oral or aural approach to communication, 39% used total communication and 2% were bilingual. Fifty one per cent of these children were in mainstream schools with specialist units or resource bases, 40% were at mainstream schools without units or specialist resources, 2% were at schools for the deaf, 1% were at preschool and 2% were in other settings (e.g. independent school or being taught at home).

Results are presented below as a series of tables. Tables 1 and 3 present the percentage responses to the statements about the decision to implant and the correlation matrix for these statements respectively. Tables 2 and 4 present the percentage responses to the statements about the implant process and the correlation matrix for these statements respectively.

Making the decision

Table 1 shows percentage responses from parents to the statements about the decision making process. The standard deviation illustrates the variability in responses, with the greater the standard deviation the greater the variation.

The strongest area of agreement was that parents should obtain as much information and advice as possible before proceeding (S46). No parent disagreed with this statement.

Table 1. Percentage of responses by category and statement on decision making

	Statement	SA	A	N	D	SD	Standard Deviation
S28	Making the decision to proceed with implantation was the most difficult part for me	26	29	5	20	21	1.528
S46	Before proceeding with implantation, parents should obtain as much info and advice as possible	71	27	2	0	0	0.505
S56	I expected her/him to learn to talk once s/he had her implant	21	42	13	19	6	1.188
S57	I worry that ultimately s/he may be neither part of the deaf or hearing world	6	17	21	37	20	1.163
S58	It was important to me that my child could hear sounds from traffic for safety reasons	59	36	2	3	1	0.769
S60	I believe now that my child will have reasonable prospects for employment	30	48	18	5	0	0.824
S68	I chose implantation for my child so she would have a chance to become part of the hearing world	52	34	6	5	4	1.041

Where SA = strongly agree, A = agree, N = neutral, d = disagree, and SD = strongly disagree

By contrast, there were a number of areas where diversity was shown. The greatest range of opinions is evident in responses to the statement about how difficult it was to make the decision to implant (S28). While approximately 55% agreed or strongly agreed that the decision 'was the most difficult part for me', approximately 41% disagreed or strongly disagreed with this. The concern that the child may become neither part of the hearing or the deaf world (S57) also shows a spread of responses across the categories, with 21% feeling neutral, 23% agreeing and 57% disagreeing. There was also a range of responses to the statement that learning to talk (S56) was an important expectation from implantation. While 63% agreed that this was an expectation, 25% of parents disagreed, showing that for a number of these parents, the expectation of learning to talk was not strongly held.

Looking at the responses to the other statements that consider the reasons for proceeding with implantation: the statement with the strongest agreement was that it was important for the child to hear sounds from traffic for safety reasons (S58). Fifty nine per cent strongly agreed and 36% agreed with this statement, with only

4% disagreeing. This was followed closely by 86% of parents agreeing that they chose implantation so that their child would have a chance to become part of the hearing world. (S68), and by 78% of parents who hoped for reasonable expectations for employment, (S60).

Table 3 provides the correlation matrix for the statements about the decision to implant, illustrating the relationships between the statements. Those parents who chose implantation so that their child could be part of the hearing world were more likely to expect their child to learn to talk after implantation and to have chosen implantation for traffic safety reasons and for employment prospects. They were less likely to have had difficulty in making the decision and to worry about whether their child was part of the hearing or deaf world. Conversely, those who had difficulty in making the decision were less likely to choose in favour of an implant because their child would be part of the hearing world, or that they would learn to talk.

The process of implantation

Table 2 presents parental responses to the statements relating to the process of implantation. Looking first at the statements (S21, S25, S36, S40, S43, S44, S49, S52) which look at what parents found helpful. A broad consensus existed on the core elements of service that parents valued. Over 90% of parents agreed that they expected only experienced teams to carry out implantation (S21), that regular tuning and checking are essential (S43) and that the implant team visit the home/school at least once a year (S44).

Over 90% also agreed that the reliability of the implant was the most important factor in choosing a device (S52). In addition, 93% agreed that it is essential their child is encouraged to wear the processor all the time (S40), 82% had found it helpful to meet other families of implanted children (S49) and 72% of parents also wanted advice from the implant centre on their child's future. While parents had found meeting other parents useful prior to implantation there was less consensus about participating in meetings with other families after implantation (S25).

Table 2. Percentage of responses by category and statement on the process of implantation.

	Statement	SA	A	N	D	SD	Standard Deviation
S10	It has been a problem getting someone to look after the family when we go to the implant centre	4	7	14	34	42	1.05
S13	The programme at the implant centre should emphasise speaking and listening	47	34	14	5	1	0.928
S21	Only experienced teams should carry out implantation	79	17	1	2	1	0.683
S22	The costs of travel to the implant centre are a problem	5	14	17	40	25	1.144
S24	Signing support is helpful for a considerable time after implantation	40	33	11	7	10	1.291
S25	I wish to participate in meetings with other families who have an implanted child	16	47	25	11	2	0.946
S29	It was a difficult time waiting for the results of the assessments before implantation	37	45	9	10	0	0.924
S34	We feel the need for advice from the implant centre concerning her/his future	22	51	15	10	3	0.996
S36	We are reliant on the implant centre for technical advice concerning her/his implant	51	41	2	4	1	0.804
S38	The process of implantation was no more obtrusive than expected	15	55	14	14	3	0.996
S40	It is essential that s/he is encouraged to wear the processor all the time	71	22	3	2	3	0.889
S42	A positive attitude is a great help towards successful use of the implant	73	25	1	1	0	0.539
S43	Regular tuning and checking of the implant system is essential	79	20	0	1	0	0.487
S44	At least one visit per year by implant staff to home/school is essential	75	24	0	1	0	0.508
S49	It was useful to meet another family with an implanted child before deciding on an implant	47	35	12	6	1	0.938
S52	The most important factor in choosing an implant device is its reliability	50	38	9	4	0	0.801
S54	I am confident that the long-term electrical stimulation will not be a problem	8	43	42	5	5	0.899
S55	The whole process of implantation is still stressful	15	28	19	26	13	1.287
S63	It has been hard to take time off work for the appointments at the implant centre	5	23	15	33	25	1.230

Where SA = strongly agree, A = agree, N = neutral, D = disagree, and SD = strongly disagree.

Table 3. Correlation matrix for decision making.

	S28	S46	S56	S57	S58	S60
S46	0.037					
S56	-0.198*	-0.020				
S57	0.078	-0.119	0.003			
S58	-0.126	0.288**	0.101	-1.112		
S60	0.108	0.248*	0.121	-0.287**	0.306**	
S68	-0.281**	0.150	0.297**	-0.252*	0.435**	0.244*
Correlation is significant at *0.05 and **0.01 level.						

Although 63% agreed with this, only 16% of these strongly agreed. A positive attitude being essential to the success of implantation was agreed by 98% (S42).

While there was strong agreement that implant teams should emphasis speaking and listening (S13), with 47% strongly agreeing and 34% agreeing, there was also agreement that signing support was useful after implantation for a considerable time (S24), with 40% strongly agreeing and 33% agreeing.

On the whole parents had not experienced problems in getting someone to look after the family while at the implant centre (S10) — 76% disagreed with this statement, and 65% disagreed that the costs of travel have been a problem. Getting time off work had not been a problem for the majority of parents (S63), 58%, although this leaves 28% who had experienced some difficulty.

With regard to the stress experienced by families, 70% agreed that the process of implantation had been no more intrusive than expected (S38). However, the most difficult time had been waiting for the results of the assessments: 82% agreed that this had been the case. There was less consensus evident in the responses to statement S55 about the stress related to the process of implantation as a whole, with 43% agreeing and 39% disagreeing that the process remained stressful three years after implantation.

The question which gave rise to the greatest number of neutral responses was S54, asking about long-term electrical stimulation being a concern; 42% responded neutrally to this question.

In Table 4 the correlation matrix for statements about the process of implantation is presented. Response to the statement that a positive attitude is a great help (S42) is positively correlated with most statements except those expressing experience of difficulty: it is significantly negatively correlated with S10 (problems in looking after the family), S22 (costs of travel) and S63 (hard to take time off work). It is significantly positively correlated to statements S43 (regular tuning is

essential) and S44 (annual visits to home and school) at the 0.01 significance level. Parents attaching importance to a positive attitude were also more likely to want the implant programme to emphasise speaking and listening, want only experienced teams to implant and to participate in meetings with other families. They were also more likely to state a continuing need for technical support, to feel that implantation was no more obtrusive than expected, to want their child to be encouraged to wear the implant all the time, have found meeting other families before implant helpful and feel that the reliability of the device is the most important factor in choosing it. In addition statements S43 (regular tuning necessary) and S44 (annual visits to home and school necessary) had the strongest positive correlation coefficient (0.841) of any of the statements suggesting that those who view the benefits of yearly visits highly also see regular tuning as essential.

The statement (S24) agreeing that signing support is helpful after implantation is significantly negatively correlated with the statement (S13) that the implant programme should emphasise speaking and listening. In addition, it is significantly positively correlated with S55; that is those parents agreeing that signing support is useful for a considerable time after implantation were also more likely to agree that they still found the implantation process stressful.

Although not all families wanted to attend meetings after implantation, those families who did wish to have meetings with other families (S25) were more likely to want continuing support and advice from the implant centre (S34, 36) and to have found meeting families before implantation useful (S49).

Discussion

A major issue to emerge from the analysis presented here is that although there was a consensus amongst this group of parents about a core service, there was also variation in the ways in which individual parents view the implant process, in what they found difficult and what they found helpful. For implant teams, set in medical and scientific contexts where goals and decisions are often clear cut, some of the diversity of views of parents may be unexpected and unrecognised.

Table 4. Correlation matrix for process of implantation

	S10	S13	S21	S22	S24	S25	S29	S34	S36	S38	S40	S42	S43	S44	S49	S52	S54	S55
S13	-0.334**																	
S21	-0.160	0.269**																
S22	0.395**	-0.220*	-0.207*															
S24	0.053	-0.200*	0.048	0.065														
S25	-0.138	0.177	0.051	-0.026	-0.020													
S29	-0.088	0.128	0.232*	-0.019	0.025	0.066												
S34	0.094	0.135	0.179	0.163	0.184	0.261**	0.087											
S36	-0.180	0.232*	0.201*	-0.109	0.025	0.222*	0.031	0.269**										
S38	-0.190	0.103	0.168	-0.106	0.076	0.090	0.273**	0.026	0.151									
S40	-0.148	0.126	0.279**	-0.363**	-0.006	-0.065	0.009	-0.070	0.049	0.126								
S42	-0.386**	0.231*	0.417**	-0.259**	0.191	0.255**	-0.019	0.186	0.380**	0.272**	0.549**							
S43	-0.304**	0.317**	0.572**	-0.216*	0.112	0.150	0.179	0.141	0.284**	0.292**	0.529**	0.694**						
S44	-0.304**	0.256**	0.494**	-0.222*	0.197*	0.210*	0.169	0.090	0.241*	0.319**	0.486**	0.700**	0.841**					
S49	-0.153	0.282**	0.149	-0.129	-0.011	0.386**	0.187	0.196*	0.204*	0.188	0.075	0.326**	0.215*	0.236*				
S52	-0.187	0.403**	0.417**	-0.246*	0.038	0.064	0.203*	0.111	0.543**	0.283**	0.239*	0.370**	0.377**	0.420**	0.212*			
S54	-0.115	0.014	0.103	0.050	-0.009	-0.041	-0.038	-0.045	-0.028	0.236**	0.040	0.087	0.112	0.070	0.046	-0.058		
S55	0.066	-0.073	0.069	0.121	0.384**	0.107	0.146	0.115	-0.034	-0.048	-0.112	-0.171	-0.095	-0.049	-0.002	0.001	-0.175	
S63	0.472	-0.252	-0.161	0.374**	0.068	-0.075	0.035	0.024	-0.088	-0.106	-0.060	-0.281**	-0.215*	-0.233*	-0.082	-0.179	-0.161	0.268**

Correlation is significant at *0.05 and **0.01 level

Consensus of opinion

Although there were interesting variations, there were also considerable areas of agreement between parents as to their core needs. The need for regular tuning and checking of the device was found to be the strongest area of agreement, with the consensus that only experienced teams should carry out implantation, and that reliability of device was important.

Having as much information as possible before implantation was the second strongest area of agreement highlighting the importance of an issue that may be neglected in tightly managed healthcare services. In the study of Spahn et al. (2003) in Germany, parents had obtained their information largely from the media and from other parents, rather than from within the medical or audiological professions. Parents making this decision for an elective operation for their child should expect to be able to easily access up-to-date, accurate information and it should be readily available early after diagnosis, if early implantation, with its recognised benefits, is to be a real choice.

The third overall area of agreement was of the value of annual visits by the implant staff to home/schools. This is a service that many implant centres are reluctant or unable to provide, given the many demands on them. However, in this study parents valued these visits.

The fourth area of agreement was that a positive parental attitude was a great help towards successful use of the implant. This was an interesting point as it concerns a vague, undefined, psychological term. However it was found to positively correlate with many statements: the need for regular tuning, annual visits by the implant staff to home/school, only experienced teams implanting, finding meetings with other families helpful, continuing need for technical support, choosing device reliability and with the feeling that implantation was no more intrusive than expected. Parents who believed in a positive attitude were also less likely to experience problems in looking after the family, with the costs of travel and obtaining time off work. It may be that parents realise that thinking and acting positively, in an optimistic way, is one of the non-measurable ingredients in their children's progress and a contributing factor to the wide variations in outcome.

Although there is consensus that speaking and listening should be emphasised, there is also consensus that signing support is useful for some time after implantation, which may seem contradictory. Traditionally, cochlear implantation has been thought of as an alternative to sign language; that parents have to make the decision between implantation and sign language. These parents are supporting both: Christiansen and Leigh (2004) also found in their study that

although parents wanted spoken language for their child they supported the use of sign language before and after implantation. Spencer (2004) also suggests that it may be possible to find a way forward with both sign language and implants and that we need to be more flexible in our thinking. A study by Watson et al. (2006) shows that the majority of children in the study used signed communication to some extent prior to implantation and changed to spoken communication over the years following implantation. Although better outcomes after implantation have been associated with oral education (Geers et al., 2003; Tobey et al., 2003) this is not conclusive (Thoutenhoofd et al., 2005). Archbold et al. (2000) showed no difference in outcomes as measured by speech perception and production three years after implant between a group using oral communication, and a group matched for age at implantation which had begun with signed communication and changed to oral communication over time. The review of the literature by Spencer and Marschark (2003) also reported that no one communication mode has yet overcome the language delay of deaf children after implantation. Cochlear implants, in providing more useful hearing than ever before for profoundly deaf children, may offer the opportunity to use both sign language and spoken language, and for parents to keep their options open, as they seem to wish to do in this study.

Diversity of views and experiences

Incesulu et al. (2003) found that parents considered the decision to implant very stressful, but for this group of parents, there was diversity of views as to whether this was the most difficult part of the process. Kluwin and Stewart (2000) in a telephone survey of 35 parents of children with implants, identified two decision sequences: those who obtained their information from medical sources and sought 'normal' communication for their children and those who actively sought a range of information from other parents, families and teachers. Cochlear implantation, while involving surgery and hence needing medical input to the information giving and decision making process, involves a broad range of issues. It involves parental considerations of how they wish to communicate with their child, their perceptions of deafness, their attitudes and family aspirations. Steinberg et al. (2000), who reviewed the role of parental values in making the decision about cochlear implantation, found little agreement amongst parents as to the value placed on different aspects of the child's well-being. There was disagreement as to what was considered the best outcome from implantation and whether the goal was wholly spoken communication or the use of sign language too. Some variation is found in

this study; although the goal is learning to talk, there is support for the use of signing some time after implantation. This is true despite the fact that families in this study come from throughout the UK and from a range of educational services, advocating a range of communication approaches.

That the decision to implant is not straightforward for some parents was also found in the study of Li et al. (2004) who looked at 83 sets of parents; only two thirds of parents whose children were eligible considered proceeding. Those who did not proceed with implantation placed lower emphasis on mainstream education, on the ability to speak and were more concerned about the costs and availability of services. The factors which influenced parents to proceed with implantation went beyond audiological and medical eligibility; they included such issues as parental preferences, goals, values and beliefs. In our study, those who found the decision most difficult were less likely to choose implantation for their child to be part of the hearing world, and to expect talking as an outcome from implantation. It may be that those finding the decision difficult were less committed to what is considered one of the major goals of implantation — providing enough hearing to facilitate the development of spoken language.

The study of Li et al. (2004) also emphasised the importance of surgical risk, which may seem comparatively less important to medical staff dealing with such risks on a daily basis than to parents. Small-scale research by Spahn et al. (2003) compared parents of children with implants and those with hearing aids for parental distress. Both groups showed high levels of distress at the time of diagnosis which then subsided; however, the fitting of a cochlear implant heightened the distress to previous levels, whereas the fitting of hearing aids did not. Any surgical procedure in a child would involve some levels of stress for parents, particularly an elective one.

Another area of diversity was whether the process remained stressful three years after implantation. The responses were also divided between those who wished to participate in meetings with other families after implantation and those who were ambivalent about it. Parents will also differ in the ease with which they can get time off work, obtain help with family commitments, or afford the costs of travel to the centre, and this was reflected in their responses. Variation reflects differences in experiences, differences in coping strategies and the support networks they enjoy. Variation may exist not just between parents at the same point in time but be shown by the same parents over time, as shown by Perold (2001) and by Sach and Whynes (2005).

Implications for implant teams and their organisation

Prior to implantation, these parents wanted to go to experienced teams, considered it important to have a great deal of information and to meet other families. There is much information available to parents, for example from the National Deaf Children's Society, but there is also a great deal of uninformed material, particularly on the internet. Cochlear implant teams have a responsibility to ensure that parents have access to information that is accurate. With rapidly changing technology it is vital that parents are furnished with the latest information, particularly as reliability of the system is seen as the most important issue in device choice.

The finding that the majority of parents find waiting for results during assessment a difficult time places a responsibility for implant teams to ensure that they are carried out in a timely manner and conveyed in appropriate and understandable language; the assessments carried out for implantation are complex and wide-ranging.

The range of information needed and the variation in parental needs and expectations places demands on cochlear implant teams to be particularly sensitive to the views of the parents with whom they work. The views of parent and professionals about their child may differ, with differing goals. For implant teams, the major goal may be that of providing useful hearing: the parents in this study had a wide range of longer term goals, and while wanting spoken language, valued the role of sign language after implantation. These goals may not always be readily understood by medically led implant teams and to engage parents of varying views and backgrounds is a challenge.

While it is common to feel that waiting for results is a difficult time, the wide variation in those who find the process to be stressful means that some of these parents continue to require support. To identify what is found to be stressful, whether travel to the centre, managing the technology, or appropriate education for their child takes time and demands flexibility of response. Further investigation of our data confirmed the variability of parental views; only two families agreed with all the statements expressing difficulties in accessing the services, the other families had difficulty in one area or another. In times of health service accountability, to provide flexible services is challenging. Meeting the differing needs of parents and families in the process is difficult to build into care pathways, or to cost into auditable services.

Implant programmes need to find ways in which to provide flexible services. Identifying stressed parents could, for example, allow programmes to target support activities more effectively both in terms of the type of support offered and in terms of who receives it. Recent work highlights those who had the highest parental stress: they were those who were earlier in the implant programme's existence, those whose child had a device failure or problem with the implant, or who lacked support (be this from work, family, the education system, or as a result of the distance they lived from the programme) (Sach and Whyne, 2005).

The parents in this study clearly wanted long term input from the implant team: at least one visit a year by the implant team to home and school and regular tuning and checking of the system. This supports the recommendations of Watson and Gregory (2005) that some non-use of implant systems could have been averted by more regular checking of the system, and supports the views of the parents in the study by Archbold et al. (2002) that a major concern was the link between the implant clinic and educational services. With regard to the support required after implantation, two statements received strong agreement: that of having a positive attitude and of ensuring the processor is worn all the time. The implant team may only be able to encourage the former, but has responsibility to facilitate the latter, ensuring that parents and local professionals supporting the child on a daily basis have the skills to manage the complex technology. These are issues that can be costed and built into service planning and audit.

Conclusions

This study provides information from a large, unselected group of families about their experiences of the implant process. While there is a degree of consensus about what they want from implant programmes and what they hope for their children, there is interesting variation in their responses, indicating that services need to be constructed to allow for variation in support. Different families want different things from the programme, and may want them at different times; for example if there are changes in the technology or problems with the system. Their needs may also differ from the professional viewpoint; this study confirmed that while wanting their child to be part of the hearing world, and having the goal of hearing and talking, these parents also valued sign language.

They do not generally appear to be taking the traditional view of choosing either implant or sign language, but to value both, with implantation providing an opportunity to move on from the old arguments about communication choices for

deaf children. Identifying need and providing variation in service delivery are a challenge for implant teams to be responsive to changing needs over time.

