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Cochlear Implants: How siblings are changed

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Abstract

The purpose of this study was to understand the adjustment families undergo when a child is diagnosed with deafness as well as their adjustment to the child hearing after a cochlear implant is in place. The participants of the study were four hearing adults between the ages of 18-28 who have a younger sibling with a cochlear implant. The qualitative study used reports from four participants to reflect on how hearing loss and subsequent cochlear implantation impacted the family's lives. Contrary to expecting findings, the themes did not change and all four reported nurturing and personal growth as key themes.

Review of the Literature

Definition and Purpose of Cochlear Implants

In August, 1977, the first child received a cochlear implant. At that time, two children were implanted, ages 10 and 14, however; due to relaxed standards of requirement and positivity towards implanting at a younger age, children are now receiving implants as early as 12 months (Christiansen and Leigh, 2002). The purpose of a cochlear implant is to, “provide some degree of sound and speech awareness to persons for whom even the strongest hearing aids...could not amplify sound to appropriate levels” (Christiansen and Leigh, 2002, p 58). Cochlear implants are surgically implanted devices placed into the cochlea that are able to bypass damaged parts of the ear and stimulate the inner ear. Individuals who are candidates for cochlear implants have severe to profound hearing loss and need a tool that goes beyond hearing aids. Alternatively, they need a device that is able to send signals straight to the brain (Flexer, 1999, p 144).

Affects of Hearing Loss on Individuals Life and Surrounding Family

Since hearing plays such a crucial role in the development of a child’s communication, it is important to understand exactly how it affects them when they do not have the ability to hear. One author describes the role of hearing as having three different functions. The first is the primitive level where the person has the ability to recognize a location by its sound. For example, when entering a restaurant, one would expect to hear a lot of conversations going on and the noise level to be quite high. However, what if upon entering the restaurant, things were silent: a person would immediately recognize something to be wrong (Flexer, 1999). The second is a passive learning level where individuals know and understand what is going on around them

because of the environment they are in. However, with a hearing impaired individual, the child will not have the ability to learn from the environment because they are not able to hear it and therefore will not know what is going on around them. Hearing individuals can be calmed by the normal sounds that they hear; however, an individual with hearing loss is likely to become anxious at being alone and without sound. The third level in the role of hearing is spoken communication. Our speech develops without much stimulation simply because we are able to hear. In contrast, communication cannot develop well without hearing. A hearing child cannot speak until about one year of age, and this is after they have spent that entire year listening and observing their surroundings (Flexer, 1999).

Hearing loss not only affects a child's communication and their development of this communication, it also affects their behavior among other things. One set of researchers seeks to answer the question of what is the specific part of hearing loss that affects the individual's behavior. It could be the hearing loss itself, or as some researchers believe, it may be the ability of the child to use language in everyday conversation. As stated in an article, "the effect of hearing loss on behavior was less marked for children with better communication skills" (Stevenson, McCann, Watkin, Worsfold, and Kennedy, 2010, p 77). After conducting their research, they found that children with hearing loss did indeed have lower scores on the tests that measured language abilities. Furthermore, they found that the behavior difficulties were not related to the severity of the hearing loss; therefore, the hearing loss itself cannot be what is affecting their behavior problems (Stevenson, McCann, Watkin, Worsfold, and Kennedy, 2010).

In addition to behavioral problems, individuals seek to better understand other problems related to hearing loss such as their quality of life and mental health. Although much research has been done regarding mental health of individuals with hearing loss, it is becoming more

important to incorporate studies of the individual's quality of life. It is difficult to get a good grasp on how hearing impaired individuals are affected in their quality of life. Parents, teachers, and the individual with hearing loss themselves will all have a different view on how exactly they are affected. Fellingner, Holzinger, Sattel, and Laucht (2008) found in their article that, "while parents of deaf children appeared to stress the positive aspects of their children's quality of life, the deaf children's self report provided a more mixed picture of both positive and negative aspects" (p. 421). Moreover, they found that parents were noticing more problems than other individuals in the child's life such as their teachers. These observations lead us to recognize the importance of the type of relationship a teacher or parent has with a hearing impaired individual in order to take into account what the teacher or parent says about the quality of life of the hearing impaired. Overall, "deaf children reported being less satisfied with life in general", and rated much higher on "areas of school and family" (Fellinger, Holzinger, Sattel, and Laucht, 2008, p. 419). In addition, they are less satisfied in areas such as recreational activities, personal interests, and their physical health; this putting a strain on peer's and their contact with other people.

