

Cochlear implants: young people's views



Our vision is of a
world without barriers
for every deaf child.

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The research in this booklet was carried out by Alexandra Wheeler, Sue Archbold and Susan Gregory from The Ear Foundation and funded by the NDCS. We would like to thank Sue Gregory for writing this booklet about their research. There is further information about how the study was carried out on page 15 of this booklet.

We would especially like to thank the staff, families and young people at Nottingham Cochlear Implant Programme and South of England Cochlear Implant Programme for their assistance with the project.

The Ear Foundation is a charity that bridges the gap between hospital specialists, families, and children and young people who have a cochlear implant. They run a full programme of parent, family and professional courses, throughout the year.

The Plain English Campaign's Crystal Mark does not apply to the quotes from young people.



Why have we produced this booklet?

The effect cochlear implants have on deaf children and young people is currently a matter of interest and concern. But little is known about the views of young people with implants. These people have experience of how implants affect their daily lives, and understand the advantages and disadvantages of them.

We have recently interviewed a group of young people aged between 13 and 17 to get their views on implants. We contacted young people, chosen at random from two cochlear implant centres. Of the people we contacted, 29 said they were happy to be interviewed. Most had had their implants for at least seven years. For more details of the group and how we carried out our research, see the notes on the inside back cover of this document.

Wearing the implant

All except two of the teenagers interviewed wore their implants all day every day. The other two still wore them most of the time, but did not wear them when they wanted to 'relax and watch TV' or 'until later in the morning at weekends'. This suggests that for these two, using the implant involved some effort and was not the same as natural hearing.

Nearly half of the group said that they were upset if there was a problem with their implant and they could not use it.

**“ I miss hearing. I like hearing.
I am always fed up when it gets broken. ”**

**“ I don't like it if it's not working
because I don't know what is happening. ”**

“ I feel very sad, a bit worried, a bit upset. ”

“ I hate it so much. Very frustrating because I can't hear. ”

The advantages of having an implant

All of the young people had positive things to say about their implant, and they described many different advantages.

A third of the group felt an important benefit of the implant was the way it improved communication with family and friends.

“ Yes cochlear implants work because you can hear more, talking to friends, understand everything, go out have a good time. If you have a cochlear implant easier to have a good time ... ”

Two-thirds of the group felt they were understood by their family all or most of the time.

A quarter emphasised their general awareness of sound, such as music.

One-sixth had experienced hearing aids and found the implants much better.

“ Without the implant I would not manage. I can hear a lot better...you feel much more confident talking to the teacher because you can hear really well with it. ”

“ It helps me relax, really good, and I miss talking. ”

“ If two people are talking if I have my implant I can hear what both saying. I can see what is going on behind me. ”

The disadvantages of having an implant

Most of the comments about the implant described advantages (there were nine times more positive comments than negative ones), but the young people also described some disadvantages.

The young people experienced problems when sounds were either very loud or very quiet, particularly when there was a lot of background noise. This was an issue for four out of ten of those interviewed.

“ In noisy situations it is hard to hear people talking. ”

“ In noisy environment, a crowded place like the town, also in the train station. ”

“ Really quiet sounds. Mum would call me and I wouldn't hear it. Wouldn't hear it in a crowd as well. ”

It was also clear that situations involving many people could be difficult.

“ My friends, family talking. Bit hard for me listen like all talking all the time. ”

“ Sometimes in my form, the children in the classroom, all chat chat chat, can't hear. ”

There were other problems affecting only a small number in the group.

- Four mentioned headaches which they considered to be caused by their implant.
- Three complained that the post aural speech processor (the part of the cochlear implant equipment worn behind the ear like a hearing aid) fell off during energetic activity, particularly sports.
- Two commented on the cochlear implant preventing them from doing things (for example, playing rugby or scuba diving).
- Two disliked having to have an operation or going in to hospital.

Because the implant was so important to them, many depended on it. This created its own problems as some young people, ten in all, were worried about it going wrong.

“ I just worry and get a bit upset because I don't like it when cochlear is gone. I like it to work all the time and I was a bit worried if no sound. Nothing.”

Four were worried about the long-term effects of having an implant.