Although there was variation in expectation and experiences, there were areas of consensus. While implantation was not more intrusive than these parents had anticipated, the major area of difficulty experienced by the majority in waiting for results of assessments may not always be appreciated by busy implant professionals familiar with hospital systems. The desire of parents for information demands that this is provided in accessible and varied formats, and includes more than just audiological and medical information. These families valued the experience of the implant teams, and the need for long-term technical support. They wanted the input from an implant programme to continue, with local contact on a regular basis. In times of ever increasing accountability and demands on services, meeting this in the long term to maximise successful implant use remains a major challenge.

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Chapter 4.3

Outcomes from cochlear implantation for child and family: Parental perspectives

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Abstract

While cochlear implantation is an increasingly routine provision for profoundly deaf children in many countries, parents still require information about the procedure and likely outcomes in order to make an informed decision. Other parents can provide them with the insights of those who have undergone the process themselves and observed outcomes at first hand.

The parents of 101 consecutively implanted children completed the questionnaire: Children with cochlear implants: parental perspectives. Average age at implantation was 4.7 years: range 1.3-12.4 years, with 86% percent congenitally deaf, and 14% acquired deafness. Parents responded to 74 statements on a Likert scale; the responses exploring the process of implantation have been reported in a previous paper. Those responses reporting the outcomes for children and families following implantation are analysed in this paper.

Parents reported that they were largely satisfied with the outcomes from implantation: that their children developed greater confidence, were more independent, that the use of spoken language had developed greatly and that communication within the family had improved. The children did not need more support from their parents than before implantation and the support parents were giving was more productive.

However, there still remained concerns: parents needed to be patient as progress took time, and a number remained concerned about future education and felt that outcomes from implantation had not met their expectations.

The children were considered reliant on their implant systems and hence on the optimal functioning of the technology; this demands long-term management to ensure that those dealing with the technology on a daily basis have the skills and equipment to manage them optimally. Copyright © 2008 John Wiley & Sons, Ltd.

Introduction

There are now over 80,000 children with cochlear implants worldwide and in many countries the majority of profoundly deaf children now have implants. Although cochlear implantation is now considered routine by many, parents are still required to make the decision to proceed on behalf of their child. Following newborn hearing screening, often they do so very early in the infant's life. While there is a great deal of research published on outcomes in terms of speech perception and production to inform parents' decision

making, there is still comparatively little published about the perceptions of parents themselves (Thoutenhoofd et al., 2005). Information on other parents' experiences and on their perceptions of the process itself and of expectations and outcomes are likely to be helpful to parents considering cochlear implantation for their deaf child. Archbold et al. (2006) reported that parents felt it important to have as much information as possible prior to implantation.

It is important that any information given to parents reflects the reality of experience as fully as possible; where studies use professionally designed questionnaires, it may be that some issues that are important to parents are overlooked. Archbold et al. (2006) discussed the perceptions of 101 parents considering decision making and the process of implantation itself, finding that parents' needs and experiences are very varied and may not conform to the expectations of others, including implanting teams. Some studies looking at parental views on the experience of implantation have found that parents may experience concerns (for example, Kelsay and Tyler, 1996; Nikolopoulos et al., 2001; Perold, 2001; Spahn, 2003; Weisel et al., 2007) and provide helpful insights for other parents. Parents' experiences and perceptions are also important to consider in relation to outcomes: for example, Lin et al. (2007) found that all outcome measures were positively associated with parental perceptions of development, while Weisel et al. (2007) found that expectations in communication and academic attainments decreased as time after implantation increased.

Qualitative research approaches provide opportunities for fresh insights to be raised by parents (for example, Perold, 2001; Steinberg et al., 2000), but these usually investigate only small groups which may not be representative of larger groups. This is the second of two papers reporting a study exploring parents' perceptions using the questionnaire *Children with Cochlear Implants:*

Parental Perspectives, developed by Archbold and Lutman (Archbold et al., 2002). It reviews the responses of a large unselected group of families, three years after implantation, using this validated and reliable questionnaire that arose from the experiences of parents themselves on the outcomes from implantation for their child and their family. This second paper explores the parents' perceptions of the outcomes from implantation for their child, rather than those of the process itself, reported in our previous paper (Archbold et al., 2006).

Method

The questionnaire Children with Cochlear Implants: Parental Perspectives is routinely used with parents of children at Nottingham Cochlear Implant Programme at the three-year assessment interval after cochlear implantation. It consists of 74 statements covering the two areas of:

- The process of implantation including decision making
- The outcomes from implantation including:
 - Communication
 - General functioning
 - Well-being
 - Self-reliance
 - Social relations
 - Education
 - Effects of implantation
 - Supporting the child

This second paper reports the data collected from this group of parents on their views on the outcomes from implantation for their child and family.

The development of the questionnaire has been fully described (Archbold et al., 2002, 2006; O'Neill et al., 2004). It arose from parental experiences of implantation expressed in their own words in open-format written responses which were then subject to content analysis. The questionnaire is therefore grounded in the issues considered important by parents rather than those considered worth exploring by the professionals working with them. The data obtained from it are a reflection of the views of the parents themselves. It has been shown to be valid and reliable (Nunes et al., 2005; O'Neill et al., 2004), to be robust (O'Neill et al., 2004) and has been used in other studies, for example, Huttunen et al. (2005) and Nicholas and Geers (2003). A study by Damen et al. (2007b) confirmed the usefulness of the questionnaire and suggested that a short form be developed.

The statements are balanced for negativity and positivity, and are not grouped according to theme in the questionnaire itself. Statements are numbered consecutively as they appear in the questionnaire - S1 being the first statement, S2 the second and so on. It is likely that parents' perceptions change over time, as reported by Perold (2001) and therefore it was decided to collect these data at one specific interval. Teachers of the Deaf at Nottingham Cochlear Implant Programme distributed the questionnaire to parents three years after implantation. At three years after implantation it is considered that parents are sufficiently distant from

the operation itself to reflect in an objective manner, and by this time both the benefits and the challenges are likely to have become clear. It is self-administered and returned to the Programme by post. This paper uses the responses of the parents of the first 104 children implanted consecutively following publication of the questionnaire, excluding a further two explanted children and two who had emigrated. The programme is funded by the UK's National Health Service, and therefore free at the point of delivery. The families came from throughout the UK and from a wide range of social backgrounds.

Parents are asked to tick their responses to the statements on a Likert scale, ranging from strongly agree to strongly disagree. For the purposes of this paper strongly agreed (SA) took the value 1, agree (A) 2, neutral (N) 3, disagree (D) 4 and strongly disagree (SO) 5. Of the 104 questionnaires, three were excluded from analysis, two because of missing data and one due to problems with data entry. Data were analysed in SPSS version 11.5 and explored using two approaches. First the distribution across the five response categories was analysed for each statement to identify the strength of opinion, and the variability in responses across parents measured by the standard deviation. Second, correlations between responses to statements were examined using Spearman's rho to explore the relationships between parental responses. A correlation coefficient indicates the nature of the association between statements, such that the magnitude gives an indication of the strength of the association and the sign indicates the direction of the association. Although a statistically significant correlation (here defined at the 0.05 level) indicates that there is an association between two variables it does not imply causation, as it may be that both the responses are caused by a third factor. Due to the size of tables produced, the results of the full correlation analysis are not tabulated but they can be requested from the authors.

Results

Of the 101 responses to completed questionnaires available for analysis, 51 per cent related to children who were female and 49 per cent male. The average age at implantation for these children was 4.7 years with a range of 1.3 to 12.4 years. The majority (86%) were congenitally deaf whilst the remaining 14 per cent had acquired or progressive deafness. Three years after implantation, 59 per cent of the children used an oral or aural approach to communication, 39 per cent used Signed Supported English and two per

cent used British Sign Language. Fifty~one per cent of these children were in mainstream schools with specialist units or resource bases, 40 per cent were at mainstream schools without units or specialist resources, two per cent were at Schools for the Deaf, one per cent were pre-school and two per cent were in other settings (e.g. independent school or being taught at home).

Tables 1-8 give the responses in each of the domains, showing the percentages responding in each category of the Likert scale and showing the standard deviation. The responses of parents to the statements are outlined below in each of the domains: communication, general functioning, well-being, self-reliance, social relations, education, the effects of implantation and supporting the child.

Communication

Table 1 shows the pattern of responses to the statements about communication; the strongest endorsement was that the use of spoken language has developed greatly (S71), with 89 per cent of parents agreeing that this was the case. Where spoken language was reported to have improved greatly (S71), this resulted in reported improvements in all communication domains. A majority (85%) agreed that their child was talkative (S72) and 73 per cent disagreed that communication was difficult (SI). Seventy~nine per cent agreed that they could now chat where lipreading was impossible, for example in the dark (S27) and 68 per cent that speaking was easier than signing (S66). However, there was a spread of views about the quality of speech with a third of parents expressing some concern about their child's speech three years after implantation (SI8). Those parents expressing concerns (SI8) about the quality of speech of their children were also more likely to report difficulties with a known speaker (SI). Those who reported concerns about speech quality (SI8) were also unlikely to be able to chat without their child seeing their face (S27).

General functioning

Table 2 shows the responses to the statements relating to general functioning. The greatest change noted is in the children responding when called - 98 per cent endorsed this statement. Parents also considered that their child could now amuse themselves by listening to music, or watching TV (90%).

Table 1. Percentage responding to statements in domain: Communication (N=101)

Communication		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S1	Comunication is difficult with known people	8	11	8	46*	28	1.205
S18	The quality of her/his speech gives me cause for concern	13	20	17	26*	25	1.375
S27	We can now chat even when s/he cannot see my face	38	42*	8	10	3	1.063
S66	I find it easier to communicate with her/him by speaking	45*	24	16	13	3	1.182
S71	Her/his use of spoken laguage has developed greatly	59*	30	6	3	2	0.886
S72	Now s/he is talkative and engages others in conversation	51*	35	4	8	3	1.045

Bold value represents strongest response

Table 2. Percentage responding to statements in domain: General functioning (N = 101)

General functioning		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S4	Before implantation s/he obtained no benefit at all from het hearing aids	52*	22	3	19	5	1.326
S6	S/he is totally reliant on her implant all the time	42*	28	13	15	3	1.187
S7	S/he knows when I want her attention because she can hear me call	67*	31	1	0	1	0.612
S35	S/he can now amuse herself listening to music or watching TV or playing games	55*	36	4	3	3	0.923
S51	I can now let her/him play outside as she is aware of the sound of traffic	16	36*	18	19	12	1.268
S53	S/he is still uable to cope in new situations	5	13	24	40*	19	1.091

Bold value represents strongest response

Table 3. Percentage responding to statements in domain Self-reliance (N = 101)

Self-reliance		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S12	I can seldom leave her/him to do something on own	10	15	8	29	39*	1.374*
S32	A significant change has been improvement in her/his confidence	44*	41	10	2	4	0.974
S33	S/he was very dependent on us before the implantation	42*	39	12	7	1	0.945
S47	S/he is as independent as most other children of her age	29	33*	12	23	4	1.234

Bold value represents strongest response

Table 4. Percentage responding to statements in domain: Well-being (N = 101)

Well-being		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S16	S/he still shows signs of frustration in her behaviour	13	39*	11	23	15	1.314
S59	Her/his behaviour has improved since she had her implant	37*	27	25	9	3	1.108
61	S/he has become argumentative since getting her implant	12	25	33*	14	17	1.245
S64	S/he is less frustrated than before she had the implant	34	49*	14	1	3	0.884
S70	S/he continues to be a happy child and good fun to be with	60*	32	3	4	1	0.819

Bold value represents strongest response

Table 5. Percentage responding to statements in domain: Social relations (N = 101)

Social relations		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S5	S/he does not have a close relationship with her grandparents	2	7	10	29	53*	1.019
S30	S/he was socially isolated before getting her implant	25	36*	17	20	3	1.150
S39	S/he does not make friends easily outside the family	5	15	9	45*	27	1.157
S41	S/he is sociable within the family	65*	31	0	3	1	0.740
S45	S/he shares in family situations more than before implantation	44*	36	12	6	3	1.029
S65	S/he takes part in family relationships on an equal footing with other members	37	44*	12	7	1	0.924
S74	Her/his relationship with brothers and sisters has improved	23	36*	24	13	5	1.125

Bold value represents strongest response

Table 6. Percentage responding to statements in domain: Education (N = 101)

Education		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S9	S/he is unable to cope with mainstream schooling	4	15	15	38*	29	1.150
S23	S/he is keeping up well with children of her own age at school	16	37*	18	26	4	1.144
S31	The local school and support services adequately meet all our needs concerning the use of her/his implant at school	29	47*	7	15	3	1.096
S37	I am concerned about her/his future school placement	17	36*	16	24	8	1.229
S48	Parents should have a choice in the use of sign language at school	34	49*	12	3	3	0.919
S50	I am happy about her/his progress at school	32	51*	10	4	4	0.969
S69	S/he is totally reliant on her implant at school	44*	35	9	11	11	1.070

Bold value represents strongest response

Table7. Percentage responding to statements in domain: Effects of implantation (N = 101)

Effects of implantation		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S2	Immediately after implantation her/his ability to communicate was poorer	5	6	22	40*	28	1.071
S8	I worry that the implant will break down	12	33*	26	20	10	1.175
S11	Progress during the first few months seemed very slow	2	39*	6	17	19	1.436
S14	I worry that s/he will blame me for my decision for her to have an implant	4	7	14	34	42*	1.095
S17	I am concerned that my deaf child will be rejected by the deaf community because of the implant	7	17	22	35*	20	1.187
S26	Progress after implantation has exceeded my expectations	32*	37	13	15	4	1.165
S73	Other children in the family resented the time and attention taken up by the implant	2	17	21	27	34*	1.157

Bold value represents strongest response

Table 8. Percentage responding to statements in domain: Supporting the child (N = 101)

Supporting the child		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Standard Deviation (SD)
S3	The help I gave her/him has become more productive now s/he has her/his implant	37	56*	2	2	3	0.832
S15	S/he has needed more help from me since she received her/his implant	9	15	21	39*	17	1.192
S19	A lot of help at first means a child needs less help later	16	27*	25	21	12	1.257
S20	I get more time to myself because of her/his increased independence	13	38*	21	25	4	1.102
S62	A parent of a child with an implant needs to be patient as benefits may take time to show	57*	37	2	3	1	0.769
S67	I give the same amount of help as before her implant	17	39*	17	25	3	1.125

Bold value represents strongest response

Chapter 4.3

Seventy per cent of this group of parents considered that their child was reliant on the implant system all the time (S6). Looking at the correlations between statements, the statement that the child could amuse him/herself (S35) correlated positively with all other domains.

Selfreliance

In Table 3, it can be seen that the majority (84%) of parents had observed a significant increase in confidence since implantation (S32), with a similar figure (80%) agreeing that their child had been very dependent on them before implantation (S33). Sixty-one per cent agreed that their child was now as independent as most children of the same age (S47), although this leaves just over a quarter of parents who considered their child was not. Where there was agreement with the statement (S47) that the child was as independent as other children of the same age, the child was likely to be doing well across all domains. Self-reliance in general is positively associated with progress in all other domains. All self-reliance statements had correlations in all the domains.

Well-being

Over 90 per cent of parents considered their child to be happy and fun to be with (S70) as can be seen in Table 4. Eighty-two per cent considered that their child was less frustrated (S64), although half of them indicated that there were still signs of frustration (S16), and 63 per cent considered that their child's behaviour had improved (S59). Responses indicating that the child had been argumentative since implantation (S61) were associated with being less able to cope in mainstream school (S9) and needing more help. Where progress was reported to be slow after implantation (S11), parents were more likely to report signs of frustration in behaviour (S 16). Those reporting signs of frustration were also more likely to report that communication was poorer immediately after cochlear implantation (S2).

Social relationships

Table 5 gives the responses from parents in this domain: 60 per cent thought their child was socially isolated before implantation (S30). Parents viewed their children as sociable in the family (S41, 96%), taking part in family relationships on an equal footing (S65, 80%) and sharing family situations more (S45, 79%). Eighty-one per

cent disagreed with the statement that their child is not close to their grandparents and half reported that relationships with siblings had improved (S74). They disagreed that their child did not make friends outside the family (S39, 71 %).

Education

The majority of parents (S50, 82%) were happy with their child's educational progress, with 75 per cent considering that the local services met their needs adequately, but over half were concerned about their child's future education, as shown in Table 6. With regard to mainstream education, the majority of parents (78%) felt that their child was reliant on the implant system at school (S69). Sixty-six per cent disagreed that their child was unable to cope with mainstream schooling (S9), but 30 per cent disagreed with the statement that their child was keeping up with children of their own age in school (S23). The majority (83%) considered that parents should have a choice as to whether sign language was used at school (S48).

Those reporting that communication remained difficult with known people (S1) were also more likely to report that their child was unable to cope with mainstream school (S9). There was a positive correlation between those reporting that their child was keeping up well with children of their own age at school (S23) and those reporting that they were happy with their child's progress (S50), also those reporting that their child was talkative (S72). Parents reporting that their child was reliant on their implant at school (S69) were more likely to report that their child was reliant on their implant all the time (S6).

Effects of implantation

Table 7 reports the parents' responses to the statements included in this section. The majority of parents (68%, S26) agreed that implantation had exceeded their expectations. However, that leaves 20 per cent who disagreed with this statement. They were not concerned (75%) that their child would blame them for the decision and a smaller percentage (54%) that the Deaf community would reject their child (S17). Almost half (44%) were concerned about the implant breaking down. Few associations appeared in this area, compared with other domains. Those who were concerned that their child may be rejected by the Deaf community (S17) were also more likely to be worried that their child would blame them for their decision (S14). Responses that progress appeared slow in the first months after implantation (S11) were negatively correlated with the responses to the statement

that progress exceeded expectations (S26) and positively correlated with the statement that communication is difficult with known people (SI).

Supporting the child

Table 8 shows that over 90 per cent of parents considered that parents need to be patient and that benefits take time to show (S62). With regard to the support their child needs, 93 per cent felt that the help they gave their child was more productive after implantation (S3) and just over half (55%) disagreed that their child needs more help after implantation (S15), with 55 per cent agreeing that they give the same amount of help to their child. Responses to the statement that 'I give the same amount of help' (S67) were negatively correlated with being unable to chat in the dark (S27) and with the child being unable to cope in new situations (S53) and positively correlated with being concerned about future schooling (S37). Views on support of the child were not clearly associated with views in other domains, for example how well they are doing. There was no clear relationship between children perceived as making better progress receiving more or less support.

Discussion

The results of this study reflect parents who, on the whole, considered that their children were happy, communicative, talkative and satisfied with their child's education. Closer scrutiny of the data, however, shows some interesting areas of ambivalence, with implications for the practice of cochlear implantation. For example, while the majority responded that progress after implantation exceeded their expectations, 20 per cent disagreed with this statement. It would be worth exploring the reasons for this dissatisfaction. We do not know if these were children who had an additional learning difficulty that became apparent after implantation, whether there were difficulties in the family or educational support, or whether there were difficulties in programming and managing the implant systems for these children: for example Geers et al. (2003) found that one of the predictors of language development after implantation was the programming of the implant, in addition to known factors of age at implantation for example. What then were the major trends from the responses of this group of parents?

Outcomes for the child

The strongest changes reported by parents in this study were that the use of spoken language had developed greatly, that their child engages others in conversation and is sociable. Incesulu et al. (2003), in a smaller study and a short period after implantation, reported major outcomes being improvements in communication skills, social relationships and self-confidence. The strongest response of all in this study was that parents reported that they were able to attract their child's attention by calling them, thus making communication within the family easier. In another study (Watson et al., 2007), parents reported that the change to spoken language at home rather than sign language was driven by the change in audition and the child's preference for spoken language as it was the easiest means of communication. It was important to parents that they could chat even when not being able to see each other's face; this reflects situations parents face in real life at home - when talking to the child from another room, when conversing round the table, or when talking in the car.

However, a third of the parents in the present study were concerned about the quality of their child's speech three years after implantation; this was also reported by Incesulu et al. (2003), Nikolopoulos et al. (2001) and Sach and Whynes (2005). Speech intelligibility develops over a longer time scale than speech perception: Beadle et al. (2005) showed that speech intelligibility is improving even five or ten years after implantation. The present study was carried out three years after implantation, and therefore it is likely that the quality of the speech of these children will improve further over time, an important concern for parents. However, the mean age at implant in this group was considerably higher than those being currently implanted, and it is likely that the speech intelligibility of a comparative group being implanted today would give less cause for concern.

Parents also reported significant changes in confidence as found by Archbold et al. (2002), that the majority of children were considered as independent as most children of the same age, being able to amuse themselves. However, although parents on the whole reported their children to be less frustrated, over half felt their child still showed signs of frustration; the study did not investigate the situations in which parents felt their child to be frustrated. However, all the children in the present study were, implanted unilaterally, and function with the equivalent of a moderate hearing loss in one ear and profound/total hearing loss in the other. The effects of a unilateral and/or moderate hearing loss are well known, particularly in school and in noisy situations (Bess, 1999; Most 2004); it is not surprising that these children will experience frustrations when misunderstanding in background

noise and when experiencing difficulties in locating the source of sounds or conversation at home or in the busy classroom environment. Outcomes from bilateral implantation may in future indicate a lower incidence of frustration.