Hearing impairment affects a large number of individuals. It is stated that "bilateral permanent childhood hearing impairment affects 1 in 750 children in Western countries" (Fellinger, Holzinger, Sattel, and Laucht, 2008, p. 414). Since such a large number of individuals do have hearing impairment, it can be concluded that many other individuals are affected such as siblings, parents, teachers, grandparents, etc. More specifically, because siblings play such an important role in each others lives, it is important to further examine their relationship and how it is affected by the hearing loss. Verte, Hebbrecht, and Roeyers (2006) state in their article, that sibling's relationships can affect one another in areas such as "social

and cognitive skills and self concept development” (p. 90). The affects that a good relationship can have on siblings is much different than the affects that a bad relationship can have.

Distinctively, positive relationships “are associated with less loneliness, anxiety, and behavior problems as well as higher self-worth” (Verte, Hebbrecht, and Roeyers, 2006, p. 91). However, contradictory to this, it is said that negative relationships can be linked to children being more depressed and feel as if they are not worthy. It is believed that the quality of the sibling relationship is not affected at all except when comparing a child’s age or their family size. These two things alone seemed to make sibling relationships worse (Verte, Hebbrect, and Roeyers, 2006).

Although there has been little research done on sibling relationships with one deaf child and hearing siblings, we do know that there are many factors that affect these relationships, and that further studying needs to be done. According to the previous study, it is said that a child’s age plays a large role in how siblings are affected. In a study seeking to understand the emotional well being of older siblings of children with cochlear implants Raghuraman (2008) says that because these siblings are older, they may feel as though they have responsibility for the younger sibling to take care of them when or if something happens to the parents. In addition, the older siblings state that they have more responsibility around the house and that they cannot bother their parents with their worries. It seems as though the children are noticing their parents are too busy for them yet still have high expectations for them. In contrast with the previous study that stated that the main factors to affect sibling relationships were child’s age and family size, the study done by Raghuraman (2008) found that older sisters were found to have more positive interactions than older brothers. In general, the study found that having a sibling with hearing loss may not be as hard for older siblings as individuals may think.

Cochlear Implant Affects on the Family Unit

Although hearing impairment can cause major drawbacks in the form of communication, behavior, sibling relationships, and language development, there is hope in the form of the cochlear implant. In a study done in 2008, researchers seek to understand what kinds of outcomes are seen after implantation. They reported that parents state, “the use of spoken language developed greatly”, and also that “their child engages others in conversation and is sociable” (Archbold, Sach, O’Neill, Lutman, and Gregory, 2008, p. 135). Not only that, but one of the most exciting things for parents was that they could now call their child from another room and the child would know they were calling them. This ability to attract their child’s attention by calling them opened up many doors in communication; a child is now able to communicate with someone in another room. In addition, they do not have to be looking at another individual to communicate, they can do it all by listening. Although there were a few negative reports on lengthy timing of improvement from the child; overall, most responses were positive. Furthermore, these researchers state that following cochlear implantation, the child became, “sociable with the family...close to grandparents, and [have] improved relationships with their siblings” (Archbold, Sach, O’Neill, Lutman, and Gregory, 2008, p. 137). In another questionnaire, parents were asked to respond to a few questions following their child’s surgery. One such question wanted the parent to state how often they were able to understand their child’s spoken language, the result being that 78% could understand their child all or most of the time (Christiansen and Leigh, 2002). As stated, there are a lot of positive outcomes of cochlear implantation. Many parents spend a lot of time wondering whether or not do to the implant, and soon following their decision; they must spend a lot of time preparing them and their child for

what will follow. In fact many parents say that “they would try to have their child implanted at a younger age” (Christiansen and Leigh, 2002, p. 204). There is a strong basis for implanting at a younger age, and despite all the positive changes that occur after implantation, parents still believe they could be better if their child was implanted younger.