“ Sometimes you start to panic, wonder whether it's going wrong on the inside. I'm fine with being deaf it's just the actual breaking down. It's like having some of your organs failing.”

“ The fact it can break down and the fact that some time in your life have to have another operation to replace it.”



Understanding how the implant works

Most of the young people did not really understand how the implant worked. Two-thirds could give only very limited information and a quarter could not give any explanation at all. Only one-tenth could give a full explanation.

However, most knew what to do if the implant went wrong, which is more relevant for them. They all discussed:

- changing the batteries;
- checking anything that might not be working; and
- telling their parents or teacher of the deaf.

Most of them said that if there was a serious problem, they would contact their cochlear implant team. They seemed confident that the problem would be put right.

Cochlear implants at school

The young people within the group were educated in a range of different settings. Nearly half the group were in special schools, including one young person in a school for children with learning difficulties. Overall, this is a higher proportion than for most people of this age with implants.

Two-thirds of the young people felt that their cochlear implant helped them to understand lessons. One young person depended on his cochlear implant so much that he refused to go to school if it was not working. However, a number of the young people said that although the implant helped them to hear, they still relied on a support worker or notetaker to help them in lessons.

Communication, language and identity

Implants are usually seen as important because of the positive effect they can have on a deaf person's spoken language. However in this group of young people, although two-thirds preferred to use spoken language, one-third preferred to use spoken language together with some signs. Many were flexible in the way they communicated, changing it in different situations. They seemed to see achieving effective communication, rather than the language used, as the most important issue.

“With my deaf friends I sign, with the others I talk.”

“I sign with deaf people but I communicate with hearing people.”



Some commented on the fact that because their spoken-language skills were good, people who did not know them well thought they could hear.

“For the first time they might think that I'm hearing but then they realise, then they ask me if I'm hearing or deaf and I tell them.”

“Don't really know because everyone thinks I am hearing. To be honest inside me I'd say I'm hearing because I can hear what everyone is saying.”

How then did having an implant affect these young people's feelings about themselves and their deafness? Did they feel like they were deaf or hearing? What were their views on whether it is better to be deaf or hearing? Did they feel part of the deaf world or hearing world or did they feel they belonged to neither?

Answering the question about whether they saw themselves as deaf or hearing, the group gave a range of replies.

“ I can't hide the fact that I'm deaf. ”

“ Some days deaf, some days hearing. ”

“ Sometimes I feel like I'm hearing, sometimes I feel like I'm deaf. ”

About one-fifth of those interviewed described themselves as hearing and belonging to the hearing world. All the rest saw themselves as either deaf, or deaf and hearing.

Overall though, rather than seeing themselves as belonging to neither the deaf world or the hearing world, they seemed positive and felt that they belonged to both the deaf and hearing worlds. They are deaf and may sign, but in many ways, because they can hear and use spoken language, they also see themselves as part of a hearing world.



Deciding to have an implant

Our research shows that these young people felt they had benefited from their implants. But the decision to have the implant is not an easy one. Some people who disagree with young deaf children having cochlear implants feel that the operation should only be carried out when a deaf child is old enough to decide for themselves. Yet research shows that cochlear implants are more effective if children receive them when they are young. This means the decision often has to be made by parents.

None of the young people who had had their implant fitted when they were young criticised their parents for making that decision. None resented their parents for making the decision or not involving them, but they were grateful to them for the choice they had made.

“I can’t make the decision myself. I was really young at the time. I didn’t know much about. I am really pleased they made that decision.”

“I respect them for making the decision.”

“I was too young to understand but I’m ok with that. I know it was for my good to have the best outcome in life.”

“When I was young I didn’t have responsibility. I don’t know anything and my mum and dad they did the whole thing.”



Those given implants after the age of 12 years were likely to have had more of a say in the decision. Two of them did not make the decision easily and considered it for a long time.

“I did not want it for a while but when my teacher told me about it in more detail, I heard more and it seemed good, I thought I will have one.”



“I said no for a while but then I decided to have one because I realised that I can’t hear anything for the rest of my life so I thought I would have a cochlear implant and see what difference it made.”

Interviewer: “Why didn’t you want it to start with?”

