



Research Report to: **Advanced Bionics**

Children with Cochlear Implants: Complex Needs - Complex Outcomes

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Executive Summary

- The parents of 10 deaf children with complex needs, who had received cochlear implants, were interviewed using a semi structured format.
- All of the parents in the study were very pleased that their child had an implant, five were extremely satisfied, and five had some minor concerns but overall were satisfied.
- Three of the children had achieved more than expected with their implants.
- For some the improvement was not mainly one of language and communication, but of being more aware of environmental sounds, or being more included in the life of the family.
- Deaf children with complex needs are a heterogeneous group. The interaction of deafness with a range of other needs and disabilities makes this a very diverse group of children with very diverse needs; cochlear implantation adds another dimension.
- Because of this diversity, it is often difficult to get assessments and support that recognises the interaction of the deafness with the other disabilities.
- It is unlikely that professionals will be experienced in the range of complex needs with which they come into contact.
- Audiological assessment, which is vital to the process of assessment for implantation, may be difficult with this group of children, and often took a long time.
- There was some reluctance in some places to implant children with complex needs. This reluctance could sometimes be attributed to applying expectations of typical developing children to children with complex needs.
- The decision to go ahead with implantation was an easy one for most parents to make.
- For some parents switch on was a 'magical' experience with their child responding to sounds very quickly.
- Educational provision often focuses on one particular need of the child rather than the interaction between their various special needs.
- Parents felt that in general not enough is known about deaf children with complex needs.

Introduction

Over the past 25 years, cochlear implants have opened up a world of sound and communication opportunities to profoundly deaf children, the majority of who can now access spoken language by listening. However, this intervention seems not to have been as readily available to those deaf children who have additional significant disabilities as well as their deafness. It is widely accepted that approximately 40 % of children with permanent hearing losses will have needs over and above their deafness, which will impact on their learning (Fortnum et al 1996). Within certain populations, the incidence of deafness is known to be even higher; so for instance within the population of children with Down's syndrome, 60-80% of them may have some degree of hearing loss (Roizen et al 1993).

The possible reasons for such limited access to cochlear implantation are discussed below, but firstly it is necessary to consider what constitutes this group which is known variously as deaf children with additional needs, with complex needs, or with additional complex needs. These needs can include learning difficulties, physical impairments, pervasive communication problems such as Autistic Spectrum Disorder and significant medical concerns. One or more of these difficulties may be present. The range of disabilities and range of severity means that the group itself is very diverse, as disabilities interact with each other in many and various complex ways.

While the term 'complex needs' has to cover a whole range of possibilities, a reluctance to group these diverse children together under an umbrella term like 'complex', has meant that all too often this group have been ignored or marginalised. There has been a tendency to fall into the trap of either focussing on the child's deafness, with their other needs being seen as somehow secondary, or looking solely at their other needs, so much so that the child's significant hearing loss is over shadowed by the other disabilities.

Clearly, grouping these diverse children together under the unsatisfactory term of 'complex needs' is fraught with difficulties. While in some ways it is inappropriate to label children with complex needs as if they form a single group, failure to group them at all may mean that they will get even less attention. It is probably fair to say that the sheer diversity of the group, as well as the low numbers within the population of implanted children, has probably hindered research with this population.

There are a number of reasons why this group of children have had less access to cochlear implantation. Firstly some of the issues raised above may be relevant, that the varying impact of the combination of different disabilities may mean that it can be very difficult for professionals to understand the implications for a particular child with a particular profile, and assessment of needs can be complex. There can also be particular difficulties with the audiological assessment in children with complex needs (McCracken et al 2008, McCracken and Pettitt 2011).

However some of the reluctance to implants may be a consequence of the ways in which cochlear implantation has developed. The gold standard by which the benefits of implantation are measured include speech perception, speech intelligibility, access to education and

improved literacy skills; and whilst for many young implanted children these are achievable goals for those children with additional and complex needs, such outcomes may be much more challenging, if not impossible to attain. This narrow range of expected or desired benefits fails to recognise other benefits which may be very significant for many children and families.

In the past, cochlear implant programmes adhered to strict criteria when assessing children for cochlear implant suitability. Children were expected to not only meet audiological criteria, but to be able to cooperate fully during the assessment phase, and subsequent follow up appointments. Emphasis was placed on the requirement for children to be able to condition for both audiological testing and implant tuning. There was also an expectation that children should be able to communicate whether or not the implant was functioning. This meant that children with complex needs were deemed to be not suitable for implants.

A further problem has arisen because deaf children with complex needs have received limited consideration in research into the impact of cochlear implantation. Those who were implanted, often because their complex needs were not identified prior to implantation, were frequently excluded from research studies looking at outcomes. It is pertinent to note that, in some of the most important studies around outcomes following cochlear implantation, children considered to have additional needs are excluded from the study (for example, Nicholas and Geers 2006).

However, over time, a small but growing number of studies have focussed on describing the benefits for this special group of children. Studies have looked at the professional's experiences of implanting children with syndromes such as Down's syndrome. (England et al 2010). Other papers have shown measurable benefits to complex children in language development (Fukuda et al 2003) speech production and listening (Hamzavi 2000) (Waltzman et al (2000), Nikolopoulos et al, 2008).

But, there are few studies which focus on the experiences of parents of these children and the impact cochlear implantation has had on their child and the wider family. One study, (Wiley et al 2004) did interview parents of children with implants and multi handicaps; however the focus of this paper was mainly around communication outcomes. A recent major study, where the focus was on all deaf children with complex needs did include some who had had cochlear implants (12 out of 51) (McCracken 2011). Based on telephone interviews with parents, it looked at parental accounts relating to accessing cochlear implants and ongoing support. It had a major focus on the role of professionals and educational and audiological management. It suggests that the services the families received were often inadequate and there were problems in audiological assessment. It found delays in children being referred for implantation, but when the child was implanted, the parents were enthusiastic about the benefit to their child. It also looked at the professional advice given about communication. Apart from this research, however, few studies take any account at all of the parental experience.

The present study is focused totally on the parents' perspective and looks in detail at their experiences and opinions concerning cochlear implantation. It considers the experiences of the family in areas including the pathway to implantation from referral through assessment, the decision making process, surgery, initial tuning and follow up. It looks at the impact of these, and of the implant itself on the child and the family. As reported above, other studies have

tended to focus on professional views of measures of benefit, and have not asked families what they perceive to be the most important outcomes for their child. By considering this diverse group of children together under the umbrella of deaf children with complex needs, it is possible to tease out common themes and experiences from these families. This can then provide valuable information, guidance to families considering an implant for their deaf child with complex needs, a resource for professionals and can inform practice.