Parents reported that their child was reliant on their implant system, and particularly at school; this has implications for the day-to-day functioning of the implant system. Parents have also reported concerns about the long-term management of the technology in everyday life (Archbold et al., 2002); a study by Brewster and Gauvreau (2006) of children attending an implant centre for annual checks found that only 30 per cent had fully functioning implant systems. In a more recent study (Wheeler et al., 2007), a major issue that arose from interviews with young people with implants was the lack of information they had about their implant systems. This has implications for those working with children with implants in everyday life, ensuring that the systems are functioning optimally at all times.

Outcomes for the family

One of the strongest issues emerging from the parents' responses was the need for patience - that outcomes from implantation take a long time to be revealed. Perold (2001) also identified a period she called the 'despondent' period in which little change could be observed, after the initial 'honeymoon' period in which mothers first observed their child responding to sound. In the present study, parents report the same trend, reflecting the reality of the length of time to develop the use of the implant system and the development of spoken language.

Parents are not concerned that their child will blame them for making the decision about implantation; this is supported by the interviews of young people by Wheeler et al. (2007), who found that young people were happy their parents had made the decision on their behalf, accepting that the decision had to be made when they were too young to make the decision themselves.

Percy et al. (2006), in their study of 62 families, reported that parents found their children to have satisfactory levels of well-being after implantation. A major issue for parents in this study was that their child had become very sociable within the family, sharing family situations, close to grandparents and with improved relationships with their siblings. The development of spoken language is an important factor in easing communication in hearing families, in which all of the children studied except one has been born hearing. The everyday language of the home, of siblings and grandparents, is likely to be spoken and the change in

spoken language reported (for example by Watson et al., 2006) after implantation facilitates full participation in family life.

Following cochlear implantation in children there has been a great deal written about the need for rehabilitation, what form it should take and its part in the cochlear implant follow-up programme. Cowan (1997) reported that the cost-benefits of paediatric cochlear implantation are largely dependent on how much rehabilitation the children need after implantation. The parents of profoundly deaf children in the present study disagree with the statement that their children need more support from them after implantation and over 90 per cent agree that the support they give is more productive than before. We also found no correlation between the amount of support parents were giving and reports of better progress. These children are profoundly deaf and require a great deal of support without implantation, and the parents in this study report that their child does not need increased support after implantation.

Outcomes for education

Education remains a major issue for parents, as reported by Sach and Whynes (2005) and Sorkin and Zwolan (2004). Although parents report that they are largely happy with their child's education, a significant proportion are concerned about the future and a third feel their child is not keeping up with other children of the same age. The attainment of mainstream schooling has been seen as a measure of success of cochlear implantation (for example, Francis et al., 1999); the majority of the children in the present study were in mainstream education, with 40 per cent integrated into mainstream school without specialist provision. It is interesting that a third considered their child is not keeping up with children of their own age. Is this because they were further behind before implantation and have in fact made progress or do parents have lower expectations for their children's education than do parents of hearing children? Wiesel et al. (2007) report that parents' expectations of educational attainment actually decrease after implantation: it would be of interest to explore the reasons for this, and if it is commonly the case.

Stacey et al. (2006) and Thouthenhoofd (2006) reported that children with implants have higher educational attainments than their peers with hearing aids, and Vermuelen et al. (2007) showed that reading outcomes from children with implants were significantly better than those with hearing aids. However, when comparing children with implants with their hearing peers, Vermuelen found that deaf children with implants do less well, and recent studies (Damen et al., 2007a; Mukari et al.,

2006, 2007) show that children with implants are having some difficulties compared with their hearing peers, in functioning in mainstream classes. Damen et al. found that age at implantation was correlated with the performance of children with implants in mainstream class; the average age at implantation of the group in the present study was 4.7 years, higher than one would expect today and therefore it is a reasonable expectation that a group implanted younger would report greater satisfaction with progress in mainstream schools. However, as Mukari et al. (2006) recommend, it is also likely that children with implants in mainstream schools require some form of specialist educational support to function optimally in a mainstream class with the attendant linguistic, cognitive, social and acoustic demands.

With regard to communication mode in school, over 80 per cent of parents felt that they should have a say in the use of sign language in school. A study by Watson et al. (2007) interviewing parents about the changes from using sign language to spoken language found that parents wanted to be able to choose communication mode. Our previous paper (Archbold et al., 2006) reported that parents valued sign language after implantation, while having the major goal of spoken language. Christiansen and Leigh (2004) also found in their study that although parents wanted spoken language for their child, they also supported the use of sign language before and after implantation. Spencer (2004) also suggests that it may be possible to find a way forward using both sign language and implants and more flexible thinking in considering communication choices would be helpful; the role of Signed Supported English rather than British Sign Language seems increasingly to be considered for these children, developing spoken language. A study by Watson et al. (2006) shows that the majority of children in the study used signed communication to some extent prior to implantation and changed to using spoken communication over the years following implantation, as audition became increasingly useful. The present study confirms others in showing that, while parents have the major goal of spoken language for their children, a majority also value the use of sign or signed support at times.

Implications for cochlear implant teams

A major message for other parents from the present study was the need for patience: outcomes from cochlear implantation develop over some time. With newborn hearing screening now common, leading to earlier implantation, this may be less true, as the duration of deafness prior to implantation becomes shorter and progress is swifter (for example, see Tait et al., 2007). However, for many parents

in the present study, speech and education remained a concern, and a number (20%) disagree that cochlear implantation exceeded their expectations three years after implantation. For implant teams, this has implications for counselling, particularly as parents are now proceeding with implantation in the first year of life, before they may have come to terms with the diagnosis of deafness and may still be looking for a 'cure' (Luterman, 2005). Additionally, in the first year of life, when implantation is increasingly considered, other learning or processing difficulties may not be apparent, which may make the hoped for outcomes of intelligible spoken language unattainable.

The long-term management of implanted children has long been recognised as largely residing in education (Geers and Moog, 1995) and the studies of Damen et al. (2007a) and Mukari et al. (2006,2007) recognise that in the long term, even where children are in mainstream, they require some levels of specialist teaching. The long-term management of the technology is an area in which there needs to be close liaison between the implant centre and local educational services, to ensure continued effective use of the implant system (Archbold and O'Donoghue, 2007). While cochlear implant companies usually keep implant centres up-to-date with developments, it is the local professionals, particularly teachers who manage children with implant systems on a daily basis, who require continued training and information (Archbold and O'Donoghue, 2007; Ben-Itzhak et al., 2005). In a European study of parents and professionals about needs following implantation (Archbold, 2007), the greatest issue to emerge was that of training local-professionals, particularly teachers and those involved in classroom management. The fact that parents report here that their children do not need more support from them and the support given is more productive than before implantation has implications for the support programmes put in place following implantation. This also has consequences for the cost-effectiveness of implantation.

Conclusions

In the present study, parents reported that they are largely satisfied with the outcomes from implantation: that their children have developed greater confidence, are more independent, that the use of spoken language has developed greatly and that communication within the family has improved. Parents considered the support they gave after implantation was more productive than before and many considered their child did not need as much support as prior to implantation.

However, there still remain concerns: parents need to be patient as progress takes time, and a number remain concerned about future education and feel that outcomes from implantation have not met their expectations.

Finally, the fact that the children are reliant on their implant systems and hence on optimal functioning of the technology demands long-term support arrangements are in place. These will ensure that people dealing with the technology on a daily basis have the necessary skills and equipment to manage it effectively.

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Chapter 4.3

Wheeler A, Archbold SM, Gregory S, Skipp A. Cochlear implants: the young people's perspective. *Journal of Deaf Studies and Deaf Education* 2007; 12: 3.

Chapter 4.4

Cochlear Implants: The young people's perspective

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Cochlear implantation is a relatively new procedure, which has already had significant impact on the lives of many profoundly deaf children and adults, in providing useful hearing to those unable to benefit significantly from hearing aids. After 16 years of cochlear implantation in the United Kingdom, there is now a body of evidence covering a range of outcomes, much of which covers perceptual and linguistic outcomes. This study looks at the impact of cochlear implantation on a group of 29 young people aged 13–16 years, using a semi-structured questionnaire. It examines issues from the perspective of the young people themselves, including their understanding of and degree of satisfaction with the way their implant works for them, their social and communication abilities and choices, their educational challenges, and their identity. It concludes that the young people in this group feel positive toward their cochlear implants and the decisions made on their behalf by parents. Many have a flexible attitude to communication modes and an identity which is not fixed in terms of conventional descriptors.

Pediatric implantation was first carried out in the United Kingdom in 1989, and since then, over 2,700 children have received implants in the United Kingdom, with over half the profoundly deaf children starting school now having a cochlear implant (<http://www.ihr.mrc.ac.uk/>) Initial studies of the impact of cochlear implantation have focused on improvements in the ability to hear and on speech perception and production. Where spoken language has been studied, research has often been carried out in controlled environments rather than in real life settings. An evaluation of recent research by Thoutenhoofd et al. (2005) demonstrated that more information is needed about the impact of implantation on children's everyday lives, at home with their family and at school, and there is a growing interest in the study of these areas.

One group of particular interest is teenagers who use cochlear implants. Adolescence is a time when individuals are developing independence, establishing their own worldview, and the sense of themselves as persons, with evolving identities. Tooher (unpublished), in her review of the literature on psychosocial issues faced by hearing-impaired adolescents, comments that during adolescence hearing-impaired young people have the additional challenge of developing their identity which may be dependent on the communication mode they use. She observes that for the first time they can make choices about their choice of communication type for themselves, independently of their parents. How these young people with implants see themselves and their deafness, where they belong

in terms of deaf and hearing communities, and how their implant affects their views is important. It is of particular interest to those making the decision about implantation on their behalf, usually their parents, and to those supporting them educationally.

Although previous studies, for example, Gregory, Bishop, and Sheldon (1995) and Cambra (2005), have looked at family, social, and psychosocial issues with reference to severely or profoundly hearing-impaired young people, a review of the literature failed to find many studies which looked in detail at the lives of those who have received cochlear implants. However in one very recent study, Huber, Hitzl, and Albegger (2006) have reported on the educational and consequent employment status of young people with cochlear implants in Austria, suggesting that cochlear implantation facilitates integration into the hearing world. Additionally, Pans et al. (2006) reported on the development of a psychosocial support program for teenagers with cochlear implants, having found evidence of “problems related to their social– emotional development.”

Implantation is more often carried out with younger rather than older children, and until recently, it has not been possible to study teenagers in any detail as there were insufficient numbers to do so. However, with growing numbers implanted, increasingly there are teenagers with their own perspectives and experiences and able to discuss these. These young people are the focus of this study. The study includes those implanted very young as well as those implanted over the age of 11 years. Clearly, those who have received a cochlear implant in adolescence will have a different perspective to those who were implanted so young as to have little memory of life as a hearing aid user, and it is important to include their views.

Hallberg, Ringdah, Homes, and Carver (2005), quoting their earlier study in 2004, describe the need to move away from purely quantitative studies in looking at the outcomes of cochlear implantation in terms of standardized questionnaires or tests of speech perception and communication and toward qualitative studies which pick up on perceptions of quality of life and other psychological issues. Using a qualitative approach also has the advantage of tapping into the issues considered important by the young people themselves. Therefore, the primary method adopted in this study was a semistructured questionnaire. This study, in reporting the views of this group of young people with implants obtained through interviews, provides some of the first information to enable us to consider their opinions.

Methodology

This research project was designed to elicit the opinions of deaf young people with cochlear implants who were aged 13–17 years at the time of interview. Their views were sought using a semi-structured interview procedure.

The sample was drawn from two major pediatric cochlear implant programs in the United Kingdom, Nottingham Cochlear Implant Programme (NPCIP) and the South of England Cochlear Implant Programme. Two mailings were undertaken. Of 128 invitations, 33 positive responses were received (26%), and 29 of the 33 were interviewed. No young person was excluded from the study. Where necessary, adaptations were made (e.g., simplification of language or ideas during the interview) and this was noted. A semi-structured questionnaire (see Appendix) was designed to elicit information during the interviews across key themes.

Pilot interviews with three young people from a different cochlear implant program were undertaken to test the effectiveness of the questionnaire. In the light of these interviews, minor amendments were made to the questionnaire to make the language and the issues clearer to the interviewee.

The interviews were carried out by an experienced teacher of the deaf who had no connections with either implant program and was unknown to the young people. They took place at the young person's home or school, as requested by them. It was emphasized that their comments would be confidential to the research group. Respondents were asked to indicate their preferred language and communication mode (sign or speech), and the interview procedure took account of this. All the young people requested either spoken language or spoken language supported by sign. British Sign Language interpretation was available but not requested.

Interviews were video recorded and transcribed by the researcher. The words of the young people were transcribed verbatim with any gloss clearly indicated. Where prompting was necessary, this was noted on the transcript.

Background data for all the young people interviewed was collected from the BCS System for Cochlear Implant Centres⁷ used by both implant centers. This covered etiology, age of deafness, age of implantation, implant system used and number of electrodes in use, home language, and gender. These data were organized in the form of an attribute table.

QSR Nvivo software⁸ was chosen as the tool for analyzing the data obtained from the interviews scripts. All scripts were imported into Nvivo together with the attribute table. This table enabled exploration of potential variables, for example,

⁷ BCS System for Cochlear Implant Centres, Release 5.2 (2005) (Info@bawtry.net).

⁸ QSR Nvivo Software, Version 2.0.163.

age at implantation across the group. Preliminary themes that had been identified in the construction of the interview questionnaire (see Appendix), for example, deafness and the cochlear implant, family interaction, and experiences in school, were used to sort the data. Responses to particular questions or groups of questions within these themes were collected together and read by members of the project team. The researcher also coded the data using tree nodes to ensure that information contained in all the questionnaire responses was identified and classified—for example, collating references to bullying which appeared outside the particular question designed to elicit information on this subject. This type of coding also enables exploration of new, emergent themes and tighter classification of data.

Nvivo was interrogated to examine responses within the identified themes and to explore relationships. Where appropriate, these responses were cross referenced with the variables contained within the attribute table to look for patterns in the data.

Table 1. Study Group attributes

Group	Gender	Etiology	Onset of deafness	Average age at implant
Early implanted (<5 years), <i>n</i> = 13	Male 6 Female 7	Meningitis 5 Viral 1 Unknown 7	Congenital 8 Acquired 5	3 years 10 months Range: 2 years 4 months – 4 years 10 months
Mdimplanted (5-11 years) <i>N</i> = 12	Male 6 Female 6	Meningitis 1 Mondini 1 Unknown 1	Congenital 11 Acquired 1	7 years 4 months Range: 5 years 1 month - 11 years
Late implanted (11-14 years) <i>N</i> = 14	Male 3 Female 1	Meningitis 1 Genetic 1 Unknown 1	Congenital 3 Acquired 1	12 years 5 months Range: 11 years 5 months - 13 years
Total group	Male 15 (52%) Female 14 (48%)	Meningitis 7 (24%) Other 3 (10%) Unknown 19 (6%)	Congenital 22 (76%) Acquired 7 (24%)	

The young people

Although the sample came from only two cochlear implant centers and consisted of mainly young people from the Nottingham Cochlear Implant Programme, it nevertheless included participants from a wide area across England and Wales⁹

⁹ The research proposal and its information and consent forms received ethical approval at both centers. Invitations were sent to the families of the young people who were asked to respond by

The young people were divided into three groups: those implanted early, under 5 years of age; those implanted between 5 and 11 years of age; and those implanted between 11 and 14 years of age. Table 1 shows the demographics of the groups.

All the young people in the research cohort were using a Nucleus Cochlear Implant; five had only partial implantation. Three young people reported that the number of electrodes in use had been reduced over time and were contemplating possible re-implantation.

Of the sample, one third (8, 33%) attended mainstream school and a further smaller group (5, 11%) a resourced mainstream school. A special school for deaf pupils was attended by half (15, 52%) the group, with one attending another type of special school.

The study group was compared against the complete group of young people aged 13–16.11 years from the Nottingham implant program. This was felt to be a fair comparison as 27 of 29 young people were registered on the NPCIP.

The age profile at implant, onset of deafness, and the range of etiologies of the study group mirrored those of the complete group and were therefore a representative sample. However, in terms of schooling, there was a bias in the study group toward education in special schools; 52% of the study group attended a special school for deaf pupils as compared with 28% in the complete group of those who were invited to participate.

Findings

A number of common themes emerged from the data:

- Using the technology
 - Advantages
 - Disadvantages
 - Understanding of the technology
- Making the decision to implant
- Communication
- Identity
- Education

signing consent forms. The young people were then approached themselves and signed consent forms on their own behalf.

- Advice to others¹⁰

Using the Technology

At the time of the study, all except two of the young people reported that they wore their processors all day every day. This was established by asking the young people how much the implant had been worn the previous day and checking this was their usual practice. The more general question: “How much do you wear your implant?” can be more susceptible to over positive responses. The two who did not wear them constantly were still showing high levels of use, but did not wear it when they wanted “to relax and watch TV” or “until later in the morning at weekends.” This in itself is interesting, indicating that for these two young people, using an implant involves some effort or choice and is not the same as natural hearing for them.

Overall, there was the feeling that the implant was essential to them, with many of the group reporting that they felt bereft if there was a problem and they could not use it (12, 41%). The following comments illustrate their thoughts on what happened if there was a problem and they could not use their implant:

- “I miss hearing. I like hearing. I am always fed up when it gets broken.” (male; 13 years; spoken language)
- “I don’t like it if it’s not working because I don’t know what is happening.” (female; 13 years; sign and speech)
- “I feel very sad, a bit worried, a bit upset.” (female; 14 years; sign and speech)
- “Can’t hear anything or understand.” (female; 13 years; sign and speech) .
- “I hate it so much. Very frustrating because I can’t hear.” (female; 16 years; spoken language)

This very high level of use may or may not be characteristic of the population as a whole, as not all those invited to take part in the study did so and ethical constraints meant the others could not be followed up. It may have been that those volunteering to take part were those who found their implant valuable. However, at the very least it does suggest that a study such as this could easily identify 29 young people who were committed users of implants and felt very positive about them.

¹⁰ The data are discussed under the emergent themes, with quotations taken verbatim to illustrate them. The quotes are felt to be representative of the point made by a number of respondents. The demographic details following the quote give gender, age, and communication mode chosen.

Advantages of implantation.

The advantages of the implants to the young people were many and various. Every young person had something positive to say about his or her cochlear implant, and overall, positive statements outnumbered negative ones by 9:1.

A couple of young people were particularly excited by the benefits of their cochlear implant:

- “The average that a hearing person can hear is 20dB. I can hear 25dB—without implant I wouldn’t manage. I can hear a lot better you feel much more confident talking to the teacher because you can hear really well with it.” (male; 15 years; spoken language)
- “When I had hearing aids when I was little (they) didn’t help at all . but cochlear implant— wow! It’s amazing to hear everything.” (female; 16 years; spoken language)

When asked “on a scale of 1–5 how much can you hear with your cochlear implant?” (5 indicating a high level of benefit), the range was from 3 to 5 with the average 4.4.

The greatest benefits of implantation cited were the following:

- Improved interaction with family and friends (15, 33%)
- General awareness of sound, music (10, 22%)
- “Better than hearing aids” (7, 16%)
- Improved speech production (4, 9%)

However, there are other advantages:

- “It helps me relax, really good, and I miss talking.” (male; 15 years; spoken language)
- “If I have my hearing aid on it embarrass me.

If two people talking if I have my implant I can hear what both saying. I can see what is going on behind me.” (female; 13 years; spoken language) Only one person gave using the phone as a main advantage of having a cochlear implant. A question directly related to telephone use revealed a range of ability to use the telephone by speaking while almost all used text communication.

When asked directly whether there were any changes that could be made to improve their implant, 24% (7) of the group were unable to think of anything and 52% (15) of the group cited suggestions that were aimed at extending the use of the implant, for example, 34% (10) suggested that the speech processor should be waterproofed. One person wanted the implant to be made permanent and another a better design such that the electrodes would last a lifetime.

Disadvantages of implantation.

