



Children with Cochlear Implants:

Complex Needs – Complex Outcomes



The Ear Foundation



Summary

The parents of ten deaf children with complex needs, who had received cochlear implants, were interviewed. All of the parents in the study were very pleased that their child had an implant, five were extremely satisfied, and while five had some minor concerns, overall they were satisfied. All of the parents interviewed would recommend other parents in the same position to explore the possibilities of cochlear implantation.

Nine children had become more vocal and were developing words or word like sounds.

For a number of the children (3), the value of the implant was that they were more aware of the sounds around them or were more included in the life of the family rather than improvement language and communication.

Three of the children had achieved more than expected with their implants.

Audiological assessment, which is vital for the decision about implantation, may be difficult with this group of children and often took a long time; this potentially is an issue, when we know that early

age at implantation is a predictor of outcome, and any delay may further disadvantage these children.

There was some reluctance by some professionals to implant deaf children with complex needs. Sometimes this was because expectations of typical developing children were made for deaf children with complex needs in ways that were not appropriate.

The decision to go ahead with implantation was an easy one for most parents to make.

It is often difficult to get assessments and support that recognises the interaction of the deafness with the other disabilities.

Educational provision often focused on one particular need of the child rather than the interaction between their various special needs. Deaf children with complex needs are a diverse group with very diverse needs.

Parents felt that special schools often did not know about the implications of deafness or cochlear implants, and teacher of the deaf expertise often not available.

Parents felt that 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 and severely deaf children. With cochlear implants, most of these children can now access spoken language by listening. However, this intervention has not been as easily available to deaf children who have additional significant disabilities in addition to their deafness.

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 their severity means that the children vary greatly, as the disabilities interact with each other in many and complex ways.

Children in this group have often been ignored or marginalised. There has also been a tendency either to focus on the child's deafness, with their other needs being seen as somehow secondary, or to look only at their other needs, so that the child's significant hearing loss is over shadowed by their other disabilities.

There are a number of reasons why this group of children have had less access to cochlear implantation. Firstly assessment of needs can be complex and it can be very difficult for professionals to understand the implications for a particular child with a particular profile. There can also be difficulties with the audiological assessment of children with complex needs (McCracken and Pettitt 2011).

However some of the reluctance to implant may be because of the ways in which cochlear implantation has developed. The benefits of implantation in typically developing children have usually been measured by improvements in speech and literacy skills. For children with complex needs, these may not be as easy to achieve.

It is possible to fail to appreciate other outcomes which may be very significant for these children and families.

In the past, cochlear implant programmes used strict criteria when assessing children for implantation. Children were expected to be able to cooperate fully during assessment and later appointments. For example, it was expected that children would be able to communicate whether or not the implant was working properly. This meant that deaf children with complex needs were often seen as not suitable for implants.

The study

This study is about deaf children with complex needs who have cochlear implants, and their families. It looks at the parents' perspectives and their opinions about cochlear implantation. It examines many aspects of their experience: the route to implantation from referral and assessment, the decision making process, surgery, the initial tuning and follow up. It considers the impact of the implant on the child and the family and focusses on what the parents themselves see as the benefits of cochlear implantation for their child.

It is hoped that this booklet will provide valuable information and guidance for families considering an implant for their deaf child with complex needs, and also a resource for professionals which will inform practice.



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
- Explore access to implantation for children with complex needs
- Explore information available and advice given to parents of deaf children with complex needs
- Consider managing the implant for a deaf child with complex needs
- Explore the benefits and challenges of cochlear implantation for deaf children with complex needs as viewed by the parents
- Explore the educational implications for these children.

Parents were interviewed in their own homes. They were all asked the same questions, and could develop in more detail any topics that concerned them. Each interview was audio taped. The interview schedule is on page **.

¹ McCracken W. and Pettitt B., (2011) Complex Needs, Complex Challenges A Report on research into the Experiences of deaf children with additional complex needs National Deaf Children's Society

The children

The children were aged between three to eleven years at the time of the interview.

They had a wide range of additional needs including Down's syndrome, Autistic Spectrum Disorder, Cerebral Palsy, CHARGE syndrome, visual impairment, severe learning difficulties, severe and chronic epilepsy.

Child	Age	Age at CI	Years of implant use
Boy	8.5	2.10	5.6
Boy	8.4	3.10	4.0
Boy	11	5.9	5.0
Boy	2.6	1.4	1.2
Girl	3.6	1.5	2
Boy	10.5	5.3	5
Girl	2.11	1.11	1 (bilateral CI use)
Boy	9.0	1.10	7
Boy	8.6	5.5	3
Girl	10	4.0	6.4

² For reasons of confidentiality, the children are not identified by their particular complex needs in this booklet, but the letters used to describe them in the quotes are consistent throughout, so child A is always the same child.



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. At first he 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 his fits and looking into the possibility of cochlear implantation, whilst also dealing with a new baby.