A study, performed more specifically on children with cochlear implants and their siblings, sought to find specific factors that would affect these relationships such as parents, birth order, and gender. Bat-Chava and Martin (2002) interviewed parents regarding their children before and after implantation, more specifically, they asked questions regarding the sibling relationship. They found that overall, the sibling relationships were positive despite a few negative responses. Most factors seemed to have some kind of effect on the relationships; these include cochlear implant versus hearing aids, birth order, gender, family size, the parents’ anxiety about deafness, and comparisons made by the parents regarding the normal hearing child and the child who is deaf. More specifically, the authors stated that “improvements in sibling relationships... [were] more often reported by parents of children who received a cochlear implant than by parents of children with hearing aids” (Bat-Chava and Martin, 2002, p. 82). In addition, children in larger families seemed to have better relationships with siblings. The factors that caused more negative reactions were when parents would give differing amounts of attention to the children. Furthermore, if the child was labeled differently from the rest of the family, this caused more distant relationships between siblings (Bat-Chava and Martin, 2002).

The purpose of this study was to understand how families adjust to deafness as well as the adjustment to their child hearing after cochlear implantation. More specifically, the purpose of this study was to understand how hearing siblings of deaf children are impacted by these two phases of a family’s adjustment. This study also looked at the time needed from family members

that is now devoted to helping the hearing impaired child develop and how this affects the relationship between the hearing individual and their sibling.

The questions of the study are as follows:

- 1) What changes in the family dynamics are important and which have affected the hearing sibling the most?
- 2) What benefits does the hearing sibling have?
- 3) What was the most difficult event that affected the hearing sibling after implantation?

Methodology

Participants

Four hearing adults between the ages of 18-28 who have a younger sibling with a cochlear implant participated in this study. All participants were female.

Materials

Participants were given an interview developed from the literature. The interview was a total of six questions and included demographic information such as birth order, how many siblings, and what age the sibling was implanted. Participants also were required to engage in a 30 minute one-on-one interview. This interview was either done face-to-face, by telephone, or by email.

Procedures

In order to find participants to interview, the study was solicited throughout Northwest Arkansas, and areas in Oklahoma. Participants were required to be nominated by the individuals who were contacted. Participants engaged in an initial interview done in person, over the phone, or by e-mail. When interviews were done by e-mail, each participant was contacted individually with attached documents including “interview questions along with the interview invitation and consent form” insuring that participants have a good understanding of the study before they make any commitments (Meho, 2006, p. 1290). Following participant interviews, all information was transcribed in order to find a theme. The themes abstracted from the interviews were member checked with each participant. However, when the interview was done through e-mail, this did not require member checking because the information did not need interpreting. The total time commitment to this study by participants was approximately 60-90 minutes. Code names that cannot be linked to identifying information were used for all participants in the study.

Only the researcher and the participant were present during interviews conducted face-to-face or by telephone, and only the primary researcher and faculty advisor read any material that came via e-mail. Furthermore, confidentiality for email interviews was maintained by following best practice protocols. These included “the use of pseudonyms and hiding the user names, domain names, and any other personal identifiers when publishing or storing interview data” (Meho, 2006, p. 1289). All notes, demographic information, and interview material was kept in a secure and safe place. Names and identifying information were not used in presentations or reports nor will they be used in future publications.

Results

Participants

Analysis of the data has provided qualitative information regarding the role of the cochlear implant in the family. In order to find participants nominations were sought from individuals. Of the four nominations received, all four were contacted, and all four agreed to participate. Due to the timing of the interview process as well as the traveling distance between the participant and researcher, all participants chose to be a part of the study by electronic correspondence.