A number of questions were asked to ascertain the possible disadvantages of cochlear implants. When asked directly to list disadvantages, 11 (38%) of the group failed to come up with anything negative about their implant. Of those who gave disadvantages, these included:

- Headaches which they associated with their implant (4, 14%)
- A number complained that the post aural speech processor falls off during energetic activity, particularly sports (3, 10%)
- Some commented on the restrictions of cochlear implantation, for example, not playing rugby or deep scuba diving (2, 7%)
- Having the cochlear implant operation/going to hospital (2, 7%)

However, in response to other questions, the teenagers also suggested that there were situations where it could be difficult to use the implant. Problems were experienced most often when noises were at the extremes, either very loud or very quiet, and 11 (39%) mentioned difficulties where there was a lot of background noise:

- “In noisy situations it is hard to hear people talking.” (male; 15 years; spoken language)
- “In noisy environment, a crowded place like the town also in the train station.” (female; 16 years; spoken language)
- “In a noisy environment. At parties, sometimes ladies talk to me and ‘sorry I didn’t get that’.” (female; 14 years; spoken language)
- “It is hard outside because the traffic very loud.” (female; 13 years; sign and speech)
- “Really quiet sounds. Mum would call me and I wouldn’t hear it. Wouldn’t hear it in a crowd as well.” (male; 14 years; spoken language)

It was also clear that situations involving many people could be difficult as well as situations where people did not understand or pay attention to the needs of the implant user. Situations in which people were talking all at once was cited by 4 (14%) young people:

- “Sometimes hard. My friends, family talking. Bit hard for me listen like all talking all the time.” (male; 14 years; spoken language)
- “Sometimes my form, the children in the classroom, all chat chat chat, can't hear.” (female; 14 years; sign and speech)

The young person may not realize what they have not understood at the time, and neither may those around them: “They just carry on, don't realise and just carry on and then a couple of weeks later I go I didn't really understand. I have a really confused face and I say I think I understand and they go ok.” (female; 14 years; spoken language)

Concerns about the technology (10, 35%) gave rise to a further problem for some young people because the implant was so useful to them that they felt dependent on it and thus there were fears and worries about it going wrong. This relates to the earlier discussion where many felt bereft if something went wrong. Ten of the young people demonstrated anxiety about this, four expressed concern regarding long-term failure of the implant, and others (9, 31%) described how much they hated to have it not working, even for a brief period.

- “The fact it can break down and the fact that some time in your life have to have another operation to replace it.” (female; 14 years; spoken language) .
- “I just worry and get a bit upset because I don't like it when cochlear is gone. I like it to work all the time and I was a bit worried if no sound. Nothing.” (female; 14 years; sign and speech)

This was a reality for three of the young people who reported that the number of electrodes in use had been reduced over time and they were having to contemplate possible re-implantation. Archbold, Lutman, Gregory, O'Neill, and Nikolopoulos (2002) reported that for parents this was also a major issue, the fear that the technology could fail and another operation would be necessary.

There were also some more general concerns about the workings of the implant and the effect that having something like that inside one's head could create:

- . “Sometimes you start to panic, wonder whether it’s going wrong on the inside. I’m fine with being deaf it’s just the actual breaking down. It’s like having some of your organs failing.” (female; 14 years; spoken language)
- “I get hit. It kill me. There’s the cochlear in the head, it is drilled into the skull. If hit head it crack. Take some bone out of the skull. Fit cochlear in place but that bit of skull is thin so when hit, crack it. Give me brain damage. If you smack hard it kill you.” (male; 15 years; sign and speech)

These comments illustrate the difficulties for some of these young people in coming to terms with an implant, although they may recognize the benefits and, in some cases, a lack of understanding of the technology they have implanted within them.

Understanding of the technology.

We were interested to find out how much the young people did in fact know about the implant itself and the way it worked. For the most part their understanding of the way the implant worked was often basic with two thirds (19, 66%) giving only very limited description of the technology and one quarter (7, 24%) not being able to give any information at all. Only one tenth (3) gave a full explanation. Examples of limited descriptions are given below:

- “There’s a little thing inside my ear and the magnet on top. It transfers the sound into your brain. It’s how I think it works.” (female; 14 years; spoken language)
- “Inside in cochlear attached to some nerves and make me hear.” (male; 13 years; spoken language)
- “Picks up electrical signal, put a little magnet in your head that makes it stick better but I don’t know exactly how it works.” (male; 15 years; spoken language)

There were some more comprehensive accounts. For example:

- “The outside sounds I hear go through the microphone then the computer imports the sound through the microphone into the cochlea. Turn them into signals that are sent to the brain” (male; 14 years; spoken language)
- “They have to put a special coil into your cochlea which then helps send impulses to your brain so that your brain can understand the noises that are

being made. The speech processor you get is the main power source, taking sounds from outside.” (male; 16 years; spoken language)

Although most could not give a full description of the technology, the majority had few problems in knowing what to do if it should go wrong, an issue which is, of course, more important to them. They all discussed changing the batteries, checking anything that might not be working and alerting their parents or teacher of the deaf. Most of them reported that if there was a serious problem they would contact their cochlear implant team and they seemed confident it would be remedied.

However, although this means that on a daily basis most were competent at managing the technology, it also means that a significant number did not have an understanding of the technology they were to be using for the rest of their lives, and maybe did not have sufficient information on which to make major decisions which may be required such as that of re-implantation.

The Decision About Implantation

Although those interviewed clearly indicated that they benefited from their implants and chose to wear them, the decision to have the implant and the operation involved is not necessarily an easy one. Colletti, Carner, and Colletti (2006), Economides et al. (2006), Ligny et al. (2006), and Nikolopoulos, O'Donoghue, and Archbold (1999) all demonstrate that implantation is more effective at younger ages, and thus, more often than not, is a decision that has to be made by parents on behalf of their child. Some authors opposing implantation as a procedure to use with deaf children have argued that because it is an elective measure involving surgery, it should only be carried out when the child is of an age when they can decide for themselves (Lane & Bahan, 1998). However, with the evidence of the effectiveness of early implantation, this is not realistic, and parents are faced with this decision earlier and earlier.

The group was asked what involvement they had had in the decision to implant and whether they felt they should have had more of an input. The majority of the group, nearly two thirds (18, 62%) were quite clear that their parents had made the decision and only 3 (10%) felt that they had made the decision themselves. The others felt they were involved but had not made the decision themselves. All those who felt that they had been involved in the decision were over 8 years of age at the time. In general, they gave the impression that the notion they should have had more of a say in the decision-making process is untenable. In this context it is

interesting that all the young people seemed aware that having a cochlear implant fitted does actually involve someone (usually your parents) making that decision for you.

- “I can’t make the decision myself. I was really young at the time. I didn’t know much about. I am really pleased they made that decision.” (male; 15 years; spoken language)
- “I respect them for making the decision.” (female; 15 years; spoken language)
- “I was too young to understand but I’m ok with that. I know it was for my good to have the best outcome in life.” (female; 14 years; spoken language)
- “When I was young I didn’t have responsibility. I don’t know anything and my mum and dad they did the whole thing.” (male; 14 years; spoken language)

None of those in the group seemed to be resentful of their parents for taking this decision, or not involving them, but rather the reverse—that they were grateful for the choice they had made. Those implanted after the age of 12 years were likely to have had more of a say in the decision. For two of them, the decision was not made easily but after some consideration:

- “I did not want it for a while but when my teacher told me about it in more detail, I heard more and it seemed good, I thought I will have one.” (male; 15 years; spoken language)
- “I said no for a while but then I decided to have one because I realised that I can’t hear anything for the rest of my life. I thought I would have a cochlear implant and see what difference it made.”
- Interviewer: “Why didn’t you want it to start with?”
- “I think I was a bit scared of the operation.” (male; 15 years; spoken language)

For another boy, although he described his mother as making the decision, he had clearly been involved and consulted:

Interviewer: “Do you remember who made the decision for you to have your implant?”

“It just had to happen, it was my choice and my Mum’s choice.”

Interviewer: “Were you involved in the decision at all?”

“When it come down to it . it was my Mum’s choice because I did not fully understand what was going on because I was young and she had to make the right decision for me.”

Interviewer: “Did you talk about it at the time?”

“We did and she explained everything.” (male; 16 years; spoken language)

Overall, the group accepted that for some children parents would make the decision, they expressed no surprise about this and felt that their parents had acted on this in their best interest. Perhaps the greatest testament to this is the assertion of three young people who were facing possible reimplantation due to failed electrodes that they would not hesitate to have the procedure repeated when the time was right.

Communication

The young people did not seem to be surprised to be asked a question about their preferred mode of communication. Many of the young people could sign, either using sign-supported English as their preferred form of communication or as a second mode/language. Twenty of the cohort (69%) used spoken language as their preferred mode of communication, the others using sign-supported English. It is interesting that although implants are associated with spoken language, many of the young people could sign and were flexible in their use of language and mode, varying it depending on the situation:

- “With my deaf friends I sign, with the others I talk.” (female; 14 years; sign and speech)
- “I sign with deaf but I communicate with hearing people.” (female; 16 years; sign and speech)

For this group, communication rather than language choice seemed to be the most important issue. They will use sign, speech, or text as seems most appropriate to them in any given situation. As already mentioned, one third state as a main advantage of the implant, improved interaction with family and friends and over two thirds (20, 70%) felt they were understood by their family all or most of the time.

“Yes cochlear implants work because you can hear more, talking to friends, understand everything, go out have a good time. If have a cochlear implant easier to have a good time.” female; 14 years; sign and speech)

This is consistent with research looking at parental perspectives on implantation, Archbold et al. (2002) and also Sach and Whynes (2005) where 57% reported that family life had benefited from cochlear implantation due to improved communication.

Identity

A key issue in the debate about the appropriateness of implantation for deaf children has been around the notion of identity. The aim of an implant is to improve the ability to hear and access sound. Nikolopoulos, Archbold, and O'Donoghue (1999) and Peng, Spencer, and Tomblin (2004), among others, have reported consequent improvement in speech and spoken language skills, which may carry the implication that to hear is better. To change or not to change? Would those with implants feel themselves to be deaf or hearing? Moreover, what would be their views on whether it was better to be deaf or hearing? Wald and Knutson (2000) questioned a group of 45 adolescents with and without cochlear implants regarding issues of Deaf identity and concluded that the groups were similar in many respects but that the cochlear-implanted group rated hearing identity as a desirable goal more favourably than the non-implanted group. The authors attribute this to the audiological benefit that the implanted group received. When asked if they saw themselves as deaf or hearing, the replies varied:

- “I can't hide the fact that I'm deaf.” (male; 15 years; spoken language)
- “Some days deaf, some days hearing.” (female; 13 years; spoken language)
- “Sometimes I feel like I'm hearing, sometimes I feel like I'm deaf. I can't feel it (gestures to implant).” (male; 15 years; sign and speech)

Only 6 (21%) of those interviewed described their identity as hearing; all the rest saw themselves as either deaf or deaf and hearing. The majority therefore perceived themselves as deaf to some degree. Six present as having a strong deaf identity because they answered “deaf ” to all three questions, asking whether they or others thought of them as deaf or hearing. There was no clear link between perceived identity and schooling, although two young people attending sign-

dominant special schools gave their identity as deaf. Beyond this there was no relationship between the use of speech and/or sign and their own identity as deaf. For some of the group implanted at an older age, implantation followed the sudden loss of hearing. Polat (2003) argues that those who acquire a hearing loss at a later stage in life may find it more difficult to accept their deafness and may demonstrate poorer adjustment than those who were congenitally or pre-lingually deaf; one young man, implanted following sudden acquired deafness at the age of 12 years was clearly struggling with this:

- “I know I’m deaf . without your cochlear implant you are always going to be deaf.... it is hard to cope with.... always want to be normal.”
- “Just the fact that it is not very comfortable to have behind your ear for a long time.... it can get to you sometimes how people have to ask you questions... people don’t understand it is just hard to get used to the whole thing about being deaf.... makes things harder than they need to be.” (male; 16 years; spoken language)

Another girl commented:

“ ...it would be harder to adjust to having a cochlear implant later on you have to get used to having a cochlear implant, to the fact that you are deaf—I have had eleven years to get used to it but there is a girl at my school she has only had a cochlear implant for a couple of years and she is really not comfortable with it at all—she can’t bear being deaf.... even though she is in a school for the deaf she is not comfortable, it takes time to adjust so you have to consider that.” (female; 14 years; spoken language)

Some commented on the fact that because of their good spoken language skills and, in particular speech intelligibility, the young people were sometimes perceived as hearing by people who did not know them well. This is consistent with the study in 2005 by Punch and Hyde, looking at “hard-of-hearing” adolescents.

- “For the first time they might think that I’m hearing but then they realise, then they ask me if I’m hearing or deaf and I tell them.” (female; 13 years; sign and speech)
- “Don’t really know because everyone thinks I am hearing. To be honest inside me I’d say I’m hearing because I can hear what everyone is saying.” (male; 14 years; spoken language)

Such comments seem to suggest some ambiguity as to whether they think of themselves as deaf or hearing. Peng et al. (2004) have reported that the speech of the majority of those profoundly deaf implanted early is easily intelligible. This may lead to a deaf young person with an implant to being perceived as hearing. To be thus perceived, yet see oneself as deaf is likely to create some tension particularly for those who felt themselves to be deaf yet also felt hearing to be desirable. It may be that they are in the position of feeling that they do not belong to either the deaf or the hearing world. In addition, it may be that, if perceived as hearing because of quality of speech intelligibility, these young people do not have the accommodations that they need in school—particularly in mainstream school and in noisy conditions, as they have already commented. This issue was also reported by Punch and Hyde (2005) who found that people who treated students “normally” forgot to make these adjustments.

Another interpretation would be that they are not only realistic but also positive about their identity with respect to the deaf and hearing worlds. They are deaf, have a hearing loss, and they may sign but in many ways, and because of their ability to hear and their use of spoken language, they also see themselves as part of a hearing world. This may be reflected in the flexible use of language and mode, which is characteristic of many of them. As for many other people, identity for these young people is not a fixed concept, setting identity in a one-dimensional way but reflects the complexity of their experience, a complexity which for many of them is positive.

As Hyde and Power comment:

“The question would seem to be not the “either/ or” one (will the implant make the child a hearing person or the non fitting make them a Deaf person) but a question which results in the best ethical appreciation of the risks and the benefits that eventuate. The best outcome for the individual may be competence and affiliations with both hearing and Deaf communities ..”
(Hyde & Power, 2006, p. 7)

Education

Within the group, the young people were educated in a range of different settings. Just over half the group were in special schools, including one young person in a school for children with learning difficulties. However, it should be noted that this was higher than the percentage across the cohort as a whole, from whom the

majority of this study group was drawn. Of the 20 who were in mainstream, 5 (17%) were in schools with a resource base for hearing-impaired children. The general trend in this study was that following on from a primary mainstream placement, the young people moved on to a more specialized provision for their secondary school education. Although this group may not be representative in terms of secondary provision, this trend was also found in the Scottish study, reported by Thoutenhoofd (2006) when faced with the more challenging acoustics and language and curriculum of secondary schooling, the young people had moved toward specialized provision.

Two thirds of the young people (22) felt that their cochlear implant helped them to understand the lessons. Six (21%) stated that their implant helped them most or some of the time with two in this group stating that the use of sign support was equally important. Some of those being educated in mainstream schools reported that they depended on their teaching assistant (TA) for support:

“Both—cochlear implant is important to listen to teacher but TA is important to work with me to understand—for example, write it down, explain, what to do, how to do it, make me understand.” (female; 14 years; sign and speech)

Some subjects are more difficult than others:

“Yes but in Spanish and science they have videos. I don't understand a word, I'm just sitting there watching the screen. In Spanish I have a CD and they speak and I've got to understand what they are saying.... I hear something but it doesn't make sense.... the implant helps me hear more but the TA helps me understand.” (female; 14 years; spoken language)

A number of the young people expressed the same view that although the implant helped them to hear, they still relied on a support worker or note-taker to help them understand. As stated before, the young people appear to rely heavily on their systems, and one young person is so dependent on his cochlear implant that he refuses to go to school if it is not working.

Overall, 33 statements from 22 young people were coded as negative experiences in relation to school (including contact with teachers). These reflected their experiences as a whole and not just in their current school. Some compared their old and new schools with mixed feelings when asked about the move to secondary education:

“Because primary school is not a deaf school, my new school got whole deaf children and we use headphones so that we can hear everybody but at my old school we just had the teacher and me.” (male; 15 years; sign and speech)

For the deaf pupil, as for hearing pupils, transfer to secondary school is a potentially stressful event. When asked if anyone had done anything to make the transfer easier, 10 (34%) said no, 8 (28%) yes, and 3 (10%) felt they got support but had to ask for it.

A couple of young people talked about the difficulty of transferring to a school where the prevailing communication mode was different from theirs.

One young lady was feeling very isolated in her rural mainstream secondary school: “Sometimes I don’t understand.... it is too hard for me, the teacher—I don’t understand what she is saying I’m quite frightened and upset” (female; 14 years; spoken language). This of course describes the situation for many of the young people at school or in social situations. It can be a dilemma to not only want to be treated in the same way as others but also needing some help or modification in such situations.

This young person was one of five (17%) who experienced bullying at school, and this together with other accounts of spiteful behavior accounted for the rest of the negative experiences cited. Dixon (2006) cites research with deaf/hearing-impaired adults where 67% reported bullying at school with transfer to secondary school being a particularly difficult time. No association was found with type of school attended. This is consistent with the results from this study. However, there was no observed association with an oral approach as suggested in Dixon’s study. One young man revealed that he had been bullied on his transfer to a special school because his speech was perceived as poor by his more oral peers and he relied on signed support. Another girl reported experienced bullying over a period of years. She was fully integrated into a mainstream school. The girl who was ostracized by her hearing peers was also fully integrated into a mainstream school and was hoping to transfer to a special school even though this meant boarding away from home. The rejection appeared to be based on her difficulties with interaction with her peers. Another teenager attended a resourced mainstream school and reported name-calling and general verbal abuse. Consideration had been given as to whether she should transfer to a special school for the deaf (using sign language) but she was reluctant to do so as she had established oral language skills.

Advice to Others

As a way of assessing their attitude as to the value of implantation, the teenagers were asked two questions about advice they would give to someone considering having an implant.

Their replies were characterized by sensitivity to the proposed situation and also the complexity and thoughtfulness of the responses.

The first scenario was a teenager who had become deaf as the result of a road accident, and the second scenario described the parents of a young deaf child who had been told that their child was a suitable candidate for a cochlear implant.

In answering the first question one young person took into account the impact that the accident itself might have on the individual involved and indicated that for those not used to the idea of implantation, the concept of an implant might seem daunting.

“If you suddenly have a car accident I’m sure you will be still shocked by it and hearing aids would be a good thing at first because if it was an implant it would be a bit too stressful.” (male; 14 years; spoken language)

Others showed an awareness that implants are not the only route to take and suggest considering hearing aids:

- “Try hearing aids first” (male; 13 years; spoken language)
- “I would tell him to have hearing aids first, because there are a lot of people with hearing aids who have brilliant hearing, good speech as well. And if he takes the cochlear implant straight away maybe he might be unhappy about it. If he’s got hearing aids and he is still unhappy you know you can still have cochlear implant later, but if you have a cochlear implant you can’t really change back.” (male; 14 years; spoken language)
- “It depends on how good (the) hearing test is. If it is bad should have cochlear implant. If it is good then have hearing aids.” (male; 15 years; sign and speech).

Some did see a cochlear implant as providing the best solution.

- “If you want to hear a lot better have it done. I think the implant is as close to normal as you can get.” (male; 15 years; spoken language)

Such concerns as to what was best for the child also featured in their response to questions about the deaf child and the family.

“It depends what you think is best for the child. A cochlear implant would be quite good but there is the side of the operation. The doctors have to be involved, have to look inside you, which might bother some people. And the cochlear implant doesn’t always work. There’s years of hard work, years of speech therapy, years of going to the hospital and having to overcome the technical problems and having to have another operation sometimes later, whereas with hearing aids you don’t have to have an operation to cope with them.” (female; 14 years; spoken language)

Overall, the view seemed to be that an implant should be considered, but after careful assessment:

- “Have cochlear implant, hearing aids not much help. Technology changing, future generations have better things.” (male; 14 years; spoken language)
- “If profoundly deaf I would strongly recommend cochlear implant because your cochlear implant is very useful, they do lots of things that hearing aids don’t.” (male; 16 years; spoken language)
- “Nowadays lots of young children have cochlear implants. I think it’s a good idea.” (female; 16 years; spoken language)

Some of the young people also perceived the need to reassure potential parents that the operation is not as worrying as it might seem:

“I would say not to worry about the operation because it is nothing really. You will recover soon and then I would say it really helps a lot and I would say the things that I can hear now but not before” (male; 15 years; sign and spoken language)

Comments

The interviews from these young people with implants gave rise to much rich information about how they viewed themselves in relation to others, their families, and education and highlight some significant issues. These may have implications for our future work with this growing group.

The young people in this study used their speech processors consistently, and any dissatisfaction that was reported was when having to manage without it. Many were unable to think of ways in which it could be improved, and the most popular suggestion was aimed at increasing the time for which it could be used, rather than removing it. Other studies have reported less strong rates of use and less adolescent satisfaction. Todini, Cavicchiolo, Ceriani, Ugazio, and Zaghis (2006) report 38% of pre-lingually deafened, late-implanted adolescents would not wish to be re-implanted should their system fail. No young person in this study offered this view. The group interviewed here all chose to be interviewed, and whether this represents the views of a larger group deserves to be investigated.

Although positive about their implants and what they give them and happy to recommend that others should consider cochlear implantation, they are pragmatic in their attitude about the relative benefits of hearing aids and implants when giving this advice. They suggest that implantation should be considered, but that it needs careful consideration.

Hyde and Power (2006) discuss the issue of informed consent at length, particularly with reference to elective surgery and Deaf cultural issues. They quote international legislation on the rights of children¹¹ supporting their right to be involved and informed in decision making, relative to their age and maturity. However, the young people in this study gave no evidence of having problems with the issue of consent. They felt that it was their parents' responsibility to make the decision on their behalf and that it had been the right decision for them. Older young people were included in discussions but might still rely on their parent's judgment. Some who were faced with the real prospect of re-implantation were clear that they would go ahead with it.