The study

The focus of the study is deaf children with complex needs who have cochlear implants, and their families. The aims of the study were:

- To consider the impact of the diagnosis of deafness for parents of children already known to have complex needs
- To explore the decision making process for parents considering an implant for their deaf child with complex needs
- To explore information available and advice given to parents of deaf children with complex needs
- To consider the audiological management of a deaf child with complex needs
- To consider aspects of maintaining the implant for a deaf child with complex needs
- To find out how deaf children with complex needs progress after receiving an implant
- To explore what parents perceive as the benefit of cochlear implantation for deaf children with complex needs
- To provide information for parents considering an implant for their child with additional complex needs
- To inform the practice of professionals with deaf children with additional complex needs

Families with deaf children with complex needs were recruited to take part in the study. The 10 families taking part in the study were members of The Ear Foundation research forum, a forum of volunteers who advise and support the research projects of the Ear Foundation and who agree to participate in research. Consent to take part in this study was specifically agreed with all families. Achieving a representative sample is an issue in such research although we would argue that given the heterogeneous nature of the target group such group does not exist. Families who elect to take part in such research may have certain characteristics but we selected, from the families who were available to us, those with children with a wide range of complex needs to cover the range of needs of which we were aware. It is important to point out that the group interviewed were those where the children had cochlear implants, and does not include those who were not selected or who were turned down for implantation and we recognise this group may have had a different perspective on the topics discussed.

It was decided to use a semi structured interview format, which allows the same topics to be covered in all interviews whilst at the same time giving the opportunity for the family and the interviewer to elaborate and develop particular topics or areas of concern. The interview schedule was developed based on conversations with experienced colleagues, a review of the

literature, and our own experience of working with families with deaf children who had complex needs. The interview was piloted and changes were made following the pilot study. Our concern was to ensure that the interview asked questions that parents found relevant, in a way that allowed them to develop topics; but also allowed them to reject those areas that were too sensitive or where our questioning might be felt to be too intrusive.

All interviews were carried out in a venue of the parent's choosing; almost always the family home. During the interview, interviewees were offered the possibility of a second session if they did not feel they wanted to cover all the topics at one sitting, or wanted time to consider further their responses to some questions. However none felt they needed to take up this offer. On average, interviews took around one hour to complete.

Each interview was audio taped and transcribed in full by the interviewer. These transcripts were read independently by the researcher and research co-ordinator who each developed a list of the themes that seemed to emerge. These were fully discussed and a further list agreed which were checked again with the transcripts to ensure they represented the interviews and that no significant material had been omitted.

The interviewer for all the interviews was a speech and language therapist with many years experience of working with deaf children including those with cochlear implants, who in addition has a special professional interest in deaf children with complex needs.

The children

The children ranged in age from three to eleven years, with a wide range of additional needs. All the children were known to have additional disabilities prior to implantation, with the exception of one, who had profound deafness and autism, the autism being diagnosed later.

The children are described in the table below which shows their gender, age and age at implantation. A list of the additional needs of all the children is also included, but this is not linked to individuals in order to protect confidentiality. Illustrative histories of four children are also given to provide some sense of the situation in which these families find themselves. Throughout the report, quotes from the families are denoted by letters, these letters are consistent in that the letter A, for example, refers to the same child throughout. However the letters are not linked to the information provided in this section.

Child	Age	Age at CI	Years implant use
1.boy	8.5 years	2.10 years	5.6 years
2. boy	8.4 years	3.10 years	4.0 years
3. boy	11 years	5.9 years	5.0 years
4 boy	2.6 years	1.4 years	1.2 years
5, girl	3.6 years	1.5 years	2 years
6. boy	10.5 years	5.3 years	5 years
7. girl	2.11 years	1.11 years	1 year (bilateral CI use)
8. boy	9.0 years	1.10 years	7 years
9 boy	8.6 years	5.5 years	3 years
10. girl	10 years	4.0 years	6.4 years

Range of disabilities

The additional disabilities of the children of the families interviewed include Down's syndrome, Autistic Spectrum Disorder, Cerebral Palsy, CHARGE syndrome, visual impairment, severe learning difficulties, severe and chronic epilepsy

Illustrative histories

Child W was born full term, but at the age of 11 months he contracted meningitis, which was not initially picked up. He was very ill indeed and sustained extensive brain damage, but initially made a good recovery but six months later he developed severe and chronic epilepsy and the fits were very difficult to control. These fits resulted in deterioration in his skills. Profound deafness was identified the same week that his mother gave birth to a little girl. The family spent a year providing W with intensive physical therapy, trying to control the fitting and looking into the possibility of cochlear implantation, whilst also dealing with a new baby.

Child X developed jaundice at one day old. She was admitted to hospital four days later with very high jaundice levels and fitting. Brain scans confirmed extensive brain damage and objective testing indicated a significant hearing loss. Over the first year of her life, feeding was a major problem, due to cerebral palsy. She had periods of low weight gain with episodes of nasogastric tube feeding. The development of reflux meant she was constantly sick. She was

eventually offered a gastrostomy operation on the same day as her scheduled operation for cochlear implantation; eventually she had these two major operations two weeks apart.

Child Y is one of twins. They were born at 28 weeks gestation, and Child Y remained in hospital for eight months. When he eventually came home, he was still on oxygen. His hearing loss had been identified during the hospital stay. He was eventually implanted at age six, but was subsequently diagnosed with cancer and had to undergo a period of chemotherapy, so his use of the implant was halted for a period of time.

Child Z was identified by the new-born hearing screening test and he was fitted with hearing aids at four months of age. He was referred for cochlear implantation and underwent surgery just before his second birthday. For the first year following implantation, the parents struggled to get him to wear his implant. One year later, device use was still poor and he was not developing language. His mother reports that at this time, he seemed to be very different from other deaf children she met in the local listening group. At the age of three and a half, his teacher of the deaf raised concerns and he was referred to the local paediatrician. Five months later, autism was confirmed.

The findings

At the start of each interview, the families were asked to describe their child and family. This was followed with questions about their child's early life and, in particular, the diagnosis of deafness.

Diagnosis of hearing loss

For nine out of the ten families, deafness was diagnosed after the child's other disabilities had been identified except for one child, where the diagnosis of autism came later than the identification of hearing loss. In addition to their disabilities, some of the children had experienced prolonged periods of life threatening illness and hospitalisation. Given the severity and complexity of the children's needs, it could be thought that deafness would be a minor concern, but for many parents in the study this was certainly not the case. Many of them found it very difficult to accept that their child had a permanent hearing loss in addition to everything else; the words parents used when describing the diagnosis often included terms such as devastated and shocked.