“I think I was a bit scared of the operation.”
(Young man aged 15)

Advice to others

To find out more about the group's attitudes to the implants, we asked the teenagers what advice they would give about cochlear implants. They were given two scenarios, one where a teenager had become deaf as the result of a road accident, and one where the parents of a young deaf child had been told that their child was suitable for a cochlear implant.

Although the teenagers' replies about implants were positive, they understood how complicated the situations were. In talking about the first situation, they considered the effect an implant might have.

“If you suddenly have a car accident I'm sure you will be still shocked by it and hearing aids would be a good thing at first because if it was an implant it would be a bit too stressful.”

Others also suggested trying hearing aids first.

“I would tell him to have hearing aids first, because there are a lot of people with hearing aids who have brilliant hearing, good speech as well. And if he takes the cochlear implant straight away maybe he might be unhappy about it. If he's got hearing aids and he is still unhappy you know you can still have cochlear implant later, but if you have a cochlear implant you can't really change back.”

Some thought a cochlear implant would be the best solution.

“If you want to hear a lot better have it done. I think the implant is as close to normal as you can get.”

When responding to the scenario of a young deaf child being suitable for an implant, the teenagers seemed most concerned about what was best for the child.

“It depends what you think is best for the child. A cochlear implant would be quite good but there is the side of the operation. The doctors have to be involved, have to look inside you, which might bother some people. And the cochlear implant doesn't always work. There's years of hard work, years of speech therapy, years of going to the hospital and having to overcome the technical problems and having to have another operation sometimes later, whereas with hearing aids you don't have to have an operation to cope with them.”

Overall though, the view seemed to be that a cochlear implant would be best.

“Have a cochlear implant, hearing aids not much help. Technology changing, future generations have better things.”

“If profoundly deaf I would strongly recommend cochlear implant because your cochlear implant is very useful, they do lots of things that hearing aids don't.”

“Nowadays lots of young children have cochlear implants. I think it's a good idea.”

Some of the young people saw a need to reassure parents that the operation is not as worrying as it might seem.

“I would say not to worry about the operation because it is nothing really. You will recover soon and then I would say it really helps a lot and I would say the things that I can hear now but not before.”

Conclusions

The young people in this study appeared to be happy with their cochlear implant. Most used them all the time and were unhappy if they had to manage without it. They were happy that their parents had decided that they should have the implant and felt it had been the right decision.



Most of the young people in this study were flexible in their use of spoken language and signs. Being able to communicate was more important than the way they communicate. The young people's ideas about themselves, where most saw themselves as neither strongly deaf nor strongly hearing, supported this attitude to communication. Many considered themselves as deaf in the sense that they could not hear without their implant, but also as hearing and part of the hearing world.

Details of study

The group

The group members came from two major paediatric cochlear implant programmes in the UK – Nottingham Cochlear Implant Programme and the South of England Cochlear Implant Programme. We chose 128 young people at random and invited them to be part of the study. We received 33 positive responses (26%) and interviewed 29 of the 33. Responses being returned late and tight timescales prevented the final four interviews taking place. No young person was left out because of extra difficulties they would present.

The research

The interviews were carried out by an experienced teacher of the deaf who was not connected with either implant programme and did not know the young people. Those interviewed were asked how they would prefer to communicate (speech, speech and signs or BSL), and the interview took account of this.

Notes

A series of horizontal dotted lines for writing notes, spanning the width of the page.

We provide the following

- A Freephone Helpline 0808 800 8880 (voice and text) and a range of publications for parents and professionals that can be downloaded from our website at www.ndcs.org.uk
- Clear, balanced information on many issues relating to childhood deafness
- An audiologist and technology team that can give advice and answer any questions about deafness and equipment that may help deaf children
- A children's equipment fund and an opportunity to borrow equipment
- Support with benefits claims and Disability Appeals Tribunals
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- Family weekends, special events and training for families of deaf children
- A network of regional staff and local contacts
- Personal development and training for young deaf and hearing people
- Sports, arts and outdoor activities for young deaf and hearing people
- A quarterly magazine for our members plus age-appropriate handbooks and regular email updates

NDCS Freephone Helpline:
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