However, many of the young people in this study did not have a good understanding of how their internal cochlear implant worked and some were unable to give any explanation at all about its functioning. This has implications for future work with this age group, who, if they are to make rational decisions in the future about situations such as re-implantation, or increasingly, bilateral implantation, need to understand the technology they wear more fully, and its implications. This is information that their parents received when they were younger and during adolescence they should have the opportunity to acquire it on their own behalf.

Although most of the young people in this study use spoken English as their main means of communication, they do not appear to have a "fixed" communication mode and are flexible, choosing to speak or use sign-supported English as feels

¹¹ United Nations Convention on the Rights of the Child; United Nations General Assembly (1989).

appropriate to them. Placement in a particular educational setting with a strong oral commitment, for example, did not mean that the young people do not use sign between themselves or with signing deaf adults. Those who prefer to use speech and sign in school may have intelligible speech, which enables them to function well in non-signing environments.

This relates to the question of identity about which they were asked and which often emerges in discussions about implantation. Flexibility in communication mode is reflected in a perception of identity which is in general neither strongly Deaf nor hearing in this group. The majority recognize themselves as intrinsically deaf in the sense that they cannot hear without their implant but do not demonstrate a culturally deaf identity. Cochlear implantation has provided a new choice for deaf children and young people and one that is now used by the majority of profoundly deaf children. With developments in technology, earlier implantation, and increasing use of bilateral implantation, the benefits described by the majority of these young people are likely to increase for the next groups implanted and growing to be adolescents.

This group of deaf young people is the first to experience growing up as deaf, but with implants. In listening to them it may be possible to provide them with real choices, not those imposed on them by worlds that see themselves as hearing or as deaf.

To conclude:

The recognition that we can choose, that we can make choices, is a central point. Another aspect is the fact that it is the individual who makes choices and that this is an existential fact from which the person can never be free. However the choices are anchored in one's own situation, not in the norms of the hearing world or the deaf world. (Ohna, 2004, p. 32)

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Appendix

Semistructured questionnaire under the following headings:

- Deafness and your implant
- Other people
- Your family
- School/changing schools
- Friends
- Deafness and other issues

Chapter 5

Discussion

Deaf education – changed by cochlear implantation?

Chapter one of this thesis described the controversies which have surrounded deaf education throughout its history: particularly that of the ongoing debate about choice of communication methodologies. Hence, when paediatric cochlear implantation began in the UK twenty years ago, comparatively recently, it entered an area where there was already profound and heartfelt disagreements. This chapter reflects on the research reported in this thesis, either led or initiated by the author, sets it in the context of other research, and looks at the issues which emerge, drawing some further challenges for deaf education for the future.

What has been the influence of cochlear implantation on the questions that were posed in chapter one? Has cochlear implantation changed deaf education? Has it brought about changes in communication, educational choices and attainments, following the provision of useful hearing? What about the perspective of parents and young deaf people on the implications of cochlear implantation for education? The papers included in this thesis provide evidence of the impact of cochlear implantation on the developing communication skills of deaf children, on their educational choices and educational attainments, involving the perspective of parents, teachers and the young people themselves.

5.1 From controversy to routine provision

Over the period of time covered by these papers, cochlear implantation has changed from a procedure for which parents had to fight, and face great opposition, to that of routine provision in most parts of the developed world, and increasingly in the developing world (Leigh, 2008). As a consequence of the growing evidence, such as that reported here, in the UK the majority of profoundly and severely deaf children now have cochlear implants. The outcomes brought about by cochlear implantation have been greater than predicted, but have taken place in a rapidly changing external context. Some of the major changes which have taken place include:

- The introduction of Universal Newborn Hearing Screening, increasing the possibility of early implantation following the earlier fitting of hearing aids
- The changing nature of the deaf population, particularly with the survival of more deaf babies with complex needs during this period

- An increased focus on outcomes for all deaf children
- Developments in a number of related fields, such as cognition, the neural sciences and linguistics during this period help to understand more fully the impact of cochlear implantation on the learning of deaf children
- The changing disability agenda, changing choices for deaf people, for deaf children and their parents, with increasing recognition of their rights, and inclusion in mainstream society, including education
- The development of a range of communication technologies, which are changing the communication needs, abilities and opportunities for Deaf people
- Greater emphasis on the need for an evidence base for intervention with children
- A more technologically aware society where technology was intruding into more and more areas of life and being generally accepted

These external changes have also influenced the decisions made with regard to the management of childhood deafness, and need to be recognised in discussion of the outcomes reported in the papers included here.

Additionally, changes in cochlear implant practice and implant technology have influenced outcomes over the period discussed here. The developments in both internal and external implant technology provide increased reliability, improved access to the speech signal, and increased appropriateness for use with young children. Improvements in surgical techniques have led to improvements in the ability to implant while preserving residual hearing, and to implant young infants safely, while developments in audiological and tuning techniques have improved the ability of scientists to ensure the implant system provides the individual child with the access to sound most appropriate for their needs. These improvements increase the likelihood that the work reported here under-represents the effectiveness of implantation.

However, the papers included in this thesis reveal levels of benefit from implantation in everyday life, at home and at school, which were not anticipated twenty years ago, when expectations were those of an aid to lipreading, and of environmental sound awareness. Now, expectations by parents of young implanted children are those of intelligible spoken language, of mainstream education, and of improved educational attainments. This emerging evidence has driven changes in candidature and practice:

- Earlier age at implantation, shown to be more effective, with children commonly implanted in the first year of life, made possible following earlier diagnosis of hearing loss
- Changing audiological criteria, with children with greater levels of residual hearing being implanted
- More teenagers choosing implants, as they see the benefits in others, and as the audiological criteria have relaxed
- More complex children receiving implants, as implant teams become more confident in their assessments, and as benefits of differing orders, which are important to their parents, become measureable in these children (Nikoloupolos et al, 2008; Berettini et al, 2008; Wiley et al, 2004)
- Bilateral implantation, as the evidence grows of the benefits of binaural hearing and bilateral implantation

In influencing this change from a controversial to a routine practice in a comparatively short time, the availability of research outcomes which were understandable to the non-specialist, while reliable and robust, has been of major importance, and the means of dissemination discussed in chapter one to be of significance (O'Neill and Archbold et al, 2002). Measures such as Categories of Auditory Performance have been used to demonstrate benefit to purchasers of health-care and to indicate comparative benefit in early implantation. Recently, in the UK, the investigation by the National Institute for Health and Clinical Excellence (NICE) of cochlear implantation, in recommending cochlear implantation in children, reflected the value of the research evidence into cochlear implantation. Perhaps more importantly, parents of children considering implantation and those managing them, particularly educators, are able to look at comparative outcomes in different groups using the measures reported here, and to consider their own child's development against them.

One significant area of research not included in this thesis is that of bilateral implantation, because it was not routinely carried out during the period covered by this research. At the outset of cochlear implantation amidst much controversy, one cochlear implant only was considered, leaving the other ear available for future developments in technology. However, over time, with increasing evidence of binaural hearing and increasing practice and experience of bilateral implantation (Steffens et al, 2008; Galvin et al, 2007; Litovsky et al 2006a), bilateral implantation has become the most researched area covered by the annual

literature review carried out by the National Library for Health in the UK, and was supported by NICE in its investigation : an indication of the progress made in the time period covered by the papers in this thesis. The emerging evidence about bilateral implantation, in terms of localisation, (Galvin et al, 2008; Litovsky et al, 2006b) but particularly improved listening in noise, (Peters et al, 2007; Wolfe et al, 2007), is important when discussing the educational implications of implantation; some of the difficulties experienced in the classroom, particularly mainstream, may be ameliorated by bilateral implantation.

In order for cochlear implantation to become a routine provision, elements reflected here are important: the need for evaluation which acknowledged the multi-professional nature of the process, the long-time scale necessary, and the requirement to involve parents and local professionals. In chapter one (1.5.1) we recognised that this is particularly true in assessing the impact of cochlear implantation on education (O'Neill and Archbold, 2002). We stressed the importance of measuring changes in the deaf child's functioning in society – in communication, in spoken language, and in family life and education. Clinical governance demands that the outcomes from a procedure are measured in terms which represent the patient perspective as well as the clinical perspective; in the child's case this requires the parent and carer perspective (1.5.1).

The educational area of the Nottingham implant programme's database, shown in chapter one, from which the papers in this thesis are taken, also involved the child's parents and educators from the outset, valuing their role in assessing the children's progress. The database included a management system in order that the processes which underpinned the delivery of cochlear implantation could be monitored over time, with the involvement of all staff in data entry. This included the input from the cochlear implant centre teachers of the deaf and the local teachers of the deaf, and an analysis of the local educational support in terms of time and staffing. The comprehensive monitoring system put in place enabled teachers at the implant programme to advise parents and teachers about their child's progress with evidence from practice.

Progress to routine provision was supported not only by peer-reviewed publications, such as those included here, but in regular progress reports and outcome reports produced for parents, teachers and others, in order to provide the non-specialist with accessible information on which to base educational decisions. Over the period very few children were lost to follow up; only those who emigrated

or had been explanted, or had died were not assessed. This ensured that the outcomes reported reflected benefit in the whole population, and not only in those perceived to be doing well and who attended for special assessments. Additionally, in the UK, the Nottingham programme was open to all via the NHS system, providing for those from a range of social backgrounds and for children coming from throughout the country and from areas of differing political and educational views, also ensuring that the outcomes reported reflect the population as a whole, rather than a small sector. Given the levels of controversy in which paediatric implantation was set, the importance of openness and clarity in reporting measures of outcome cannot be over-emphasised, responding to the criticisms of Lane and Bahan (1998), and the later criticism of others about the robustness of implant research, including Marschark et al. (2007).

In chapter one, (1.6.2), we emphasised once more the long-term management of cochlear implantation, and that parents and local community-based professionals are crucial to successful long-term outcomes, and traditional, clinic-based models of service are unlikely to be able to provide for the growing numbers of implanted children in the long-term (Archbold and O'Donoghue, 2007). We also argued that local professionals, particularly educators, have skills and expertise which should be utilised in the management of children with implants, and that to ensure this ongoing cooperation between the implant centre and home and school is essential. This is a recurring theme in the parents' views in chapter four, and it is recommended that such engagement of local expertise will utilise those who know the child best, will ensure the implant technology is used effectively wherever the children live, and will be cost-effective (1.6.2). Moving the focus of long-term management from specialist centres to the local community, as recommended in 1.6.2, reflects this progress in the evolution of cochlear implantation to routine provision.

Chapters two, three and four provide the evidence of outcomes seen following the implantation of young children in the context of communication, family life, and education, utilising measures which were developed to meet the challenges of evaluating this population. However, much of the research reported in the papers arises from implantation practice several years ago; measuring outcomes in children and young people takes place over comparatively long time scales. For example, language takes years, rather than months to develop, and reading data is only measurable meaningfully at least ten years after early implantation. In the meantime, practice has changed, in terms of the population being implanted, and

the technology and the process of implantation itself has changed. Much of the evidence reported here, gathered from children with older age at implantation and with older technology, is likely to under-represent the effectiveness of cochlear implantation. This is a major problem in cochlear implant research in general, and the reader of the following discussion needs to bear this in mind.

5.2 Outcomes - better than predicted?

Despite the early controversy about introducing the intervention at all, the outcomes from cochlear implantation in children have largely been better than predicted, particularly in terms of the development of spoken language in children born deaf, the population about which there was most controversy. This quote, from two researchers initially cautious about implantation, recognises the change brought about by implantation on the choice of communication mode and the opportunities for the development of spoken language, once a major challenge for those profoundly deaf, brought about by implantation in young children:

“..... spoken language development of deaf children may be more possible today than ever before. We are poised on the threshold of what seem like unlimited possibilities.”

Marschark & Spencer, 2006, P17.

The papers included in this thesis, published largely from the data collection at Nottingham Paediatric Cochlear Implant Programme during this period, reveal, from a population which was unselected, from the range of social and educational backgrounds throughout the UK, the extent of the changes brought about by cochlear implantation in the paediatric population and the implications for deaf education.

5.2.1 Measuring outcomes in young deaf children

The papers in Chapter two looked at the challenges of measuring those outcomes likely to influence education in the long-term in children. Crucial to being able to assess the impact of early implantation on deaf education has been the ability to measure early changes in communication skills, in the use of audition, and in the development of spoken language. Nottingham Early Assessment Package, NEAP, as described in Chapter Two, (2.1), was developed with colleagues to monitor

progress in young children in order to inform the decision making process, to monitor the functioning of the implant system at home and school, the habilitation and educational support provided, and to help identify the presence of other learning difficulties. Previously most measures used in cochlear implant test batteries, such as that used for FDA approval, required language skills not present in young children and certainly not present in babies in the first year of life. There was a need for a measure to use with very young children, and the lack of measures which would enable clinicians to monitor progress over time. NEAP includes seven measures specifically designed for Nottingham Paediatric Cochlear Implant Programme, one modified for use with permission, and two others, commercially available. Together, these measures provide a framework for monitoring progress in both the short and long-term, and in doing so enable additional difficulties residing in the child to be highlighted, and therefore appropriate intervention strategies to be identified and implemented by local educators. It has produced measures such as the Listening Progress Profile, and Categories of Auditory Performance, which have been used routinely world – wide by educators of deaf children. They produced key indicators not only of outcomes, but of progress over time, crucial to making decisions about changing educational management, a recurring theme from parents (Chapter four).

The video measures and profiles and questionnaires of carers included in NEAP allow both researchers and practitioners compare the progress of groups of children, and of one child against expected progress (2.1). Thus the use of NEAP assessments can provide evidence of likely benefit to those invested with making choices: particularly parents and the educators who work with them. Following implantation, progress as expected in one domain may highlight delayed progress in another, as illustrated in the case studies in the paper, and lead to further more detailed investigations and a full differential diagnosis to be made. The translation of the assessments in NEAP into many languages illustrates its usefulness, and the confidence felt in it is also illustrated in its use in major international studies, for example Wiefferink et al, 2008.

One of the auditory measures included in NEAP, Categories of Auditory Performance, (CAP), is a profile we developed specifically to provide a measure of the use of audition in everyday life which would be useful over a long-time frame, would reflect change in everyday life, and be used by educators. A major criticism made of measures developed for such purposes is their perceived lack of rigour. CAP was developed over a period of time, the terms and guidelines revised during

its use, and then subject to an inter-user reliability study. Comparing the CAP assessments of local teachers of the deaf with the assessments made of the same children at the same intervals revealed a high level of agreement between the users, establishing its reliability, (2.2), and endorsing the involvement of local educators in the assessment of children in their care. CAP measures progress in the long-term from having no awareness of environmental sound through seven broad categories to using the telephone with a known speaker. The use of CAP has been instrumental in illustrating to non-specialist educators, such as those working in mainstream, in understandable terminology, such as “understanding conversation without lipreading” the changes that cochlear implantation can bring about for deaf children, and to enable comparisons to be made between differing populations, for example, those implanted at differing ages. Its international use by educators has been supported by its translation into over twenty different languages, and its use in educational studies, for example that of De Raeve et al, 2009, reflects its value to educators.

In comparison with CAP, another auditory measure, the Listening Progress Profile, (LiP), was developed to assess the early listening progress of young children, to indicate the small steps marking progress, or the lack of it, in using their new hearing. The profile covers a range of abilities from the first response to environmental sounds to the highest level of achievement, that of identification of own name. During the study, (2.3), 68 children, congenitally deaf or deafened before the age of three and implanted before the age of five, were assessed prior to implantation, and up to 24 months after implantation. LiP was designed to be used by teachers, and had previously been validated (Archbold, 1994) showing high levels of inter-user reliability. This study showed ceiling effects 24 months after implantation, and we recommended its use only in the first two years after implantation. They also found that poor performance on LiP, as measured by functioning at below the 10th percentile, could be an indicator of device problems and of additional difficulties. Those children in the study functioning at this level one year after implantation were more likely to have device failures than those functioning above. However, the mean age of implantation in this group was 43 months; this is now considered to be late implantation. Most implant programmes today, with earlier implantation and improved technology and implant techniques, would expect children to make faster progress than that reported in 2.3, to achieve maximum score within the first year after implantation, and begin to be concerned about lack of progress at six months after implantation. Infant LiP (ILiP) was later developed to make LiP more appropriate for the very young population currently

being implanted, and is included in the NEAP assessment package (NEAP 2007). LiP is included in the LittleEars Test battery developed by MEDEL, one of the cochlear implant manufacturers.

Further studies using the measures in NEAP, for example Tait et al, (2007a, 2007b), have also provided considerable evidence to show that the development of early communication skills is facilitated by earlier implantation, and by bilateral implantation (Tait et al, 2010). Tait video analysis has become an accepted procedure for assessing progress in very young deaf children.

One measure of outcome in young implanted children which is not included in NEAP is Connected Discourse Tracking, (CDT), which can be used once spoken language has developed and was used in the research of O'Donoghue et al (2.4). It was not included in NEAP, but would be a useful addition, to assess higher order auditory perception beyond the measures included; particularly as the implanted population has changed, and children are making better progress, more quickly. It was included in the Nottingham protocol on the database to be utilised by the implant team teachers of the deaf and a range of age-appropriate texts with rigorous guidelines were developed by the author in response to the criticisms of subjectivity made of the measure (Tye-Murray & Tyler, 1988.) In asking children to repeat long portions of a story without lipreading, CDT makes great demands on the child's ability to remember and decode spoken language by audition alone. It closely resembles the situation in which children find themselves when participating in conversation with their family or peers and in carrying it out, a teacher can learn much about the difficulties a child may experience in following classroom conversation. Age at implantation and mode of communication were significantly positively correlated with CDT results five years after implantation; number of inserted electrodes, origin of deafness (congenital or meningitis) and social class were not (2.4). Those who were younger at implantation, and who used oral communication did better on this test of benefit. However, a key finding of this study is that reported by others: that of variability. When both factors were taken together they did not explain more than 43% of the variance. An additional point of interest in this study is that no ceiling effect was found five years after implantation, and the recommendation that progress be monitored using this measure for longer periods of time.

One outcome measure of interest to educators is whether the children are using their implants in the long-term; use of the implant system is a pre-requisite for the

attainment of other measures of benefit, and significant levels of non-use could have both psychological implications for the individual and family and cost implications for society (2.5). An early study by Rose et al (1996) raised concerns that use of implants in the long-term was likely to be low and that as children reached adolescence, able to make decisions for themselves, they were likely to stop using their implants; they reported 47% of adolescent implant non-users in schools for the deaf in the USA . More recent studies such as that of Todini et al, 2006, also raise concerns about long-term implant use in adolescents. However, in the studies included here (Archbold et al, 1998c and Archbold et al, 2009), 2.5 and 2.6, we reported that children were likely to continue to wear their implants in the long-term, particularly when implanted early. Eighty five children who had been implanted for one year, and 37 who had been implanted for three years, were assessed independently by parents and teachers as to whether they were wearing their implants all the time, most of the time, some of the time or none of the time. Consistent with the emphasis on clinical governance outlined above, none of the children were lost to follow up in this study. None of the children at one or three years after implantation were non-users or occasional users (2.5). One year after implantation, parents and teachers, respectively, rated 79 (93%) and 82 (96%) of children as full-time users of their implants. The figures three years after implantation were 33 (89%) and 34 (95%). These encouraging results, from a group of children coming from a wide range of social backgrounds, and from the full range of communication and education backgrounds in the UK, indicated that high levels of use were possible, given appropriate support locally. Rose et al's work indicated the importance of educational input to the wearing of the implant system; with only 3 schools, out of 43 responding, accounting for 65% of the children wearing their implants. In the studies reported in 2.5 and 2.6, the children were receiving most of their input from their local educational services, and the implant programme had invested much resource into ensuring the local services were equipped to deal with the technology and to have close liaison with the implant programme in case of any problems.

However, the study reported in 2.5 merely reported the usage rates in the group and did not investigate reasons for any lack of consistent use. It also looked at a comparatively short time-frame. The further study (2.6) explored the pattern of usage in 138 children who had been implanted for seven years. The same measure was used, with parents completing an annual questionnaire, as to whether their child was using the implant system all the time, most of the time, some of the time, or none of the time. Seven years after implantation, 115 children

(83%) were using their implants full-time, 16 (12%) most of the time, three (2%) some of the time, and four (3%) were non-users. This group, of consecutively implanted children, showed high levels of full-time use; factors linked to full time use were early implantation, oral mode of communication, and mainstream educational placement.