She was very premature so she was in hospital for the first six months and she didn't have any hearing screenings at all. Because she was very poorly for the first four months, then she got transferred to different hospitals and just kept missing the screenings so we didn't know she was deaf until she came home. Then she just went for a routine appointment and there was no response to anything. I'd had an idea that she wasn't responding, but everyone just kept saying she's been sat next to a monitor beeping for the first six months of her life, I bet she's just switched off from things. So I was told that, but I could tell that she wasn't responding. When they did tell us I was devastated. Child G

However, some of the parents suspected that their child had a hearing loss and, for them, the eventual diagnosis actually brought a form of relief.

They'd sort of given up on trying to assess him at around four and a half, so they referred him to a different hospital and then he had a general anaesthetic, cos they were putting more grommets in, so at that point whilst he was under they decided to slap some electrodes on him to see what he was hearing and when they came back they were very serious and said, look we have very bad news, he's profoundly deaf in both ears –and we were delighted and they thought we were absolutely insane! Cos it was the first time we'd had a diagnosis so we were delighted and honestly they thought we were mental! But then we felt like okay, we know exactly what the issue is now and what we have to deal with. Child I

One issue, hinted at in the last quote, was the perceived amount of time taken to get a firm diagnosis. Several parents expressed frustrations when audiological tests were frequently repeated, and yet professionals seemed unable to reach a conclusion. Parents were able to appreciate the fact that with such complex children diagnosis might not be straightforward, but criticized the lack of communication between themselves and the professionals.

They kept bringing us in for appointments, same appointments, brain stem hearing and all that and there was just nothing there and there was never anything there, but nobody dared, nobody wanted to say there's nothing until she was about 12 weeks old...and one of the technicians...he was brave enough to say... but what was hard is that they could not tell us how profound it was –. Child E

For some families, the sheer number of repeated assessments that they had to attend seemed an unnecessary imposition given the demands that were already being made on them.

Finding out about cochlear implants

All the families were asked to describe when and how they found out about cochlear implantation. Many had reached the conclusion that assessment and provision of cochlear implants for complex children depended very much upon who you spoke to and where you lived- in effect a postcode lottery.

Some centres did see implants as an important intervention for all severely to profoundly deaf children, including those with complex needs, unless there were clear contra indications.

Because of his physical disabilities, they felt that if he didn't have it potentially he would never be able to communicate at all... So they made the decision very early on that the implant might give him some form of hearing and therefore if it was just knowing that someone was going to enter a room that would be better than nothing at all- even for him to just be able to turn- so for them it was an all-round decision. Child D

Other centres however were very reluctant to consider implanting complex children, citing “lack of benefit” and “waste of resources” as their reason for not going ahead. For one family, not only did the statement about lack of benefit seem cruel, but the way in which it was delivered was totally insensitive.

We know A has got brain damage and I was really conscious that we had to have him at his best, so they could see him at his best for this appointment, so tried to time it, cos he was being nasogastric fed then, so anyway gave him his feed and did everything you know to make sure he was at his absolute best and the consultant was absolutely horrible to us, he was the most awful man. We walked in, and he had A's brain scan up on the wall, which we hadn't seen since he was in intensive care. But we know it was bad and there were two other people sat there who he never introduced us to and he just said "he's got too much brain damage and it would be a waste of our resources to operate on this child and he wouldn't benefit from it" and he was just awful to us and we were just devastated... it was just horrendous, a waste of our time and I tried to argue with him a little bit, as much as I could, saying look we know he's got brain damage we can see what the scan is but he is making progress and just because he's got brain damage doesn't mean he won't make progress and he won't benefit from it and that's what we argued. Child A

Families felt that many professionals lacked knowledge about deaf children with complex needs, and while some parents could accept this was not that surprising, considering the relatively small number of such children and the range of additional disabilities that can occur, others were surprised and dismayed. One family searched themselves for contact with a professional who had some understanding of the impact of deafness on a child with Down's syndrome.

Also there are so few, and we found one doctor in the end who had knowledge of both Down's syndrome and deafness and he was based up north somewhere and we ended up calling him up and saying can we have a chat and he called out of hours and that was the only person we could find- so in the professional consultant area, very few have the understanding of both deafness and special needs... I guess with these special need kids you need more drastic measures earlier to actually get the proper assessment done. Child I

Interestingly though, one parent commented on the lack of knowledge of professionals from a different perspective, expressing surprise at the lack of understanding some paediatricians had about implants

And even now I constantly amazed that the doctors, apart from ENT, have no knowledge about what an implants is, once we went in and it wasn't about his implant or his tumour and the doctor asked us what it was and we said oh it's a cochlear implant and the doctor said well what does that do then? And I said it gives him access to sound! And I'm thinking, you're in a hospital and I know it's not your speciality but surely you should have some basic understanding of an implant. Child C

Families felt that there was a tendency for cochlear implant teams to either underestimate or simplify their child's additional needs other than the deafness. The teams often considered the deafness in isolation and failed to consider how the child's other difficulties were also having an impact on their development.

In other contexts, the deafness could be almost ignored as consideration of the other needs could take priority.

He's a complex child, he has loads of other needs and because of that deafness and hearing loss got pushed way down the list of priorities and now with the knowledge we have now we think it should be the opposite. Because if he'd have had sound input earlier it could have helped everything else, so I think if we could influence that for the future that would be one thing. Child I

As described in the introduction, there has been a tendency for implant teams to assess complex children for implantation using the same criteria as they would for “typically developing” deaf children- namely the potential for developing communication, listening and speech production. This resulted in children being refused cochlear implants by certain teams, and indicated an uncertainty and ultimately a lack of recognition as to what deaf children with complex needs can achieve.

I mean he has lots of challenges but he can still contribute a lot and there is no reason, it might take him longer and it does take him longer to do different things and to reach different milestones but with a lot of things he gets there. And I think there is a danger in some people of not expecting anything, there are no expectations of children with disabilities and actually, they can really surprise you and if we had listened a lot to the doctors when he was first diagnosed, severely disabled, and actually it's impossible for them to say at that stage I think, so it's all about maximising their chances and they have just as much to give and to develop as anyone else. Child F

A marked contrast is provided by this family who found that when they were eventually in contact with hearing services who were they got the support they needed.