Child X developed jaundice when she was one day old.

She was admitted to hospital four days later with very high jaundice levels and because she was having fits. 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 his 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 had his implant just before his second birthday. For the first year after implantation, the parents struggled to get him to wear his implant. One year later, he was still reluctant to use it 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.

Diagnosis of hearing loss

For nine out of the ten families, deafness was diagnosed after the child's other disabilities had been identified. For the other child, the diagnosis of autism came after the identification of hearing loss.

Because the children's needs were severe and complex, the deafness could have seemed to be a minor concern, but this was not the case. Many parents found it very difficult to accept that their child was deaf as well as everything else.

The words parents used to describe the time when their child was diagnosed often included words 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... 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 feelings of relief.

"At around four and a half, 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

For many families one problem was the amount of time taken to get a definite diagnosis. For some families, the number of repeated assessment appointments that they had to attend seemed an unnecessary burden given the demands that were already being made of them. Several parents expressed frustrations that audiological tests were frequently repeated, and yet professionals seemed unable to reach a conclusion. They realised that diagnosis might not be straightforward, but criticised 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." Child E



Access to cochlear implantation

Parents were asked how easy it had been to get a cochlear implant for their child. They told us that some centres did see implants as important for severely to profoundly deaf children 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 the reason for not going ahead. For one family, not only did the comment about 'lack of benefit' seem cruel, but the way in which they were told 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." Child A

Many families, while not actually advised against the implant, were made to feel that professionals were not enthusiastic about implanting their child. Several of the families reported long delays throughout the assessment process, particularly from the time they decided they would like to go ahead with the implant to agreement being given by the cochlear implant centre.

"I wouldn't say advised against it. I would say I pushed for it more that they would have liked- 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

The lack of urgency about implanting their child contrasts with the evidence of the benefits of earlier implantation which influences the management of typically developing children

"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

Three 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.

Families felt that many professionals lacked knowledge about deaf children with complex needs.

Some parents felt this was not that surprising given the relatively small number of children and the range of additional disabilities that can occur but others were surprised and dismayed.

Some parents felt that sometimes cochlear implant teams underestimated or simplified their child's additional needs. Often the focus was almost totally on the deafness and the assessment did not look at the ways in which the child's other disabilities also affected their development.

Some implant teams assessed deaf children with complex needs for implantation using the same criteria as for typically developing deaf children - the ability to cooperate with assessment and the development of spoken language. This seems to reflect a lack of recognition of the different but important things that 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

Making the decision to go ahead with the implant

Many of these children in the study had already experienced significant amounts of medical intervention, even before a cochlear implant was considered. This might have made it difficult for families to agree for their child to have a further operation to insert a cochlear implant.

However, for five parents it was not a problem for them to decide to go ahead, often because they had had experiences of operations with their child:

“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 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

Five parents however did feel they needed to think carefully about the surgery involved:

“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.” Child G

For all families their confidence in the surgical teams was justified, with only minor problems occurring during the surgical and post-surgical phase which were soon sorted out.

Many families felt that making the decision to go ahead with the implant gave them feelings of empowerment. Other decisions that they had made for their child had been inevitable and often essential due to their child’s life threatening conditions. Parents felt that by choosing an implant for their child, they themselves were deciding to provide them with the possibility of a better quality of life.

“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

Cochlear implant teams are responsible for making sure that the expectations of implants are realistic and not too high and some parents talked about this. They were honest about their own hopes but also 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

Choosing the device

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

For some, the teacher of the deaf had been particularly helpful in suggesting what they needed to consider when deciding 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 the initial tuning, when the implant was first switched on, was a 'magical' experience, as their child's response to sound fully justified their going ahead with the implant.

"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 others 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 eight of the families, one of the most difficult challenges was getting their child to wear the implant and keep it on.

Sometimes this was because of other aspects of their complex needs, such as their physical disabilities. As the quote below shows, a number of professionals were resourceful in finding solutions to these problems. Some made a real 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...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 where children were less physically disabled, making sure they wore their implant all the time was difficult for parents 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 ... 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**

For typically developing children, the amount the child wears the implant is used as a measure of success. It is a question often put to parents. But is the amount of time a child wears their implant a measure of success for all children? It may not always be appropriate for deaf children who have other disabilities and different needs. This may be yet again an example of the expectations of the typically developing implanted child being applied to this special group without considering their special circumstances.



Education

Six families mentioned how supportive their local teacher of the deaf had been.

Because of the new-born screening programme, the teacher of the deaf was often the first professional to visit them at home regularly and several parents commented on how much they valued 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

Other parents too emphasised the importance of consistent support.

“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

Of the ten children in the study, seven of them were placed in schools for children with severe learning disabilities. On the whole, parents felt that the schools were doing excellent work, but some felt unsure about how well informed and well equipped these special schools 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 make sure that special school staff understood the difference cochlear implants and hearing aids made for their children.