When the pattern of use over time of the group who were not full-time users was explored, the picture became more complex. Non-use could occur after several years of use, and follow a fluctuating pattern of use over time. During a period of fluctuating use, psycho-social issues such as family and educational support could be crucial, as could contact and support from the implant programme, listening to concerns of family and child, as found by Watson and Gregory (2005). Waiting for routine visits to the implant programme may be too late to address an issue: it is crucial that the local community based professionals have the skills to identify potential problems and the skills and expertise to deal with them as they arise. The presence of other learning difficulties could also impair the continued wearing of the implant system. For educational services, there were many implications from this study, in that a fluctuating pattern of use could indicate some fault with the system or with the support provided and identifying and addressing the issue could ensure the child became a fulltime user with benefit once more. Cochlear implantation uses complex, changing technology and where issues of its management occur, they need to be speedily addressed in order to maintain the system fully functioning. The paper by Archbold and O'Donoghue, 2007, in chapter one, emphasises the need for the care in the community to be informed and educated to manage implant systems effectively there, as does the work of others, including that of Chute and Nevins, 2006.

5.2.1.1 Evaluating educational outcomes

If the majority of profoundly deaf children are now receiving and using their implants in the long-term, what about the impact of cochlear implantation on educational decisions? The major decisions of educational placement and of communication mode are the subject of the first five papers in chapter three.

What of the impact on educational placement?

There was an expectation that implantation would lead to great opportunities for mainstream placement for profoundly deaf children, for example by Daya et

al,(2000). The two papers in this thesis, in chapter three, provide evidence of this trend. Interest in educational placement arose partly out of the studies looking at cost-effectiveness of implantation: cochlear implantation is an expensive procedure, demanding life-long maintenance, and the possibility of cost savings in education being offset against the health-care costs was of interest (O'Neill et al, 2000; Francis et al, 1999). In Archbold et al, 1998b, age at implantation and duration of deafness were significant predictors of educational placement, with those implanted prior to beginning school being more likely to attend mainstream schools than those implanted later, when educational decisions had been made. In the later paper (Archbold et al, 2002), we illustrated that profoundly deaf children with implants, three years after implantation, were following a similar pattern of educational placement as those less deaf (severely deaf rather than profound) with hearing aids when implanted before beginning school. However, in both papers, these were children in the primary stages of education; it is not known whether the trend remains as the children get older.

Studies from other centres, (for example Geers et al., 2008; Francis et al, 1999; Chute and Nevins, 1994) also report the trend to mainstream placement. However, the picture may be more complex than this and assumptions must be made with care. Other factors influence the ability to make judgements from these studies. These studies were early in the provision of cochlear implantation; both the implanted population and the educational environment in which implantation takes place has changed. With the current trend to earlier implantation, there is likely also to be an increased trend to mainstream education, and during the period reported here there has also been an international movement towards the inclusion of all children with disabilities into mainstream education (Chute and Nevins, 2006). In addition, care must be taken in making assumptions about the perceived benefit from mainstream education and it being assumed to be a positive outcome measure from implantation for every child. The support matrix of Francis et al (1999) illustrates the complexity of the relationship between support services and educational placement. For example, a child in a mainstream educational provision may be receiving more support, and hence costing the educational services more, than a child in a specialist provision.

Other studies, for example, (Wheeler et al, 2007) reveal that as the children become older than the children included in these papers, (3.1, 3.2), the educational setting becomes more challenging for them. In our study (Wheeler et al, 2007) we questioned young people, their parents and teachers about their

experiences of secondary school, revealing a more complex situation: the challenges of increasingly complex language and concepts, of poor acoustic conditions combined with a greater number of teachers and teaching styles, with increased use of group work, combine to make access to the curriculum and classroom language increasingly difficult. Additionally, the excellent levels of speech intelligibility typically achieved by those implanted early may mask the young person's language delay or difficulty with the more subtle pragmatic skills required in the classroom.

Later work indicates that functioning in a mainstream class may be more challenging than these studies imply. The more subtle skills of functioning required in the mainstream classroom have not been addressed in the papers included in this thesis, and it is an area of omission which has been partially redressed by others. The work of Damen et al (2007a;2007b) looking at the children with implants in mainstream classrooms used the Assessment of Mainstream Performance (AMP) and the Screening Instrument for Targeting Educational Risk (SIFTER; Anderson, 1989) to compare them with their hearing peers. Their studies revealed a wide variation in functioning and although the results are encouraging, the cochlear implant group scored significantly less well than their normal-hearing peers on areas of both the AMP and the SIFTER. The most important variables for the outcome in this study were age at implantation and duration of deafness. Mukari et al (2007) also used SIFTER, and found that children with implants were rated poorly in the SIFTER communication assessments. They conclude that children with implants continue to need specialist support in mainstream classes, and that linguistic delay may be one of the causes, in spite of the levels of hearing provided by the implant.

What of the impact of cochlear implantation on communication mode?

The other major educational decision involves that of communication mode. In transforming the opportunities for spoken language, has cochlear implantation removed the controversy about decisions on communication mode? Oral communication has often been linked with improved outcomes from implantation (for example Geers et al, 2003; Geers, 2006; Svirsky, 2000), but some studies comparing outcomes from implantation in children using oral communication and those using signed communication may imply that communication choice is a "once and for all" decision, and communication does not change over time. However, children with cochlear implants do change communication mode after

implantation, particularly if implanted early, as we reported in Watson et al (2006) in chapter three. The previous study (Archbold et al 2000; 3.3) showed that children could change communication mode after implantation and found no significant difference in those who used oral communication three years after implantation between those who had used sign communication and those who had used oral communication prior to implantation, in terms of speech perception and intelligibility. The concept that parents have to make a “once and for all” decision about communication mode, shortly after diagnosis, may have been changed by cochlear implantation: while cochlear implantation may have brought about new opportunities for spoken language, the decision may not be as clear cut as once was predicted. Other studies (for example, Tait et al 2000) showed that it is the quality of the communication prior to implantation which predicts the outcome, rather than the mode of communication.

Parents’ views on communication were sought and a questionnaire was sent to families of children who had received implants at least five years previously, asking if their child had changed communication mode, if so in which direction, and why (Watson et al 2006; 3.4). The children had changed markedly towards oral communication, and parents’ views were that the change was largely driven by the change in access to audition provided by the implant and was a led by the child’s changing needs. Those implanted younger were more likely to change communication mode from sign to oral and did so more quickly than those implanted later, with 83% of those implanted below the age of three using oral communication five years after implantation. Interestingly, a minority of children changed communication mode to sign from oral: this was usually as a result of the identification of another learning difficulty.

For parents followed up by interview in the study reported by Wheeler et al (2009) (3.5), cochlear implantation had introduced the concept of a communication journey. While clearly the goal of cochlear implantation for parents was the development of spoken language, as also reported in the papers in chapter four, parents were also pragmatic about communication, which was crucial to family life. Prior to implantation they wanted the most effective form of communication, which, for hearing families, was likely to be spoken language, with or without some signed or gestural support, and following implantation to see the reduction of signed support as spoken language developed through increasing access to audition via an effective implant system. Later, parents and young people showed increased interest in the use of some signed support or Sign Language itself, once

an effective language, a spoken language, had been established. Thus, while cochlear implantation offered increased opportunity for the development of oral communication, parents recognised that differing approaches may be appropriate at differing times. However, obtaining flexible provision in their educational service had often been a source of tension between parents and local teachers, as also reported by Sorkin and Zwolan (2004), and Sach and Whynes (2005). Sach and Whynes (2005) reported that parents had to “fight” for the provision they felt appropriate for their child, and in Sorkin and Zwolan’s study 30% of parents reported being unable to obtain the educational provision they wished for their child.

What of the impact of cochlear implantation on educational attainments?

Educational attainments and children’s functioning in the classroom are crucial for educators, and these are outcomes from implantation which are only measurable in the long-term and only now being assessed. Prior to the advent of cochlear implantation, little progress had been seen in the educational functioning of deaf children since the study of Conrad in 1979 (Archbold et al, 2008). Although investigation into educational attainments following implantation is still in its infancy, and there is little beyond investigations into reading, early reports are encouraging. We explored educational attainments in the form of reading outcomes in Archbold et al 2008, in chapter three, with age at implantation being a significant factor in the development of reading skills. Those children implanted before the age of 42 months, and with a non-verbal IQ in the normal range, had age-appropriate reading scores both 5 and 7 years after implantation. This is very encouraging, given the previously low reading attainments of deaf children. Other research (Spencer et al, 1997; Spencer et al, 2003 ; Spencer et al, 2008; Geers, 2004) also illustrate encouraging reading results in children after implantation.

However, the children reported in 3.5 were tested five and seven years after implantation, making the oldest in that group ten years of age. It remains to be seen as to whether these encouraging results hold up as the children become adolescents. Geers et al (2008) reported on the long-term outcomes from their large study of children implanted in the pre-school years. While speech perception scores improved over the long-term, and average language scores improved at a faster than normal rate, reading scores did not keep pace over time. They concluded that early cochlear implantation in the group of 85 adolescents tested

impacted positively on auditory and verbal development, but it did not result in age-appropriate reading levels in high school for the majority of students.

The current literature reveals that, in spite of reports of age-appropriate language development (Dettman et al 2007; Ching et al, 2008) in children implanted young, reports of progress in educational attainments in the longer term are more cautious. Vermeulen et al (2007) in their study of reading attainments in 50 deaf children with at least three years of implant use also found that those with implants had significantly better reading comprehension than those with hearing aids but remained substantially behind hearing peers. Their educational attainments were also found to be poorer than those of their hearing peers by Thouthenhoofd, (2006) in his study of deaf children in Scotland. He showed that those with implants had better educational attainments, particularly in mathematics, than those with hearing aids, but scored more poorly than their hearing peers. Stacey et al (2006) investigating a large group in the UK, found paediatric cochlear implantation to be associated with reported improvements in some aspects of educational achievements and quality of life, provided that children receive implants before 5 years of age. Other studies looking at academic attainment beyond reading are rare, (Marschark et al, 2007) and Marschark et al, while recognising benefit in educational attainments from early implantation, also emphasised the variability in reported outcomes, and criticised studies into outcomes from implantation for their lack of research rigour, and lack of recognition of the variables found in this heterogeneous group.

Recent papers, in addition to seeing a trend towards the benefit of early implantation, now compare the progress of children with implants with that of normally hearing children, which was rarely done prior to implantation, and is significant in considering the educational implications of cochlear implantation. For example, Dettman et al, 2007, looked at 19 infants implanted below age of one (mean age at implant 0.88 years) finding that implantation was safe in this group. They found that language growth was significantly greater in these infants than in a matched group implanted between 12 and 24 months, and their growth rates matched the growth rates of normally hearing infants. Nicholas and Geers (2007) used the Pre-School Language Scale with 76 children aged 3.5 and 4.5 years of age, implanted below the age of three, and compared them with hearing children of 4.5 years of age. Those implanted between 12 and 16 months were more likely to achieve age-appropriate spoken language. Ching et al, (2008) reported that children implanted below the age of 12 months developed normal language skills

at a rate comparable to hearing children, also as measured by the Pre-school Language Scale. Using TAIT video analysis to explore the developing communication skills of deaf infants with implants, Tait, De Raeve and Nikolopoulos (2007a) also compared the pre-verbal communication skills of children implanted before the age of one, with normally hearing children: 10 implanted under one and 10 normally hearing infants. The development of vocal autonomy was close to that of normally hearing children as was the development of non-looking vocal turns; normally hearing children progressed faster but the difference was not significant.

Educational implications: the parental and young people's perspective

Cochlear implantation has changed educational choices and attainment; chapter four went on to explore the parents and young peoples' perspective of the influence on education.

Archbold and Lutman developed a questionnaire (Children with cochlear implants: parental perspectives) based on the analysis of open responses by parents to a number of questions, thus reflecting the issues thought important by parents, rather than the ones anticipated by professionals. The questionnaire's development is described in O'Neill et al (2004) and its independent validation by Nunes and Pretzlik (2005). Several papers have been published with data obtained from this questionnaire, and two are included in this thesis, 4.2 and 4.3. In Archbold et al, 2002, (4.1) we explored the qualitative data which formed the basis of the questionnaire development. The 30 parents who provided the original data were parents of the first children implanted in the UK, and it may be held that their experiences were not typical of later groups: however, the questionnaire developed from this material continues to be used and translated. Damen et al (2007b) in evaluating its use to arrive at a shorter version concluded that it was a valuable tool to assess the parent perspective. It is also currently being used in a major audit of bilateral implantation in the UK, and is used in current international studies, for example that of Huttunen et al (2009).

For this first group of parents, (4.1), for whom the choice for implantation had been made when there was little evidence on which to base the decision, and for whom the option of spoken language communication in the family had previously seemed unattainable, the major area of change spontaneously reported was that of increased confidence and easier communication. This was attributed to the new

ability to hear and develop spoken language, rather than to maturation. These parents raised the issue of the reliance on long-term technical support from the implant centre, for long-term support and for liaison between implant centre and school. Educational issues were important to these parents: they viewed that implantation had influenced their educational decisions, supporting a move towards spoken language and towards mainstream provision (4.1) which was reported in the previous work in chapter three.

Further analysis of the questionnaire responses from a group of 101 parents of implanted children, three years after implantation, reported in Archbold et al, 2006 and Archbold et al 2007, (4.2 and 4.3) raised some interesting areas of both consensus and diversity. There was a consensus of opinion as to the need for information prior to implantation, for long-term support from the implant team and for long-term maintenance of the implant system. However, interesting diversity emerged in differing families perspectives as to how stressful the process had been. The greatest area of diversity was in considering how difficult it had been to make the decision as to whether to proceed with surgery. A further interesting area of difference was in considering whether learning to talk was an important expectation. Although for the majority (63%) this was the case, a significant minority (25%) did not hold this expectation so strongly (4.2), indicating a flexibility about communication mode which may not be provided in the available educational provision.

When the 101 parents' views on the outcomes from cochlear implantation were analysed, (4.3), parents once more reported themselves to be largely satisfied with the outcomes, with the majority (68%) agreeing that cochlear implantation had exceeded their expectations. The greatest changes were seen in the development of confidence, in spoken language and the ability to converse. However, it leaves a significant minority who had some reservations; 20% disagreed with this statement (4.3). A third of parents expressed concerns about speech intelligibility, as also reported by Incesulu et al (2003), Nikolopoulos et al (2001) and Sach and Whynes (2005). Speech intelligibility has been shown to improve up to ten years after implantation (Beadle et al, 2005) and this study was carried out three years after implantation, which may be too early to judge speech intelligibility in children. For those children in mainstream education, poor speech intelligibility may hinder their ability to participate in conversation with their peers. Over half of the parents were concerned about their child's future education, with one third of parents expressing the opinion that their child was not keeping up educationally with their

hearing peers; this corresponds with the research reported above, in which children with implants outperformed their peers with hearing aids, but did not perform as well as their hearing peers, as did that of Thoutenhoofd (2006) and Vermeulen et al. (2007).

One of the strongest issues emerging from parents in this study was the need for patience and the recognition that outcomes from implantation may take a long time to emerge. This has implications for educational management, where educational decisions may be required to be made early in the child's life, when their needs may not be known. However, the mean age at implantation in this group (4.7 years) is significantly higher than those currently being implanted, and they received earlier technology; it is likely that the outcomes in this group do not reflect those currently being achieved.

In order to access the opinions of the growing group of young people with implants, we explored the views of 29 young people by interview (Wheeler et al, 2009; 4.4); in this group there was a positive attitude to implantation, and no young person regretting the decision made by their parents on their behalf. All but two wore their implant all the time; consistent with the data reported in 2.5 and 2.6, and on a scale of 1-5, with 5 being high, the average rating was 4.4. Their responses indicated a reliance on the technology, and a dislike of being without it; one young person refused to go to school if his implant was not working. A majority felt that their implant helped them understand lessons: however, there was a trend in this group towards specialised provision at secondary level – half of the group attended a special school for the deaf.

Adolescence is a time when a young person develops a sense of identity and a major concern was expressed at the outset of cochlear implantation that these young people might experience significant psycho-social difficulties. There was also the concern that with more profoundly deaf children with implants attending mainstream schools, they would lack the peer-group identity they would find in a school for the deaf. The majority of the group interviewed saw themselves as either deaf and hearing or as deaf, recognising that without their implants they were deaf, with only 21% of the group expressing a strongly 'hearing' identity (4.4). Leigh et al (2008) reported that adolescents with cochlear implants tend to be more hearing orientated whilst those without an implant tended to be more deaf orientated.

These young people refer to being treated as 'hearing' or 'normal' because they can communicate with hearing people and they may be perceived by others as hearing because of the clarity of their speech. This is consistent with previous studies of those young people considered "hard of hearing" or moderately deaf in the past; for example Punch and Hyde (2005). One interpretation of the range of views given by the young people and their thoughtful comments is that they are positive and realistic about their identity. Comments such as "some days deaf, some days hearing" may indicate different levels of functioning in different situations. Identity may not be a fixed concept; the notion that these young people have to see themselves as deaf *or* as hearing may be outdated. For most (69%) speech was the chosen mode of communication, with the others using Sign Supported English. We reported that the group appeared pragmatic about choice of communication mode and were flexible in its use, using sign or speech or text as appropriate (Wheeler and Archbold, 2009; 4.4) this group, the first to experience growing up as deaf, with an implant, a positive view of implantation is given, as by those studied by Percy-Smith et al, 2008; Christiansen and Leigh, 2002; Wald and Knutson, 2000; Toohar et al, 2001; as is a flexible view of communication and identity.

5.3 But.....remaining uncertainty and variability in outcomes

The research reported in this thesis provides evidence that the outcomes from paediatric implantation have surpassed expectations, even of those who were sceptical at the outset, with the major predictor of positive outcomes being early implantation, in the papers in 2.1,2.3,2.4,2.5,2.6,3.1,3.2,3.3,3.4 and 3.6.

However, even though it appears throughout this research and other literature (for example Dettman et al, 2007; Connor et al 2006; Fortnum et al 2006) that the main predictor of benefit is early implantation, there are some provisos in the literature. For example, Holt and Svirsky (2008) queried whether earliest is always best and found that although earlier implantation favourably influenced language outcomes, there were few differences in those implanted before the age of 12 months and those implanted between 13 and 24 months. The advantage in implanting before the age of one was only apparent in receptive language development, not in expressive or word recognition development. Leigh (2008) comments that the empirical evidence base for early implantation is "incomplete and equivocal"; he criticises studies which do not take account of the influence of

early intervention itself, known to be a positive factor (Yoshinaga-Itano, 2004), and which do not highlight the inter-subject variability which is revealed in many studies (Sivrsky et al, 2004; Dettman et al, 2007; James et al, 2008), where at least some of the later implanted children do well.

The other major finding has been that of diversity of outcomes and opinions. This is consistent with others' findings; outcomes throughout the literature are characterised by variability and uncertainty as to predictive factors, as commented upon by Thoutenhoofd et al, 2005; Pisoni et al, 2008; Leigh, 2008 and reported in 2.2, 2.3, 2.4, and the parents' reflections reported in chapter four. When cochlear implantation was in its infancy, the necessary goal was to establish its safety and efficacy, to answer the critics and establish services. Cochlear implant clinic test batteries were often set up in isolation and designed to demonstrate benefit in the prevailing climate of controversy. They naturally looked at "end points", rather than how the children achieved the goal, and usually at the child's functioning in the clinic, where some of the variables can be controlled and where more specific abilities can be measured, such as listening in differing conditions. Research into outcomes from cochlear implantation traditionally focussed on assessing the impact on the peripheral auditory system, rather than looking at learning as a whole, and the role improving audition could play in learning for deaf children.

The establishment of cochlear implant programmes within medical settings led to the medical approach to assessment and outcomes; concentrating on the measurable restoration of hearing and its direct impacts as the achievable goals, may have led to missed opportunities to engage researchers from other related fields who could have thrown light on the impact of cochlear implantation on learning for deaf children. Additionally, the imposition of one model of therapy after implantation may be attractive, particularly following a surgical intervention, but does not recognise individual learning differences, of communication style or learning style, of levels of IQ, or of family and educational input. This may lead to increased variability in outcomes, and loss of the opportunity to utilise the technology to the full for individual children. When looking at outcomes in "real-life" such as in the home and in educational settings, as in the research reported here, then the complex interaction of the many influences on progress increases the likelihood of variability in outcome.

There is a need to look at how children with implants learn, to understand the reasons for the variability, to improve outcomes for all children. Cochlear implant

research has traditionally been isolated from the ongoing research into deaf education, cognition and the neural sciences, with some rare exceptions, such as the work of Chute and Nevins, and of Tobey et al at the University of Texas in Dallas. The developments in these related fields is influential as developing communication and spoken language does not take place in isolation, either from the rest of the functioning of the brain, or from interaction with the external world and others. As Pisoni et al, 2008, P91 comment:

“ We cannot continue to view profound deafness as merely a sensory loss that is disconnected from the rest of the mind and brain.”

Similarly, the impact of cochlear implantation on education cannot be assessed, without exploring the current knowledge of mind and brain on learning:

“Developments in a number of related fields are providing greater opportunities for deaf children to access spoken language than at any time in history.” Leigh, 2008, p24

If the opportunity is taken to learn from the current studies of learning and cognition, then it may be possible to utilise the technology of cochlear implantation for individual deaf children more fully, and lessen the variability currently seen in outcomes. For educators, this variability with the corresponding uncertainty about predictive factors makes advising parents about educational decisions and providing appropriate educational support for deaf children with implants challenging.