That's the time when we got in touch with the local hearing services and they have been fantastic, and that shifted it from just being about ridiculous assessments to trying to get some strategies in place and trying to get an understanding of all kinds of communication from a sensory point of view that really helped us. Child I

Making the decision to go ahead with the implant

It might be thought that, given the complexity of these children's needs and the amount of medical intervention many of them had already experienced, agreeing for their child to have an implant with all that is involved in that might be a very difficult decision for parents. However, for many families it was not a problem for them to decide to go ahead.

For me, there wasn't a decision to be made- it was; if she was suitable it must be something that we would definitely explore and if they think it'll work for her then we must do it. Child E

Many families felt that making this decision gave them a feeling of empowerment, in contrast to other decisions that they had made for their child, which had been inevitable and in some cases essential due to their child's life threatening conditions. Parents felt that by choosing an implant for their child they were providing them with the possibility to attain a better quality of life. They

often had a very clear idea of what the implant could do for their child and the possible benefits there could be.

Interviewer: What did you hope that implant would do for him?

Mother: Just give him access to some environmental sounds, so he could perhaps hear the TV, hear music be aware of people talking to him or approaching him be aware of things like doorbells things like that- give him an awareness of his surroundings Child C

When we were talking about our expectations from a parent's point of view we never said we expected him to speak, it was always about we hoped that he would get a better understanding of the environment he lives in, and the sound scape and danger and things like that, and we wanted him to hear his mummy and daddy's voices and that kind of stuff- it was more around that what we wanted for him, opening up his universe, cos he was closed in his own little world. Child I

For me it was easy- I just felt that he should have that chance there was no question about it. Dad was a bit more unsure about him having an operation, putting him through more than he'd already been through, because he'd been through so much already, but I just felt that if there was a chance and we could help him then that's what we should do. So in the end we decided we should try and see... just for his learning I felt that was the way he was going to learn and be able to understand the world understand the world that's going on around him through his hearing. Child A

Cochlear implant teams have a responsibility to ensure that expectations are not too high, and some parents commented on this, and were honest about their own hopes, even though, at the same time, they were realistic about what was likely to be the outcome.

I mean I suppose in the back of your mind you would hope that it would open up this whole world and suddenly she'll be able to hear and it'll be great and start talking- I suppose that is what you hope- in reality, and I do think that the cochlear implant people are very good at telling you that that's not how it will be but obviously, you do have that little dream that it might just be a the wonder thing- so yes, realistically, Our hope, which I think we have achieved is that she will hear something and just feel included in the family and in the world. Child E

Cochlear implantation does involve an operation and it could have been that for parents of children who have already undergone surgery, or experienced long periods of hospitalization, the idea of yet more surgery would be a major concern.

It was hard because we knew it would involve an operation and everything that she'd already been through we didn't want to put her through any more trauma. But at the same time, she had other problems as well, which was obvious, so we thought if the implant can help her in anyway at all, we'd got to give her that chance... she was still on oxygen when she came home, she has chronic lung disease and being ventilated for the surgery would make that worse, and we knew that would only be for a short period while she was in the operating theatre we just kept thinking it would make her lungs even worse than they already are, but after speaking to the doctors, who basically said if we didn't think she was fit enough we wouldn't operate on her so we had

to go with their advice and touch wood it all went fine. We were told it would take between three and six hours and it took just over three. She came home the day after. But that was the hardest decision, the surgery, not her having an implant. Child G

However for many other families there was in fact little anxiety about the operation as the child had already had many such experiences, often far more complex and serious than implantation

No, that didn't really worry me Obviously it's surgery but they know what they are doing and they have a good reputation- it was more about there's no going back than anything else. And I guess it was always about how can we maximise his chances with everything and that was just another example and if it's going to help him then we ought to go for it. Child F

For all families in the study, their confidence in the surgical teams was justified, with only minor problems occurring during the surgical and post-surgical phase.

Parents were asked whether anyone outside the medical profession had suggested that they should not go ahead with cochlear implantation. Two families had been explicitly advised not to, both by deaf professionals.

We were going to a group with deaf children and a couple of the ladies tried to put me off...they just said he's deaf why do you want to mess with that, why do you want to put him through something else, why can't you be happy with him just being deaf they made me really feel bad as if I was doing it for me and not him. Child B

At the time we found out she was deaf, we signed up for BSL classes at college and the tutor went round the room and asked us various things and he didn't seem impressed! He didn't give us any advice either way, he just wasn't impressed with the implant- he was deaf with hearing aids. Child G

In both these instances, it is worth commenting that the deaf professionals concerned probably viewed cochlear implantation negatively for all deaf children and not just for those with complex needs.

Many families found that while not explicitly advised against the implant, the obstacles that were put in their way made them feel that professionals were not hugely enthusiastic about implanting their child. Most significantly, several of the families reported long delays throughout the assessment process, particularly from deciding they would like to go ahead with the implant, to agreement being given by the cochlear implant centre and then the actual operation,

I wouldn't say advised against it. I would say I pushed for it more that they would have liked- they would have waited they would have definitely waited a bit longer... we'd been through the assessment process and they had already said that we do think that she would be a good candidate, but because of her complex needs I think we should wait, we should wait until we can get a bit more from her, until we know her. Child E

Families also reported a perceived lack of urgency when it came to implanting their complex child, which contrasts with the “sooner the better” approach taken when moving typically developing children along the implant pathway.

He was about five - I just couldn't believe that we had waited so long to have it - it shocked me but that's what I was told that they were still a bit funny about doing children with other needs because he was so physically disabled they weren't sure it would be of any benefit to do him - cos obviously it costs a lot as well. Child B

Some parents described feelings of guilt about the delay they had experienced because they felt it could have made a difference for their child if they had heard sounds earlier.

Choice of device and reasons given

Families were asked whether they had been given a choice about which implant to have for their child and if so, what factors had influenced their choice. Often, decisions were made from a practical and logistical standpoint.

We were given a choice and one of the main reasons we went for that is that we had a look at them all, cos she's so tiny and her ears are so tiny we went for the tiniest thing on her ear and when we went for the fitting of it because her head control isn't brilliant, they gave us a body worn one, so she has the coil on her head and the body worn. Plus she wears glasses as well, so it would have been too much on her little ears! We did ask was one better than another but they said no they are just different manufacturers, so we went with what would suit practically. Child G

Some parents commented on how helpful the teacher of the deaf had been in focusing the discussion around which device to choose.