Three parents commented that schools had a problem in providing a good listening environment when other pupils enjoyed being noisy. The importance of cleanliness also meant there were limits on the use of carpets, curtains and soft furnishings which can reduce 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

Three parents felt their child’s school was unable to support their child’s complex learning and physical needs and at the same time encourage them to use their cochlear implant. This led to constant questioning and searching for the best school for their child. There were also feelings of isolation, as they met few other families in a similar position to themselves.

“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.” Child ?

“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

The benefits of cochlear implantation

Parents were asked to tell us about the impact the cochlear implant had had on their child's life and their life as a family. Seven families noticed improvements in the early development of language and communication.

"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

For two others, implantation had helped to bring about development of words and word like sounds.

"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

For three families, the benefit of the implant was not as evident in communication, but was still important to them as a family. Several felt that the implant had meant their child could 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 hearing sounds had encouraged their child to explore their environment, and this had shown in development of their physical skills.

"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

Even where change was slow it was important:

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

For this child the change has been dramatic, with professionals and his family realising that he does not have severe learning difficulties as was previously thought.

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 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.

"His support worker at school, she is the second most 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 think deaf children with complex needs should not be considered for an implant.

Parents saw it as an equal rights issue, believing that to deny children access to technology that could help them was discrimination:

"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**

For some the evidence for implanting children with complex needs was 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**

Some stressed it was important to give 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**

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 considered. They appreciated that firstly, a great deal of thought needs to go into making such a decision and secondly, 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 it's 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**

The interview schedule used

Deaf Children with Complex Needs and Cochlear Implants

Name:	Date of interview:
Gender:	Age at time of interview:
Date of birth:	Special needs:

- 1 Can you tell me about N. How would you describe N to someone who doesn't know him/her?
Prompt: social, communication, physical, emotional, behaviour

- 2 Can you tell me about N's immediate family?
Prompt: Whose lives here at the moment?

- 3 Who would you say are the most important people in N's life?
Prompt: family members, professionals, friends

- 4 Can you tell me when N's disabilities were first diagnosed?
Prompt: had you thought that there was anything wrong before that? Can you remember what was said to you at that time?

- 5 Can we talk now about the diagnosis of N's hearing loss. If not already mentioned, was this at the same time as the other diagnosis or was it later?
Prompt: Had you thought that there was anything wrong before that? Can you remember what was said to you at that time?

- 6 Can you remember how you were feeling at the time of the diagnosis of hearing loss?

- 7 How do you think the hearing loss has affected N's development?

- 8 Can you tell me what life was like in the time following the diagnosis

- 9 Moving on now to think about implants, who first suggested and implant for N?
Prompt: If they came up with the idea themselves, where did they get the information from; if a professional, did they know anything about implants before they were suggested

- 10 Was it easy or difficult to make the decision that N should have an implant? What sorts of things did you consider at the time?
Prompt: The surgery itself, the anaesthetic, post operative issues?

- 11 At what point did you decide to go ahead? What did you hope the implant would do?

- 12 Can you remember if anyone advised against going for it?
Prompt: Family? Professionals?

- 13 How long was it from first hearing about implants to deciding to go ahead?

- 14 Once the decision had been made how long was it until the operation?

- 15 How old was N when he/she was implanted?

- 16 What device does N use?
Prompt: were you given a choice and what influenced your decision

- 17 How was the operation?
Prompt: for you? For N?

- 18 After the operation, how long did it take for N to recover?
Prompt: was this as you expected?

- 19 What preparation did you have for the operation?

- 20 Did you do anything to prepare N for the operation?
Prompt for both parent and N; If yes, did this help Knowing what you know now would you have done anything differently?

- 21 Tell me about the initial tuning of the device. Was this as you expected?

BREAK: give option of going ahead or continuing another day

- 22 How do you communicate with N now and how does he/ she communicate with you?

- 23 Can you describe any changes in communication that have taken place since implantation?

- 24 Can you tell me about other differences you have noticed in N since he/she had their implant
Prompt: social, communication, physical, emotional, behaviour

- 25 Have other people mentioned any changes to you?
Prompt: Like family members or professionals

- 26 Can you describe a typical day now? If no typical days; what did N do yesterday?
Prompt: Is this different from the time before the implant. If yes how?

- 27 Have you been generally pleased or disappointed with the implant?
Prompt: the opposite

- 28 Thinking about the whole process, is there anything that has surprised you that was better than you expected?

- 29 Is there anything you would like to have been done differently?

- 30 What would you say to those who think you should not implant children like N?

- 31 What would you say to someone with a child with similar problems to N if they were thinking about and implant for their child?

Further reading and information

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Further resources available from The Ear Foundation:

Champions – children with additional needs and cochlear implants (with Advanced Bionics)

Deafblindness and cochlear implantation (with SENSE)

Deafblindness and cochlear implantation: a practical resource (with SENSE)



The Ear Foundation