5.4 Deaf education: changed by cochlear implantation?

“This is the best time ever to be a deaf student, or the parent or teacher of one” Leigh,2008, p17

Why should Leigh say this in 2008 and what has it to do with the title of this thesis: deaf education, changed by cochlear implantation? In spite of the controversies surrounding its introduction, cochlear implantation, in providing access to spoken language via hearing, has changed deaf education and opened up new opportunities. In a comparatively short time, compared with the centuries of deaf education prior to this, deaf children are attaining levels of spoken language

previously unattainable with the most dedicated teachers of the deaf, and with the most strongly espoused teaching methods. As Spencer and Tomblin comment:

“For the first time in the history of the education of deaf individuals, achievements in speech and language development in this population are changing faster than researchers can keep up.”

Spencer and Tomblin, 2006, P 187

One might add, and faster than educators and educational services can keep up.

Firstly, with regard to communication choices; Chapter one described the communication controversies which characterised deaf education in the past. The introduction of cochlear implantation has led to:

- The increased use of spoken language by profoundly deaf children
- The possibility of changes in communication mode over time, and in differing situations
- The need for parents to make a “Once and for all” choice, often implied by educators and providers of educational services, may no longer be necessary
- The need for flexible communication and educational provision which offer the opportunity for change over time, and for differing communication options in differing places
- The increased need for educators to monitor the child’s developing auditory abilities over time, to ensure any implications for changing communication are driven by the needs of the child, rather than led by political, philosophical or bureaucratic decisions

Many studies, for example Geers et al, 2003 and Kirk et al, 2002, show that the use of oral communication, rather than sign or gesture, is related to improved outcomes following implantation. Hence parents may feel under pressure not to use any sign or gesture at all. However the picture is not clear cut, with other studies showing a more complex picture as we did in 3.5: there may be pre-existing differences in the groups, the modality in which the test is given influences results and there is the old question of “the chicken and the egg” . Do children do well because they are using oral communication, or are they in oral education because they are doing well?

The parents in chapter four reported consistently that the biggest change following implantation was confidence and communication, whatever communication choice had been made. Some young people reported flexible use of communication mode (Wheeler and Archbold, 2007; 4.4). Moving on from old arguments about communication choice may be possible with the provision of better levels of hearing than ever before and earlier implantation. With very early implantation, communication mode is unlikely to be well established prior to surgery; the development of effective communication skills after early diagnosis, combined with early implantation, is likely to bring together vision and audition in early communication skills and hence language in a natural way, as with hearing babies, reducing the oft made demand made by educators for parents to make a choice early in life. In deaf education the term “total communication” has been used to cover a range of educational provision, although it originally described educational provision using spoken English (in the UK) together with Signed Support, sometimes called Simultaneous Communication; Spencer and Tomblin, (2006), define total communication as a philosophy of communication utilizing multiple modalities to fit the needs of the child. This is a much more flexible definition and fits well with the communication journey we described in 3.5, offering the potential of changing communication mode over time and in different settings. In this changing time of earlier diagnosis, and of ever earlier implantation, there is increased interest of a more flexible approach to communication choices, for example Spencer and Tomblin, 2006. Our research (3.5) suggests that the majority of children using some signed support prior to implantation change to becoming confident users of oral language over time. There is an increased interest in the use of speech with signed support internationally, and Spencer and Tomblin (2006) suggest that these children using a truly “total” communication system could become confident code switchers later, as indicated in our studies.

Research and practice in this controversial area needs to take care in its use of terminology; the use of British Sign Language, with its own grammar, and without the use of voice, has very different language learning and educational implications, than that of using Sign Supported English, which was using English grammar and using voice, and to report in research only the comparison of sign and speech masks this. Similarly, educators, in planning educational provision must be very clear about their terminology and what they are providing.

Secondly, with regard to educational placement, cochlear implantation has changed educational options, with increased access to mainstream provision, particularly for those implanted early. However:

- Their needs in mainstream may be overlooked, when they appear to hear well, and to speak intelligibly. Teachers, particularly mainstream teachers, may fail to realize the impact of profound deafness, even with the advantage of cochlear implantation, and not to realise their needs, especially in secondary and further education (Preisler et al. 2005; Wheeler, et al 2007). The majority of children included in the studies reported here have only one implant. The effect of a unilateral hearing loss in education is well known; Bess (1986) showed that children with a unilateral hearing loss were ten times more likely to fail a grade, and twice as likely to have behavioural difficulties in the classroom. Even a mild, unilateral hearing loss can affect a child's performance in the classroom (Most, 2004). Children with implants who achieve intelligible, age-appropriate language are not hearing as their hearing peers in the classroom. They are receiving a degraded auditory signal, particularly in noise and in groups, and are more likely to be dependent on visual clues in order to access language in a busy mainstream class, and to miss some information. (Hauser and Marschark, 2008). Their communication needs are likely to be more subtle than those of profoundly deaf children in the past and easily overlooked.
- On the other hand, there are those who do not do as well as was expected prior to implantation. Up to 40% of deaf children are likely to have another difficulty, and the advent of cochlear implantation has facilitated the identification of some of these; prior to implantation, it could be difficult to diagnose additional difficulties, such as autism, or a language learning difficulty in the presence of profound deafness. For teachers of the deaf, working with teachers with other specialisms such as those working with autistic children, is now even more a necessity.
- Managing the challenges of the changing technology in the classroom is challenging – particularly in the mainstream classroom with non-specialist teaching staff. Young people and parents highlighted the reliance of implanted children on the technology, and the necessity of long-term technical support.

Thirdly, with regard to educational attainments: cochlear implantation has changed the potential for profoundly deaf children to increase the level of educational attainments commonly accepted in the past.

- Their language, reading and other educational attainments are now being compared with those of their hearing peers
- Their educational attainments are better than their peers with hearing aids, but not yet as good as those of their hearing peers in the long-term
- There is little evidence to show what type or level of educational support leads to improved educational outcomes for these children

Fourthly, from parents and young peoples' perspective, education is a major issue, and one on which cochlear implantation has made a major impact. While the majority of parents are satisfied with outcomes from implantation, as reported in chapter four, and in other studies, a major concern for them is that of education, for example, Sach and Whynes, 2005. Parents:

- Expressed concerns about the management of their children into adulthood, and of the technology in the long-term.
- Wanted local educators to be trained in the management of the technology
- Wanted good liaison between implant centres and local educational services
- Wanted choice and flexibility in educational provision and communication methodology and recognition of their child's changing needs and abilities over time.

The young people:

- Valued their implants in school
- Wanted them fully functioning all the time
- Had a pragmatic view of communication choices
- Saw themselves as both deaf and hearing

It may be that cochlear implantation demands more of deaf education, rather than less. For a large group of deaf children, education may be more straightforward and their needs may be more subtle than previous groups; however, there remain those whose needs may be complex and require very specialist teaching. Deaf children remain a heterogeneous group; it appears that cochlear implantation has added further to the factors producing variability rather than reducing it. To the already established influences on progress, are now added others such as age at implantation, device functioning and programming, duration of use of implant system, and numbers of functioning electrodes inserted.

For educators, cochlear implantation has provided new opportunities, but also new challenges to address:

- The provision of flexibility in educational provision over time
- Effective, trained support in mainstream education

- A more diverse population to support, with more subtle communication needs
- The skills to monitor subtle changes in progress over time, and identify difficulties which may impede progress, whether residing in the child, the environment, or in the technology
- The provision of appropriate education for those whose main difficulty is no longer deafness, but may be an additional learning disability
- Providing appropriate support in the secondary, or high, school, with the increased demands
- The management of complex, changing technology in a busy educational environment
- Challenges to their previously accepted areas of expertise from other professionals
- Providing peer-group support for the psycho-social needs of the increasing numbers of those in mainstream provision

There remains the challenge of long-term management in education for this new group of children, who are deaf but functioning with levels of hearing provided by implantation not previously possible for profoundly or severely deaf children, and who are increasingly using two implants. They are not functioning as profoundly deaf children in the past, but neither are they functioning as hearing children. The research here indicates this as does research such as Pisoni's study of the short term memory functioning of children with implants considered to be doing well, which found that this group differed from hearing children in their functioning (Pisoni et al, 2003).

Historically there has been a divide between those who research and those who practice, as described in the personal forward to this thesis. The research reported here involved parents and teachers and the young people themselves and was published in a range of professional journals in order to be accessible to educators and to influence practice. If the changing needs of this new group of deaf children and young people are to be met, changing practice needs to be evidence-based and to be informed by rigorous and reliable quantitative and qualitative research, as recommended by Hauser & Marschark, (2008), and preferably in the classroom, as that of Damen et al (2007a,2007b).

“teachers, deaf individuals, and parents.....must be involved in establishing the research agenda. Otherwise, valuable insights into real-world functioning of deaf students will be lost to generalizations or sample limitations of laboratory research.” Hauser and Marschark, 2008, p454.

Gathering this data also needs to be carried out over a long-time scale, without conclusions being drawn too quickly. There is a dearth of comprehensive, long-term data with only two such published studies (Beadle et al, 2005; Uziel et al, 2007). Such research into the “real-world” functioning of deaf pupils will then be available to influence service planning and teacher training as well as influencing the decisions made about appropriate educational support for individual children. How this is done remains a major issue: with the move world-wide towards mainstream education and more generic teacher training, ensuring that educational services have the skills, expertise and knowledge to provide for the changing needs of today’s deaf children is a major challenge.

Cochlear implantation in children has not turned out as either the critics or the supporters predicted twenty years ago in chapter one. It *has* changed deaf education, influenced educational choices, and improved educational attainments in ways not foreseen. However, the education of children with implants clearly remains a major issue for parents. Are educational services up to the challenge of ensuring that the potential of cochlear implantation is available for all deaf children with implants? If practitioners in deaf education work with parents and researchers to plan the future, it may be possible to utilise the opportunities brought by the new technology to fulfil the future depicted by Marschark and Spencer, and to use cochlear implantation to enable deaf education to move on from some of the old arguments:

“ Spoken language development of deaf children may be more possible today than ever before.we are now presented with the opportunity to learn from earlier mistakes and misunderstandings and to synthesize the best ideas of the past with the technological, programming and social advances of today.we may finally be able to fulfil the promise of effective support for speech and spoken language with hearing loss.”

Marschark and Spencer, 2006, p17.

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Chapter 6

Summary / Samenvatting
Acknowledgements
Curriculum Vitae
List of publications

Summary

Deafness from birth has a profound impact on the development of communication and language skills, and hence on the child's educational needs and attainments, which are traditionally very delayed. Cochlear implantation, in providing useful hearing to those unable to access spoken language through conventional hearing aids, has brought new opportunities for deaf children and had a huge impact on deaf education and its practice in a comparatively short time.

This thesis begins by describing the personal experience of the influence of deafness on educational practice by the author, a teacher of the deaf who also became a researcher, and of the frustrations of bringing together the interests of practitioners and researchers. Chapter one explores the impact of deafness on communication and language and the ways in which educators have, over centuries, endeavoured to overcome its effects. The challenges this brought led to much controversy about the relative merits of differing methodologies in deaf education. Research into the practice of deaf education was limited for many years to comparisons of the differing methodologies but also by the divisions between practice and research. In addition, the heterogeneity of deaf children as a group presents great challenges for traditional research methods.

The technology of cochlear implantation offered to many parents and teachers the hope that new hearing provided by electrical stimulation would provide a means of overcoming many of the difficulties caused by childhood deafness by providing access to spoken language. However, the implantation of deaf children was very controversial, and strongly opposed by supporters of Deaf culture, including many educators. Chapter one goes on to describe the development and introduction of this technology for use in children and the reasons for the controversy. It describes the establishment of Nottingham Paediatric Cochlear Implant Programme, of its multi-professional team, and the database designed both to manage the programme and to monitor the progress of the children. From its inception, the programme involved parents and teachers in the collection of data, ensuring that both qualitative data and quantitative data were included; to do so measures were developed and validated, and all the implanted children were followed to ensure that none were lost to follow up. The author led the development of the data sets with her colleagues, and the educational data collection, which is reported here, was her responsibility. As a teacher of the deaf, then working within the medical context of a cochlear implant programme at its outset, there were some key issues

to be addressed. What has been the influence of cochlear implantation on the questions that were posed in chapter one?

- Has cochlear implantation changed deaf education?
- Has it brought about changes in communication, educational choices and attainments, following the provision of useful hearing?
- What about the perspective of parents and young deaf people on the implications of cochlear implantation for education?

In the implementation of the cochlear implant programme, and its attention to the data collection, the highest standards of clinical governance were established, recognising the importance of being explicit about outcomes to all stakeholders, as described in 1.6.1, and ensuring that the data collected was useful in influencing practice and management. From the outset, the programme valued the skills of the local educational services, and in 1.6.2 the author describes the importance of ensuring that these skills were utilised in the long-term management of cochlear implant technology by children. Unless the implant technology is fully effective at home and school, the work of the cochlear implant clinic is will not be used to maximum benefit and the opportunities brought by this technology lost.

In chapter two, the author described the challenges of evaluating outcomes in young deaf children, with little or no language, or formal skills, and the measures developed to overcome these challenges. The Nottingham Early Assessment Package, NEAP, was developed to include measures looking at communication skills, auditory perception and speech production in the short and long-term, including some measures developed by the author, and others developed or adapted by her colleagues. This package enables progress to be monitored over time, and to be shared with parents and teachers, in order to make informed decisions, to influence management, and to identify if other problems are present (2.1). Two specific measures of auditory perception, Categories of Auditory Performance (CAP) a long-term measure, and Listening Progress Profile, (LIP), a short-term measure, were reported in detail; these measures are important in monitoring the use of the implant system in providing useful hearing, and changes in listening skills over time. CAP was shown to have high inter-user reliability (2.2) and LIP to be sensitive to the changing auditory skills of young deaf infants (2.3) and to be able to highlight when other difficulties may be hindering progress. This is important; up to 40% of deaf children may have another difficulty which may influence the use of audition in the development of spoken language.

Predicting outcomes from implantation in children was a challenge from the outset, particularly with the recognised large range of variables involved. In 2.4, the author and colleagues used a measure, Connected Discourse Tracking, CDT, with materials developed by the author. They monitored 40 children over five years, and considered the variables of age at implantation, number of inserted electrodes, origin of deafness, mode of communication and socio-economic group. In the study, only younger age at implantation and oral communication were determinants of later speech perception as measured by CDT results.

Lastly in chapter two, two papers investigated the amount of use of their implants by the children over time, as reported by parents and teachers. Although the implant is surgically inserted, the external parts can be removed, and any indication of large-scale disuse would indicate significant dissatisfaction with the devices by the children themselves. The first study (2.5) looked at use over three years, finding high levels of usage over this period of time. The second study (2.6) looked at larger numbers, over a longer period of time, and investigated more closely the factors which were significant in the non-users in the study. Looking at 138 children over seven years, high levels of use were found: 83% were wearing their implants all the time, with 12% most of the time, 2% some of the time, and 3% were non-users. Factors linked to high usage of the implant system were early implantation, oral mode of communication and mainstream educational placement. The study pointed out that non-use often followed a fluctuating pattern of use over time, rather than being a sudden decision not to wear the device. This indicated the need for local expertise to be available in managing the implant system and careful monitoring of use by cochlear implant teams.

Chapter three went on to explore the impact of cochlear implantation on educational outcomes: in particular the educational choices of placement and communication mode and the educational attainment of reading abilities. Two studies (3.1 and 3.2) found that increasing numbers of children with implants were going to mainstream schools when compared with those with hearing aids. Those implanted early were more likely to go to mainstream schools than to schools for the deaf; however, these groups were still young and in primary schools and it remains unknown as to whether this trend is maintained as those with implants enter secondary schools. This is an area which needs further long-term investigation.

The choice of communication mode for deaf children has long been a major controversy, and this has continued with the advent of cochlear implantation: whether to use oral or signed communication with deaf children with implants. Three papers looked at communication in deaf children with implants; in 3.3 the author found that those children using oral communication three years after implantation outperformed those using signed communication. However, when those who had always used oral communication were compared with those who had used signed communication and changed to oral communication there was no significant difference between them. Investigating changes in communication after implantation, in 3.4 the authors found that those implanted early were more likely to use or change to oral communication and to change early after implantation. The change in communication was likely to be led by the child and by their change in the use of audition after implantation. Exploring with parents by interview children's communication after implantation, parents discussed a communication journey, with a pragmatic view of communication in which it may change over time. While for parents the goal of implantation remained spoken language, they also saw the value of sign support for their children.

Traditionally, deaf children have very delayed reading attainments, and in 3.6 the author and colleagues investigated the reading abilities of children after implantation. Age at implantation was a significant factor in reading attainment, with those implanted before the age of 42 months achieving reading ages in line with their chronological ages seven years after implantation. This is a huge change, when compared with the reading levels of profoundly deaf children in the past. In providing useful hearing to deaf children, and early access to the phonology of the language, cochlear implantation is already being shown to have a positive effect on the reading attainments of deaf children. However, these children were still young, and further long-term research is required to investigate whether this improved progress holds up in the long-term.

Chapter four considered the educational issues of implantation from a parent perspective, and that of the young people themselves. The author, with colleague Lutman, developed a parental questionnaire on outcomes from cochlear implantation, Parental Perspectives. The questionnaire was developed from issues arising from the parents themselves, and it was externally validated by interview. In the work in developing the questionnaire, parents, three years after implantation, reported increased confidence and easier communication (4.1). They raised concerns about the long-term support of the implant system, given their

child's reliance on it, and the importance of liaison between implant centre and school, to ensure its continued effective use. These parents, in one of the first studies to consider their opinions, recognised that cochlear implantation had influenced their educational decisions: towards mainstream placement, and towards the use of spoken language. In a further analysis of a larger group of parents using the validated questionnaire itself, an interesting diversity of views emerged, illustrating the lack of homogeneity in the group (4.2 and 4.3). Although the goal of implantation remains spoken language, there was recognition of the value of sign support, indicating flexibility in communication mode. They also emphasised the long-term nature of development of outcomes from implantation, which has implications for educational decisions. Over half of parents expressed concerns about their child's future education, with one third feeling that their child was not keeping up with their hearing peers. Education remains a major issue for parents of implanted children: as found in other studies and in other research by the author.

Chapter four explored the opinions of young people with implants; they expressed their reliance on the implant system, and the majority considered that the implant system helped them understand lessons in school (4.4). In the study, other issues were explored by the authors, including whether the young people viewed themselves as deaf or hearing: the majority seeing themselves as deaf, or deaf and hearing. With implants, these young people appear to be developing a more flexible notion of identity - in which they may function as deaf in some situations, and as hearing in others, influencing their choice of communication. This has implications for educational practice: for the increasing numbers of deaf young people in mainstream, how best to support their psycho-social needs remains an issue. These young people, like their parents, were pragmatic about communication mode, the majority using spoken language as their main means of communication, but using other visual means of communication by choice.

Throughout the research, which encompasses the development of implantation from a controversial process to that of a routine procedure for deaf children, there are several findings which have an impact on deaf education. These are:

- earlier implantation being more effective, although we don't yet know how early is most effective
- increased use of spoken language after implantation
- greater flexibility in choice of communication mode over time, and in different situations
- increased numbers of deaf children attending mainstream schools

- improved reading abilities in those implanted early
- high long-term use and value of their implant systems by children and young people
- concern by parents about appropriate education of their children
- concern by parents about the long-term management of the implant systems in school

In influencing the educational decisions made for deaf children, and improving their educational attainments, deaf education has indeed been changed by cochlear implantation, and in a comparatively short time. However, further changes are needed. Although outcomes were better than predicted, the research also revealed variability in outcomes and diversity of views; robust predictors of outcomes are as yet largely unknown. Nor is it yet known what type of educational provision best supports children with implants in the long-term: children with implants are not performing as hearing children, but neither are they performing as deaf children in the past. How this developing and ever-changing technology is best supported in mainstream schools and how children are learning with their implant systems is as yet unknown. This diversity and variation is challenging for teachers and may have added to their challenges in training teachers of the deaf and in planning educational systems.

In order to meet the changing educational needs of this new population, the author suggests that further research is required and that this is best carried out by bringing together researchers, teachers, parents and children and young people. Research into pupils with implants will then be based on the “real-world” issues, and will also benefit from the research developments in other fields such as that of cognition and neuro-science. This will enable us to focus further on how children with implants best learn, rather than on their functioning and on outcome results per se. Thus changes in practice and management of individual children will be based on robust evidence, supporting deaf educators in moving on from the controversies of the past, and providing them with the knowledge to secure the long-term support of children with implants within local deaf educational services. Cochlear implantation in children, in bringing together medical and educational perspectives, has, in a comparatively short space of time, had a major impact on deaf education, on the choices made for deaf children and their educational attainments. The research reported in this thesis provides some of the evidence for this, and highlights the need for further changes in educational practice. This thesis recognised the value of practitioners, parents and young people’s involvement in research into the impact of this new technology: further research

bringing together different disciplines may enable us to bring together the best ideas and practice of the past with the exciting developments of today. This may enable deaf education to maximise the benefits for deaf children and capitalise on the greatest opportunities there have ever been for deaf children to acquire spoken language and thus to ameliorate the effects of childhood deafness on language and education which have been the driving force for teachers of the deaf for so long.