I suppose what influenced our decision was that at that age a body worn processor was much better for him cos his ears were so small he couldn't keep his hearing aids on very well and that wouldn't have worked at that age, so it was more about the body worn processor provision. We were given stuff to read there didn't seem to be much difference in the quality of the devices, so really we just went with that. And the implant teacher was quite useful, although she couldn't say either way; she did say “if I was you I'd be thinking about.” so she was helpful pointed us in the direction of things to think about. Child F

Initial tuning

For some initial tuning was a ‘magical’ experience, as their child’s response to sound fully justified their going ahead with the implant.

Magical! He heard! It was quite obvious that he heard so yes, we know you don't see that very often even with typical children, but there was a definite reaction to sound admittedly it was a

loud sound- it sounded like a hiccup and even now he doesn't like the sound of the hiccup on the machine- so yes, it was a really positive thing. Child D

It went really well I think his brother and sister came along so it was a whole family event I remember being with the teacher and the SLT (speech and language therapist) and they made loads of noise and he did react to it straight away so they were really over the moon, I think he did laugh and jumped or started or something- there was an immediate reaction, which everyone thought was really good. Child C

It was really exciting the first time cos seeing his reaction to input was just it literally was- we talk about it being one of the best days of our lives- that and when his sister was born- and I remember leaving switch on and walking to the car and we turned to each other and said, we did the right thing there and it was that feeling of he was wearing his implants, he was standing on the buggy board behind his sister and he was looking round to the sound of noisy cars and it was just absolutely amazing! Child I

But for some, initial tuning was less exciting.

Well I suppose about what we expected really-well it would have been great if he'd really reacted but I think at that point with his epilepsy and everything we didn't expect anything fantastic. Child A

No nothing obvious, but because he had hearing before and even sometimes in testing you know you can hear the noise and I know that he can hear that with his good ear. No nothing, it wasn't like a miracle, remarkable response, it was more over time. Child F

Wearing the implant

For some of the families, one of the most difficult challenges arose around getting their child to wear the implant and keep it on. This could be related to other aspects of their complex needs, such as their physical disabilities. As the quote below shows, a number of professionals were dedicated and resourceful in finding solutions to these problems and some made a significant effort to achieve this.

(I) probably (should) have put my foot down a bit more firmly with the consultant regarding the side which he was going to have it on, cos it has had an effect on him wearing it because he bangs it all the time, if it had been on the other side he wouldn't have banged it nearly as much it's led to complications in his sitting seat and buggy- we have had to make adaptation because of it and it's just been such a learning curve. Not only have we had to learn how to deal with the physical disabilities, but having them as well as a cochlear implant- it has been quite challenging at times for us to get the equipment right for him wearing the cochlear implant. That has been a challenge, and not just for me but for the professionals involved, cos they've had to come up with different solutions

Interviewer; so they have to be quite creative

Mother; yes, cos it's not an everyday occurrence so we've had to be quite – you know pinching bits off one chair and putting it on another and drilling holes

Interviewer; keeps them on their toes!

Mother: some of the technicians have quite enjoyed the challenge, cos we've said how important it is for him to be wearing it constantly and, they've rose to the challenge and done really well- it's been quite successful. Child D

Even for those families whose children were less physically disabled, the goal of ensuring the implant was worn all their child's waking hours proved to be very difficult to achieve. One parent spoke movingly about her feelings about this.

It's a much much harder journey than I thought it would be and the fact that after two and a half years, we'll have days when he'll wear it for 10 minutes- I find that really frustrating. And I had it in my head that he'd wear it from the minute he got out of bed until he went to bed and even I guess actually the pictures you create for people in your head, there are so many different levels of wearing the cochlear and I guess all we'd heard about is people that thrive and speak beautifully and that's almost the mess you put yourself up against, so you think oh my god we've failed I think there is definitely a sense of that and I guess to be really good and pragmatic about it in the context of I's world we haven't failed, we are helping him as much as we can, but in the context of the standard way of progression it feels like total failure. Child I

This raises the interesting point as to whether the amount of time a child wears their implant should be seen as a measure of success for all children. For typically developing children there is no doubt that this is one of the measures that is often used to indicate success, and a fairly standard question seem to be to ask parents how much the child wears the implant.. It is debatable if this standard can be applied as easily to all those children who have other disabilities and different needs. It is yet again an example of professionals imposing the goals and expectations of the typically developing implanted child onto this special population.

Educational concerns

Although the families were not asked any questions directly about the education of their children, during the interview important themes emerged. Firstly, the vast number of professionals involved with a child with complex needs and their family was an issue raised by several of them. As this mother describes, key professionals become very important to the child and their lives can be significantly affected when these professionals move on.

His support worker at school, she is the second most important person after the family definitely. He is very attached to her. A couple of months ago she was very unwell and there was another lady standing in for her and it was fine for the first few days, but then you could tell, he was becoming distracted and it mostly comes out to him not listening to what you want him to do and not complying, showing resistance, so she's very big. Child H

Families also mentioned how supportive their local teacher of the deaf had been. Because of the new-born screening programme, the teacher of the deaf was frequently the first professional

to visit them at home regularly and several of the parents commented on how much they valued the consistency of this support.

She has a special relationship with her physio -she's known her since she was 6 months old, and her teacher of the deaf, because she has seen her since she was really tiny, doing moulds for hearing aids to start with. Though she used to scream her head off and now her teacher sees her twice a week at nursery so she is consistent person. Child E

Of the ten children in the study, seven of them were placed in schools for children with severe learning disabilities. Although on the whole, parents felt that the schools were doing excellent work, certain themes emerged about how well informed and well equipped special school settings are to support children with hearing losses in addition to their already significant needs. One parent felt that a lot more work needed to be done around deaf awareness to ensure that special school staff appreciated how much difference hearing technologies can make to such children and advances in diagnosis and assessment.

Mother. Although school sometimes still think he's not deaf!

Interviewer; really?!

Mother; They will creep up behind him and shake stuff and say look he responds! But he's had two or three brainstem tests- he is profoundly deaf! Child B

Other parents found there was a dilemma for school in how to provide a good listening environment where the other pupils can be noisy and the importance of cleanliness means an absence of carpets, curtains and soft furnishings which can combat background noise.

It's a really noisy class and even though it's only got eight kids in they all have very different needs, so it's very noisy! So I went to pick him up one afternoon and I just thought I'm not sure that this is really the right environment to learn to keep your implant on, cos this is just so noisy- I mean if I had that choice I'd take mine off! Child I

Crucially however, several parents talked about feeling as if their child's educational placement was unable to fulfill the tasks of both supporting their child's complex learning and physical needs, whilst at the same time encouraging them to use their cochlear implant. This led to constant questioning and searching for the best school and also feelings of isolation, as there were few other families that they met that found themselves in a similar position.