Samenvatting

Doof geboren zijn is zeer ingrijpend voor de ontwikkeling van communicatie en van taalvaardigheid en hieruit volgt een behoefte aan een daarop gerichte scholing en opvoeding. Desondanks worden deze ontwikkelingsstadia van oudsher zeer vertraagd doorlopen. Cochleaire implantatie verschaft gehoor aan hen die niet eerder gesproken taal konden horen ook niet met behulp van hoortoestellen. Door toepassing van cochleaire implantatie ontstonden nieuwe mogelijkheden voor dove kinderen en dat had een enorm effect op het onderwijs aan dove kinderen en de uitvoering daarvan en wel in een relatief kort tijdsbestek.

Dit proefschrift begint met de beschrijving van de persoonlijke ervaringen van de auteur die eerst als dovenonderwijzer en later als wetenschappelijk onderzoeker, zich bewust werd van de effecten die doofheid had op de wijze van scholing. Het verhaalt ook over de frustratie en de moeite die het kostte om het gemeenschappelijk belang van de dovenonderwijzers en de wetenschappelijke onderzoekers op een lijn te krijgen.

Hoofdstuk 1 handelt over de effecten die doofheid heeft op communicatie en taalvaardigheid en de vele wegen waarlangs gedurende eeuwen onderwijzers gepoogd hebben die nadelige effecten te overwinnen. Deze uitdagingen over hoe dus met behulp van welke methoden de gebarentaal of de orale methoden deze taalvaardigheid en communicatieproblematiek het beste overwonnen konden worden, leidde tot vele en heftige tegenstellingen in de onderwijswereld van de doven. Het wetenschappelijk onderzoek over hoe het beste dove kinderen op te voeden en te scholen was vele jaren beperkt tot het vergelijken van deze verschillende methoden. Los daarvan sloten de vragen die de onderzoekers zich stelden niet aan bij de dagelijkse praktijk van de dovenonderwijzers. Daarbij komt nog dat de groep van dove kinderen door de heterogeniteit in de eigen mogelijkheden van deze kinderen om te kunnen leren, grote problemen oproept bij toepassen van de traditionele onderzoeksmethoden.

De techniek van cochleaire implantatie stemden vele ouders en dovenonderwijzers hoopvol, dat door deze nieuwe wijze van horen, die toegang gaf om gesproken taal te kunnen horen, en die mogelijk gemaakt werd door een elektrische stimulatie, vele van de eerdere problemen die het gevolg waren van vroegkinderlijke doofheid overwonnen zouden worden. Echter het (gaan) implanteren van dove kinderen werd een zeer controversieel onderwerp en er was

een forse oppositie vanuit de dovencultuur gesteund door vele dovenonderwijzers. Hoofdstuk 1 verhaalt verder over de ontwikkeling en de eerste toepassingen van deze technologie bij kinderen en waarom er een controversie was. Het beschrijft de oprichting van de Nottingham Paediatric Cochlear Implant Programme, de multi professionele samenstelling van het team, en de database die ontworpen was om enerzijds het cochleaire implant programma te managen en anderzijds om de vooruitgang van de afzonderlijke kinderen te registreren. Vanaf het begin van dit programma werden de ouders en de dovenonderwijzers betrokken bij het verzamelen van de gegevens om er voor te zorgen dat kwantitatieve en kwalitatieve gegevens verkregen werden; om dit te bereiken werden methoden ontwikkeld en gevalideerd en alle geïmplanteerde kinderen werden in hun ontwikkeling gevolgd om te voorkomen dat er geen een voor de follow-up verloren zou gaan.

De auteur van dit proefschrift gaf leiding aan de ontwikkeling van deze data bestanden samen met haar collega's. Het verzamelen van de gegevens over de ontwikkeling van elk kind, waarover hier gerapporteerd wordt, was haar verantwoordelijkheid. Als dovenonderwijzer werkend vanaf de start in de medische context van een cochleair implant programma voor dove kinderen, waren er enkele hoofdzaken die om een evaluatie vroegen, namelijk wat was de invloed van cochleaire implantatie op de vragen zoals verwoord in hoofdstuk 1.

- Heeft cochleaire implantatie het dovenonderwijs veranderd?
- Heeft cochleaire implantatie geleid tot veranderingen in communicatie, in keuzes van onderwijs en de daaruit voortkomende resultaten. Leidde het tot het verschaffen van een nuttige manier van horen?
- Wat is het perspectief van ouders en jonge doven als gevolg van cochleaire implantatie op het gebied van opvoeding en ontwikkeling?

Bij het implanteren van het cochleaire implant programma en bij het verzamelen van de gegevens, werden de hoogste standaarden van clinical governance aangehouden, rekening houdend met het belang van alle betrokkenen om duidelijk te zijn over de resultaten zoals beschreven in 1.6.1 en er voor zorgend dat de verzamelde gegevens nuttig zouden kunnen zijn om het dovenonderwijs te kunnen beïnvloeden. Vanaf het begin evalueerde het programma de vaardigheden van de lokale onderwijssteunpunten en in 1.6.2 beschrijft de auteur het belang dat vaardigheden in het verzorgen van cochleaire implant technologie ook op de lange termijn beschikbaar zijn voor deze CI-kinderen. Wanneer het cochleaire implant thuis en op school in technische zin niet optimaal werkt, dan zal het werk van de cochleaire implant clinic niet maximaal benut worden en blijven mogelijkheden gegeven door deze nieuwe technologie onbenut.

In hoofdstuk 2 beschrijft de auteur de uitdagingen om de resultaten te evalueren in jonge dove kinderen met weinig of geen taal of andere vaardigheden (formal skills) en de maatregelen die ontwikkeld werden om deze uitdagingen aan te kunnen. De Nottingham Early Assessment Package (NEAP) was ontwikkeld om meetinstrumenten te verschaffen voor communicatieve vaardigheden, geluid- en spraakwaarneming en spraakproducten op de korte en lange termijn. Sommige van deze meetinstrumenten werden door de auteur van dit proefschrift ontwikkeld, terwijl andere meetinstrumenten werden ontwikkeld of aangepast door haar collegae. Dit NEAP maakt het mogelijk om een vooruitgang over de tijd te registreren en te delen met de ouders en de onderwijzers om op die wijze gefundeerde besluiten te nemen, het beleid aan te passen en om op te sporen of er andere problemen een rol spelen. Twee specifieke meetinstrumenten voor de auditieve waarneming, te weten Categories of Auditory Performance (CAP), een lange termijn meetinstrument en Listening Progress Profile (LIP), een korte termijn meetinstrument, worden in detail beschreven; deze meetinstrumenten zijn belangrijk voor het registreren van het gebruik van het cochleaire implantaat in het voorzien van een nuttig gehoor en veranderingen in het luistergedrag over de tijd. CAP bleek een hoge betrouwbaarheid te hebben onafhankelijk van wie de test afnam (2.2) en LIP bleek gevoelig te zijn voor het waarnemen van veranderingen in de auditieve vaardigheden van jonge dove kinderen (2.3) en bleek in staat om andere problemen die de ontwikkeling belemmerden op te sporen, wat zeer belangrijk is. Immers wel 40% van de dove kinderen hebben ook een ander probleem naast hun doofheid, wat kan beïnvloeden of dat kind gebruik zal maken van auditieve prikkels in de spraakontwikkeling.

Vanaf het begin was het een uitdaging om de resultaten van cochleaire implantatie te voorspellen in het bijzonder vanwege de gekende grote variatie in mogelijkheden tussen de kinderen onderling. In hoofdstuk 2.4 gebruiken de auteur van dit proefschrift en haar collega's een meetinstrument Connecting Discourse Tracking (CDT) geheten, welk meetinstrument door de auteur van dit proefschrift was ontwikkeld. Zij vervolgden de ontwikkeling bij 40 kinderen gedurende 5 jaren en evalueerden de variabelen zoals leeftijd van cochleaire implantatie, het aantal geïmplanteerde elektroden, de oorzaak van de doofheid, de wijze van communicatie (oraal of gebaren) en de maatschappelijke sociaaleconomische achtergrond. In deze studie bleken alleen een jongere leeftijd op het moment van implantatie en orale communicatie bepalend voor het latere niveau van spraakverstaan te zijn, zoals blijkt uit de resultaten van de CDT-metingen.

Tenslotte worden in hoofdstuk 2 2 publicaties gepresenteerd waarin de mate de kinderen hun CI-implantaat in de tijd benutten gemeten, zoals dat werd opgegeven door de ouders en de leerkrachten. Alhoewel het implantaat chirurgisch inwendig geplaatst is, kunnen de uitwendig te dragen delen verwijderd worden.

Iedere aanwijzing van het op ruime schaal niet benutten van het CI-implantaat zal leiden tot een opmerkelijke ontevredenheid bij de kinderen met het cochleaire implantaat. De eerste studie (2.5) keek naar het gebruik over een periode van 3 jaar en er werden hoge percentages van gebruik gevonden over deze tijdsperiode. De tweede studie (2.6) keek naar grotere aantallen personen en over een langere periode en onderzocht intenser de factoren die kenmerkend waren voor de niet-gebruikers in deze studie.

Bij 138 kinderen over een periode van 7 jaren werden hoge percentages van gebruikers van het CI-implantaat gevonden: 83% gebruikten hun implantaat steeds, 12% meestal, 2% zo af en toe en 3% gebruikten het implantaat niet.

Factoren die gerelateerd waren aan een hoog percentage van gebruik van het implantaat waren vroege implantaten, de orale methode van communicatie en het plaatsen van het kind in het reguliere onderwijs. Deze studie toonde evenzo aan dat het niet gebruiken van het cochleaire implantaat vaak volgde over een langere tijd een wisselend gebruik maken van het cochleaire implantaat en dat er veel minder sprake was van een plotseling besluit om het cochleair implantaat niet meer te gebruiken. Deze resultaten geven aan, dat er op lokaal niveau een behoefte is aan expertise om het cochleaire implantaat te kunnen afstellen en dat de cochleaire implant teams zorgvuldig het gebruik van het cochleaire implantaat op het moment zelf moeten kunnen registreren.

Hoofdstuk 3 gaat verder met het evalueren van de betekenis van cochleaire implantaten op de resultaten van onderwijs, in het bijzonder op de effecten van keuzen voor het te volgen type van onderwijs (gebaren of oraal) en de daarmee gepaard gaande resultaten in leesvaardigheid. Twee studies (3.1 en 3.2) stelden vast dat in toenemende mate aantallen kinderen naar het reguliere onderwijs gingen in vergelijking met kinderen die alleen gerevalideerd werden met conventionele hoortoestellen. De kinderen die vroeg geïmplanteerd werden bleken vaker het reguliere onderwijs te bezoeken dan dat zij het onderwijs op een Instituut voor Doven volgden. Echter deze groepen kinderen waren nog jong en verkeerden in de periode van de lagere school en het is nog onduidelijk of deze trend om het reguliere onderwijs te bezoeken doorzet in de periode van het middelbare onderwijs. Dit behoeft in de nabije toekomst verder onderzoek.

De keuze voor de wijze van communicatie voor dove kinderen via de gebaren taal of via gesproken taal is lang een belangrijk punt van heftige tegenstellingen geweest in het onderwijs van dove kinderen en na de introductie van cochleaire implantatie is dit voortgegaan namelijk of de orale methode of de gebaren taal gebruikt moest worden bij dove kinderen met een cochleair implantaat.

Drie publicaties in hoofdstuk 3 behandelen de communicatie bij kinderen met een cochleair implantaat. In hoofdstuk 3.3 stelt de auteur vast dat de kinderen die orale communicatie benutten 3 jaar na implantatie veel beter presteerden in vergelijking met de kinderen die gebarentaal gebruikten. Echter, wanneer degenen die al steeds orale communicatie gebruikten vergeleken werden met hen die eerst gebarentaal gebruikten en daarna overgingen op orale communicatie was er geen significant verschil meer tussen beide groepen.

In hoofdstuk 3.4 worden veranderingen in de wijze van communicatie na cochleaire implantatie onderzocht. Gevonden werd dat degenen die vroeg geïmplanteerd werden er vaker toe overgingen om over te stappen naar orale communicatie of al direct orale communicatie gebruikten. De veranderingen in communicatiewijze leek heel duidelijk bepaald te worden door het kind zelf en daarmee door de verandering in het gebruik van auditieve signalen na implantatie. Door ouders te interviewen over de wijze van communicatie na implantatie werd duidelijk dat de ouders een reis maakten langs de verschillende wijzen van communicatie met een vrij pragmatische manier van doen en waarbij de methode van communicatie, verbaal of via gebaren, over de tijd kon wisselen. Terwijl voor de ouders het doel van een cochleaire implantatie was om tot gesproken taal te komen, zagen zij heel wel het belang van een ondersteunende gebarentaal voor hun kinderen.

Van oudsher hebben dove kinderen een zeer vertraagde leesvaardigheid en in hoofdstuk 3.6 worden de leesvaardigheden gepresenteerd van kinderen na cochleaire implantatie. De leeftijd waarop de cochleaire implantatie plaats had bleek een significante factor bij het verwerven van leesvaardigheid. Immers degenen die nog geïmplanteerd werden voor de leeftijd van 42 maanden bereikten een leesvaardigheid 7 jaar na implantatie die vergelijkbaar was met die van horende kinderen op diezelfde leeftijd. Dat is een enorme vooruitgang wanneer wij deze resultaten vergelijken met de leesvaardigheid van vroegkinderlijke doven in het verleden. Door aan dove kinderen een nuttig gehoor te verschaffen en hen tegelijk toegang te geven gesproken taal te leren kennen, is al aangetoond dat cochleaire implantatie een positief effect heeft op de leesvaardigheid van dove kinderen. Wij spreken hier echter over nog relatief jonge kinderen en lange termijn

resultaten zijn nodig om te ervaren of deze verbeterde resultaten ook op de lange termijn zich zullen gaan voortzetten.

Hoofdstuk 4 behandelt opvoedkundige aspecten na cochleaire implantatie vanuit het perspectief van de ouders en vanuit de jongere zelf.

Archbold en Lutman ontwikkelden een vragenlijst voor ouders over de resultaten van cochleaire implantatie. Parental perspectives geheten.

Deze vragenlijst was ontwikkeld over onderwerpen die door de ouders eerder waren opgebracht en deze vragen werden elders gevalideerd met behulp van de interview methoden. Tijdens het verder ontwikkelen van deze vragenlijst melden de ouders 3 jaar na de cochleaire implantatie een toegenomen zelfvertrouwen en een gemakkelijker communicatie. Zij toonden bezorgd te zijn over de technische ondersteuning van het cochleaire implantaat op de lange termijn gezien de afhankelijkheid van hun kind op dit punt. Verder benadrukten zij het belang van een directe band tussen het Cochleaire Implant Centrum en de school om zeker te zijn van het voortgaande effectieve gebruik van het cochleaire implantaat. In deze eerste studies die de mening van ouders onderzochten lieten de ouders weten dat zij herkenden dat cochleaire implantatie hun besluiten inzake opvoedkundige aangelegenheden had beïnvloed en wel in de richting van het plaatsen van hun kind in het reguliere onderwijs en het gebruiken van de orale communicatie. Bij een verdere analyse bij een grotere groep ouders met de gevalideerde vragenlijst kwam een interessant verschil van meningen naar voren wat aangaf dat er geen homogeniteit in deze groep bestond (4.2 en 4.3). Alhoewel het doel van cochleaire implantatie blijft het komen tot gesproken taal, werd de waarde van gebarentaal erkend, wat tekenend was voor een flexibiliteit in gebruik van de communicatiemethoden. Zij benadrukten evenzo dat de resultaten van cochleaire implantatie ook op lange termijn verder verbeterden wat weer effect heeft voor de opvoedkundige verdere besluitvorming.

Om beter te kunnen inspelen op de toekomstige verdere behoeften van deze nieuwe populatie personen pleit de auteur van dit proefschrift ervoor nader onderzoek te blijven verrichten en zij stelt dat dergelijk onderzoek het best uitgevoerd kan worden door bij elkaar te brengen de dovenonderwijzers, de ouders, de kinderen en de jong volwassenen. Onderzoek naar resultaten van cochleaire implantatie bij kinderen zal dan gebaseerd zijn op de werkelijke van belang zijnde kwesties. Zo zal ook gebruik gemaakt kunnen worden van de ontwikkeling in andere onderzoeksgebieden zoals op het terrein van cognitie en neuroscience. Dat zal het ons mogelijk maken om ons er verder op te richten op

hoe kinderen met een cochleair implantaat het beste kunnen leren, veel meer dan ons alleen te richten op hun functioneren en de verkregen resultaten. Op die manier zullen veranderingen aangebracht in de praktijk en in het begeleiden van het individuele kind gebaseerd zijn op een overduidelijke evidentie, en gedragen worden door de dovenonderwijzers, die dan de tegenstellingen ja de barricades over het voor en tegen van de orale methode en de gebarenmethode zullen verlaten. Zij zullen dan voorzien worden van kennis om zeker te stellen hun lange termijn ondersteuning van de kinderen met een cochleair implantaat binnen de bestaande lokale faciliteiten van het doven onderwijs.

Cochleaire implantatie bij kinderen heeft in een relatief korte tijdspanne de medische en de orthopedagogische aspecten bijeen gebracht en heeft daarmee een enorme invloed gehad op het dovenonderwijs en op de keuzen die voor dove kinderen gemaakt worden en de daarmee verbonden schoolse prestaties.

De in dit proefschrift opgenomen onderzoeksresultaten verschaffen enige evidentie voor dit alles en vestigt de aandacht op verdere veranderingen in de opvoeding en scholing van deze dove kinderen.

Deze proefschriftstudie bevestigt de waarde om dovenonderwijzers, ouders en de jong geïmplanteerden allen te betrekken in het onderzoek naar de waarde van deze nieuwe technologie.

Door in de nabije toekomst verschillende wetenschappelijke disciplines samen te brengen in nieuwe researchprojecten zal dat ons in staat stellen met de beste ideeën op te komen en tegelijk de bestaande kennis uit het dovenonderwijs uit het verleden samen te brengen met de nieuwe technologische ontwikkelingen van heden ten dage. Dit kan het onderwijs aan doven in staat stellen haar resultaten voor de dove kindere verder te verbeteren ja zelfs te maximaliseren en daarmee te realiseren de nieuwe enorme mogelijkheden ooit beschikbaar geweest om dove kinderen de gesproken taal zich eigen te laten maken en daarmee de negatieve betekenis van vroegkinderlijke doofheid op het verwerven van gesproken taal en hun verdere ontwikkeling verder te helpen wegnemen.

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Employment:

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1977 -1978 Teacher of the deaf, Royal School for the Deaf, Birmingham

1978 -1980 Teacher of the deaf, Longwill School for the Deaf, Birmingham

1980 -1989 Teacher in charge, Hearing Impaired Unit, Worksop

1989 - 2004 Coordinator and Director of Rehabilitation, Nottingham Paediatric Cochlear Implant Programme

2004 - 2007 Education Co-ordinator, The Ear Foundation

2007 - 2008 Development Manager, The Ear Foundation

2008 – date CEO The Ear Foundation

Positions held:

1990- 2004 Member of National Executive Committee, British Association of Teachers of the Deaf (BATOD)

1992 to date Member, International Board of Presidents of European Symposium on Paediatric Cochlear Implantation

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1993 to 2004 Trustee of The Ear Foundation

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1998 to date Member, National Deaf Children's Society (NDCS), Paediatric Audiology Working Party

1998 to date Member, Quality Standards Group, NDCS, Working Party on Cochlear Implantation

1999-2002 President, BATOD

1999- 2003 Tutor, Master's degree course, Birmingham University

2000-2004 Member, Executive Committee, Universal Newborn Hearing Screening Programme, Dept of Health

Chapter 6

2001-2003	Member, Educational Guidelines Project on Cochlear Implantation, Royal National Institute for the Deaf
2001-2003	Trustee, Mary Hare Grammar Schools
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Overview

Sue is a teacher of the deaf who co-ordinated the Nottingham Paediatric Cochlear Implant Programme from its inception in 1989, playing a major role in it becoming one of the largest and most experienced paediatric programmes in the world. She developed the database which is now used in many centres in the UK to manage the programme and evaluate outcomes, ensuring that long-term follow up and evaluation of children's progress in the community is undertaken. She has developed many outcome measures and materials to support the monitoring of children with implants at home and school.

During her fifteen years at Nottingham implant programme, Sue published widely, including books, teaching materials and peer-reviewed papers, and has taught and lectured internationally on the implementation and management of paediatric implantation, and in the educational implications of cochlear implantation. She was pivotal in the development of a widely used database for managing implantation, and developed several outcome measures which are now used as standard practice. Sue has led several research projects which have resulted in peer-reviewed papers and is experienced in qualitative research methods. She is now Chief Executive at The Ear Foundation, Nottingham, where she leads the internationally renowned education programme for all those involved with paediatric implantation, supported by a growing research programme.

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