And since his deafness or cochlear journey started three years ago, we have felt strongly that he falls between two stools- so he doesn't quite fit in with the traditional, I mean broad pattern of progress within cochlear implantation and the broad or traditional pattern of progress for kids with Down's and he falls right between both of them. So we have an awful lot of times when we feel a bit isolated- as parents we don't quite know where to put the focus, the priority. We instinctively feel at the moment we need to shift the focus more onto his deafness and almost push Down's to the background; cos you can't change Downs but you could change his deafness if we could get him to understand the importance of sound on a consistent basis better. So what we're talking about to his current special school which is an excellent special

school, but it doesn't have the right hearing environment and we need to look at another school, and the school we know about round here is a brilliant school for the deaf, but you have to be deaf and visually impaired and then he's not visually impaired enough to go there- and there is another school for the Deaf which is brilliant- but not for kids with extra special needs, so he gets kind of lost in the education system in terms of his needs and that's so difficult- and where you could do with some broad information about what the hell do you do, how do you approach it and how do make sure you make the right decision for your kid, not just the right decision now but the right decision in the long term. Child I

I think it's a bit of everything- it got an exceptional OFSTED, brilliant and enthusiastic staff, but its staff that know about special needs and not cochlear implants- so we either keep him in that school and get someone in 1 to 1 whose got greater deaf knowledge- cos we have a fantastic teacher of the deaf coming in on a weekly basis, but it's making sure that the knowledge that she comes in with gets transferred to the staff group- and it doesn't it sort of stays with her- and that's the hard bit. Child I

. So now because of what I know, I do think a deaf school with special needs help would be better for her, but I have to wait and see what the professionals say. There really isn't any school that will help meet these children's needs. And we went to another school, which said on the web that is was Total Communication and then they told me that if she went there she would have to learn BSL- that's not what they say on the website. Child J

The impact of cochlear implantation

In reflecting about the implant and the whole process, families were asked to comment on the impact the cochlear implant had had on their child's life and their life as a family. In terms of communication, families noted improvements in some of the early foundations of listening and interaction.

I don't think in his communication, but in his enjoyment of sound. If you look at his communication, what he has achieved, actually I'm lying! I'm being really stupid, thinking about words and language- if you think about that triangle and at the bottom of the triangle, you've got those real basics of communication skills which is like attention skills and then the top of that is language- where he's improved massively is his attention skills and his tracking skills and his interest and understanding of facial movements- so he's still at the bottom of the speech triangle. Child I

I think he is more vocal, and when he is good, he is more vocal and responsive like listening. He does seem when he's going through a good phase to be listening to you, turning his head to you and listening at the same time to see what you are saying and he will, if you speak to him he will turn his head to look at you, so I think he does recognise voice. Child A

I mean they never dreamt that he would be able to speak. They never anticipated that potentially he would get that out of it or would be able to hear as much as he hears- it's just been a plus point. Child D

For others, implantation had helped to bring about development of more formal language with words and sounds emerging.

Definitely more sounds. He is trying to say more words, his vocabulary has increased, and even though some words might not be perfect, there are definitely the sounds and the syllables there. More recently he has been a lot more proactive in initiating speech than he has done before.

Child F

He's a lot more vocal and also changes in vocalisations- he changed from quiet to loud cos he can hear himself more, down to sounds coming out where people think he's actually speaking! We've had a couple of words that we thought were words but he's not said again- he said no, up, out, mum, but doesn't say them very frequently, it's just sporadically, different tones that we've noticed now, sounds that are coming out now tend to be more regular like mumumumum.

Child D

And for one family in particular, implantation had resulted in their child accessing language to such an extent that he was able to communicate fully with his friends and family, and fulfill his potential at school.

Before, he was just blank, he'd started pointing as I say, but once it was turned up to a point where he could start to understand people he just changed. He was more interested in things, he was asking what everything was, pointing to everything, and you had to tell him what things were called. We'd started going to signing classes, so he'd started to pick that up quickly and because he's had the implant at the same time he was learning the word and the sign together. He was constantly making noise just babbling like a baby- they said that was a positive sign cos before he was quite silent so yes, and we started to realise, he started to pick up at school, maybe he's not got such severe learning difficulties, maybe he just wasn't understanding what was being asked and that became more obvious later on in the last year, started really picking up! Child B

For others, the impact of the implant was not always in such a clear and definable area like communication, but was nevertheless important to them as a family. One development mentioned by several families was the feeling that the implant had brought with it the chance for their child to be more easily included in family life.

I think inclusion is the main thing really- we feel that she is more included in the running of the house, people coming, kids running about talking a bit of reassurance, so from that respect that has definitely made a difference. Child E

He's a bit more cheeky! He gets jokes now! If he's watching something like 'You've been framed' he'll sit there chuckling to himself, and dogs barking and cats meowing and he likes certain programmes like Mr Tumble- and he loves music so he's quite happy if music is on, doesn't care what music it is, rock music, classical, just loves all music and gets a lot out of music and loves to be around other children in general- likes watching children and gets a lot of pleasure out of that. Child D

Others mentioned how access to sound had acted as a motivator for their child to explore their environment, which had the positive effect of encouraging their physical skills to develop. For one parent, this new interest in her surroundings brought with it unexpected health benefits.

She's definitely been more alert and listens a lot more- like when you first came she was quite settled listening to you, what you were saying. Yes, I think it's really helped her. And at nursery she has a specific key worker and she said that she's so noisy--- and nosey! And the physio who works with her says it's hard actually working with her at nursery cos she's too busy looking at what's going on and listening to things rather than doing the physio. Child G

Well I think since she had the implants she seems to have come on in other areas. So for instance, she wouldn't reach out for anything- she still struggles now but you can tell she purposely tries to get there you know her hands are going in the right place. And that seems to have improved since her implants were switched on. She's very alert, much more alert I just think it has really helped her. Child G

She started to pull herself up on the furniture and started to sit up, obviously its balance isn't it and it all clicked into place. The chest infections reduced, cos she was up and on the move- lots of things. Child J

For some change has been slow;

It was difficult at first cos it took so long to get it working, get a reaction from him and because he was refusing to wear it a lot that was difficult, I didn't think we were going to get anywhere with him but then obviously he started progressing and it was beyond anything we thought it would be it gave him a whole new lease of life. Child B

But for one child the change has been dramatic, with professionals and his family realizing that rather than having severe learning difficulties as was previously thought, he actually has the potential to learn alongside his hearing friends.

Cos before the implant he was diagnosed with severe learning difficulties cos he didn't know what people were telling him to do he didn't know what signing was or anything, but after he had it and he started to make progress and to understand what's being asked of him, they now say that he's got no learning difficulties, it's just a communication problem so yes, it held him back a lot, but since he's had the implant he's caught up and he's pretty much mainstream, there are still some gaps but they are just trying to build up them gaps now. Child B

Overall impressions

Towards the end of the interview the parents were asked whether, overall, they had been pleased or disappointed with the implant. All of them felt that overall they had been pleased, some of them expressing their opinion forcibly.

Oh I'm very pleased. I want another one- no question about it! Child H

I swear by that cochlear implant- she once lost her implant on a Friday and I freaked... For me that implant is crucial, it's, she wouldn't be her without it. Child J

I think we have been really really pleased with it. Cos although I've not been able to give you anything concrete about you know, I think it has added to his general awareness and wellbeing and I'm sure he gets a lot from it. Child C

Some were more measured in their praise, often because of their own child's particular circumstances.

Generally pleased, cos I think that it has done what we hoped for, give him a chance and whatever he does pick up it can only help and it's just those few seconds, you know it might only be a few seconds in an hour when he's actually able to concentrate and he's not having a fit or a lot of absences, but just for those few minutes or few seconds even at least he's getting that chance and can respond so it's not a lot but it's something. Child A

Nobody said they had been disappointed with the implant or that it had not lived up to their expectations. When pressed to describe anything at all that had disappointed them, a number of points were raised, including the difficulties in actually keeping the implant on, or the feeling that it should have been implanted the other side. The parents of the child who had achieved excellent outcomes in terms of speech and language wished that he had been implanted earlier.

Of the ten parents, five were totally pleased and five, while being pleased overall, were more measured as there were aspects that had not worked quite as they would have hoped.

Deaf children with complex needs and cochlear implantation

We asked the parents to tell us what they would say to people who feel children with complex needs should not be considered for an implant. They all felt very strongly about this.

For some the evidence for implanting children with complex needs lay in their own child;

I'd just show them!?? What do you think now! They don't know what they are on about! Why, would you want to keep a child like that when you see how he could be now? Child B

I would tell them to come and look before and after. I'd say come and look at the videos before and look at him now because that is just an amazing thing to see. Child D

For some it was a matter of giving every child the best opportunity that they could.

I would say you need to give them the best chance they've got and if that involves having an implant, if they are fit and well then they should go ahead and have it. Child G

I'd say that every child needs a chance and even if they get a little bit of something from it and a little bit of a better quality of life, only a small understanding about the world, it would be worth it. Child A

Other parents saw it as more of an equal rights issue, stating that denying children accessing to technology that could help them was discriminatory.

I'd say rubbish! That would be my reaction- at its purest level it's just discriminatory, cos you're not allowing children with complex needs to have the same opportunities as those without.

Child I

I don't know! I suppose I would say if it was your child what would you do? You shouldn't discriminate especially in this day and age. Child C

We also asked the parents what advice they would give to other families who are thinking about cochlear implantation for their deaf child with complex needs. Their responses were very positive, but measured, showing how much they realized firstly how much thought needs to go into making such a decision and secondly, how each child's needs must be considered individually.

I'd definitely tell them to explore it- I do think only that parent can make the decision, it's not a decision that somebody else can make and you do need to be sure and you do need to talk to the professionals about it, but you also need to be aware that where some people will encourage, some may put you off as well. Child E

I'd say to look into it, it's not for everybody, but look at all the information, talk to other families to just get as much info as possible and then decide if it's the right thing to do and if you decide its right for your child then go for it if I went back I wouldn't not do it- I don't regret it at all. Child A

Discussion

This study clearly shows the benefits and pitfalls of cochlear implantation for complex children from the families' perspective. All of the parents in the study were very pleased that their child had an implant, five were extremely satisfied, while five had some minor concerns. Three of the children had done better than expected with their implants. For some the improvement was not mainly one of language and communication, but of being more aware of environmental sounds, or being more included in the life of the family. For the families this development was important and significant for the life of the families as a whole, and they were emphatic that this should not be undervalued.

The families were very considered in their opinions about cochlear implants. When asked how they would advise other parents in a similar position to themselves rather than simply endorsing implants they pointed out a number of points that should be considered, including getting as much information as possible, and thinking through the implications of implantation.

Despite the sometimes difficult history and ongoing issues for all the families in this study, the interviews were by no means gloomy or pessimistic. The families clearly enjoyed their children and rejoiced in their achievements, however small they might seem to those on the outside. In this respect, the findings echoed McCracken's study of 50 families of children with complex needs, who stated that "despite the considerable challenges faced by families physically, emotionally and personally, a common thread was of the joy in the children themselves" (McCracken 2011). The resilience and pragmatism towards cochlear implantation was also a theme that came across strongly in each of the interviews, with families showing less concerns about the surgical procedure than would have been expected.

All of the families interviewed had children with very different strengths and needs- and it is this heterogeneity that has made this group a very difficult one to study. It is clear from the literature, that combinations of two or more conditions interact with each other and will impact on individuals in different ways- so all children with complex needs should be looked at holistically (Knors and Vervloed 2003; Fisher 2004). However, this study shows that through semi structured interviews it is possible to extract themes which are common to the families of these children, and each of these themes will now be considered.

In the introduction we described the limited access that deaf children with complex needs have had to cochlear implantation and some of the possible reason for this. While the children considered in this study all had received cochlear implants, it can be seen that for some families obtaining an implant had been difficult and often there were delays, sometimes unexplained. Audiological assessment for cochlear implantation can be difficult for this group of children, and whilst some centres view the provision of implants as an important intervention, others are less supportive. In this respect, audiological testing within the population going forward for an implant is not so different from those receiving hearing aids; McCracken (in Bamford et al 2000) described findings from an interview study, where 57% of parents of children with complex needs were not satisfied with the manner in which hearing tests were carried out on their children. In this study, there was a feeling from some of the parents that difficulties with audiological testing and in particular the lack of consistency across both tests and testers acted

as a delaying tactic to avoid making the decision to proceed with an implant. Several parents commented on the length of time taken up by assessment, meaning that the age at which these complex children received their implants was in some cases much later than it needed to have been. Again, this finding is consistent with the literature; Tharpe (2000) for instance found that children with autism and hearing impairment received their hearing aids later than typically developing children.

The time taken in some instances to reach a diagnosis in order to feel confident to proceed to implantation raises another issue. Evidence shows that for deaf children in general, the earlier that implantation takes place the greater the benefit is likely to be (Dettman et al, 2007; Tait et al, 2008). It is not clear whether this applies in the same way to deaf children with complex needs as in this study, those implanted at four and five years showed significant benefit. However, age at implantation is likely to have some effect, which suggests that delays in diagnosis should be avoided as far as possible. However when such delays do occur, this on its own cannot be used as an argument against going ahead with implantation.

Whilst the time taken to assess a child's suitability for an implant may have been clear to the professionals concerned, the parents were not always informed or consulted about the decision making process, leading to possible misunderstandings. This again echoes the findings of McCracken in 2000, where 43% of the respondents were not satisfied with the explanation of tests and the results, and over half claimed that their own observations had not been sought during testing.

Another theme to emerge from the interviews was that although the parents appreciated just how difficult it must be to understand the wide range of complex needs that children may present within the clinic, examples of good practise were not being shared either within or across cochlear implant teams. They were also surprised and in some cases dismayed at the lack of understanding about cochlear implants from other medical professionals.

This lack of understanding of the complex interaction that takes place when several conditions come together resulted in some cochlear implant teams underestimating or simplifying the extent to which these additional needs impact on the child and thereby treating the child as simply deaf. The tendency to "normalise" this special population may result in inappropriate and irrelevant goals being set for the child and family, leading to feelings of failure and inadequacy. Measures of benefit which focus exclusively on speech recognition and production for instance, are, in many cases not appropriate for this group of children. A few studies do recommend that benefit from implantation for this population should not be limited to speech production, for example Nikolopoulos et al (2008), Filipo et al (2004), Edwards (2007)

Conversely, there is also evidence of the well documented phenomena of "overshadowing", where the presence of one condition or disability can overwhelm another or others (Krahn et al 2006; Fisher 2004). In extreme cases, this may mean that deafness is ignored or misdiagnosed entirely; within the population of children with cochlear implants in this study, overshadowing was demonstrated when certain professionals tried to dissuade families from cochlear implantation because of their child's other needs, or an unwillingness on the part of school staff to insist on cochlear implant wearing.

One of the key issues that needs to be addressed to combat both the tendency for other conditions to either be ignored or overwhelm the deafness is for professionals to work together to agree outcomes and what constitutes benefit for this group of children. As stated by McCracken (2011) “a lack of clearly defined outcomes for this group of children may be contributing the poor recognition of potential and low expectation.” This study starts to explore the area of outcomes and benefit by talking to the people who are best placed to talk about the issue; the parents themselves. Clearly, for all the parents interviewed, cochlear implantation has benefitted both their child and the whole family, with changes in communication, and social changes, where the child is now integrated far more into family life.

From a practical perspective, all the parents in the study emphasised how important it is for implant manufacturers to consider the needs of the special population when designing the external components of the implant system. Poor head control, malformed pinna, poor vision and low tone can all affect the wearability of the system and for all families in this study; device choice was based purely on how easily their child would be able to keep the cochlear implant on. For two of the families, this issue was a cause of major stress and they appreciated practical help and input from professionals and other families to help them find solutions to this problem.

Important themes around the education of implanted children with complex needs emerged during the interviews. For many families the teacher of the deaf was an important and supportive person in the early days, someone who was there from the child being young, visited regularly and got to know the family. This seems to emphasise the need for families with children with complex needs to have one professional who is able to get to know and understand the child's special and different needs and contribute to the decision making process. However, in common with the 2011 report by McCracken for the National Deaf Children's Society, concerns around the lack of deaf awareness from school staff and the dearth of specially trained staff was mentioned. From a cochlear implant perspective however, parents commented on the need for education staff to be aware of and balance the needs and limitations of the implant technology within the special school setting. Crucially, the feeling that educational placements are struggling to meet their child's diverse listening and learning needs was very apparent from several of the interviews and the need to share good practice was implicit in their comments.

This study set out to explore the experiences of cochlear implantation for ten families of deaf children with complex needs following a semi structured interview format. Clearly, there are limitations with this type of investigation. Firstly, the group was small, and families were self-selected, meaning that their comments and experiences are not necessarily representative of this population as a whole. However, saying that, it would be virtually impossible to find a “representative” group for this heterogeneous group of children. Also, all the children had been eventually implanted and no figures or studies exist which explore the experiences of those families whose children were not accepted for implantation in any depth- this would clearly be a further area to research. Nevertheless despite these limitations the study has added much to our understanding of implantation for this group of children and leads to a number of recommendations and suggestions for action and future research.

Recommendations

- Cochlear implantation for this group of children is often an important option and should be considered positively.
- Professionals need to discuss how best to measure the benefits of cochlear implants within this population. Standard measures of benefit used to measure progress in typically developing deaf children may not show change or be appropriate, but that does not mean that there is no benefit.
- Research needs to be carried out into the impact of delay in assessing deaf children with complex needs for a cochlear implant, and the effect of any delay on benefit.
- There may be some key principles which can be applied to all complex children coming forward for cochlear implantation; good practice guidelines for this group are needed which will influence practice.
- Cochlear implant teams need to have in place procedures for the assessment of deaf children with complex needs to inform practice
- When diagnosis is complex, as it often is, it is important that professionals keep parents fully informed as to what is happening and the reasons for any delay.
- It would be highly unlikely that all professionals working with deaf children would ever be able to develop a comprehensive and working knowledge of all the complex needs with which children may present. Even if they did develop such a knowledge base, all children are different and the ways in which different conditions interact with each other in individuals will also differ. What is needed is a resource for those working with complex needs children where they can obtain authoritative information, share experiences and problem solve with others, perhaps in some sort of web based discussion forum.
- The importance of one particular professional who can get to know the children and families and their particular needs is of great importance for these families and children.
- Although the group of deaf children with complex needs is overall a heterogeneous one, there are subgroups that would benefit from further and detailed investigation in thinking about cochlear implantation, for instance deaf children with Down's syndrome, Children with Autistic Spectrum Disorder, cerebral palsy.
- A further study looking at children who were not accepted for cochlear implantation would be informative

- Work is needed within the special schools population to make them aware of the specific needs of deaf children with implants - particularly how listening can be incorporated into the school day.
- Further awareness of cochlear implantation within the wider medical community is likely to be beneficial in meeting the needs of deaf children with complex needs.

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