All four participants were assigned a code name. The code names are as follows: Anne, Betty, Carly, and Darla. The ages of the participants ranges from 18-26. All participants were female and were older than the sibling who received a cochlear implant. The age of the participants when their sibling was implanted ranged from 8-13 years, and the age at which the younger siblings received their implants was 2 years old for three of the siblings and 8 years old for one sibling. This information is arranged below in Table 1.

Table 1. Summary of Participants.

Participant Code name	Anne	Betty	Carly	Darla
Participant Gender	Female	Female	Female	Female
Participant Age	18	26	21	19
Participant Age at CI Implant	6	13	8	11
Sibling Age when Implanted	2	2	2	8
Birthorder	Older than sibling	Older than sibling	Older than sibling	Older than sibling

Analysis Procedure

All participant materials were read one time through for each question of the study. For example, the responses for all four participants were first read for comments and reflection on family dynamics. The second reading focused only on benefits to the hearing sibling, and the third on difficult events. Themes for each of these constitute the data that addresses each question.

Question One

The first question of this study focused on family dynamics. It specifically sought to understand how having a child who was deaf impacted this and how changes in the family dynamics might have most affected the hearing sibling.

Common themes. The common themes identified were the same for all four participants. They reported that the main change in family dynamics was the families went in to a helping mode. They all came together as a whole and became one unit in order to help the deaf child. Not one family member was left out; it became a group effort to help out. Examples given by the participants included attending speech therapy sessions, going to the audiologist, and learning to sign. Overall, the family dynamic stayed mostly the same.

With regard to how this impacted the hearing siblings, who are the participants in this study, all indicated that they played the role of the big sister and helper around the family. None indicated that this was difficult for them or a negative experience. They all had the attitude of a caring sibling and it seems they would have had this same attitude despite whether or not their sibling was deaf. The participants said they enjoyed attending the speech language pathology sessions and audiology visits. Some even stated that they looked forward to attending the sessions and that they would not miss it. All of the study siblings learned some sign language or

used some new mode of communication in order to communicate with the deaf sibling. It was natural for them to adjust and do whatever was needed to better communicate with their sibling. Lastly, the participants stepped into a protective role. As the family shifted to become helpers to the deaf sibling the older sisters gained the desire to protect the younger sibling and take care of them.

Secondary themes. Secondary themes are those not reported by all participants. Two of the four participants noted that after the diagnosis of hearing loss, the therapist took on the role of teaching the sibling who was deaf to communicate. The responsibility no longer fell on the family but on someone outside the family. On the other hand, the other two participants noted that the family continued to help the sibling who was deaf to communicate and begin to learn language. In this instance, they kept the responsibility for themselves. One participant stated that she does not remember her parents ever telling her that her sister was deaf and that it was never a big deal for the family. In addition, other participants noted the hearing loss never made a big impact on the family; it was just something that was a part of their life.

Question Two

The second question of the study sought to discover if the participants thought they derived any benefits from having a sibling who was deaf and then received a cochlear implant

Common themes. Several common themes emerged from the information provided by the participants. After going through the cochlear implant process as a family, all siblings indicated they were able to better appreciate what cochlear implants are. This was in part due to better understanding the technology of a cochlear implant and seeing firsthand what it does for individuals, such as their younger sibling, on a daily basis. For instance, one participant stated she was able to see the speech improvement in her sibling. Another sibling stated that her

brother is now mainstreamed in school and that he is able to hear and communicate at a normal level. All participants stated in some way what an amazing device the cochlear implant is and that their sibling would not be the same without it. When asked what it was like when her sibling could hear with the cochlear implant Annie stated it was “Phenomenal”. Betty stated, “It was really hard to believe he couldn’t hear because he was so interactive.” Another participant noted her brother’s whole world changed and was opened up for him.

Secondary themes. Only one participant expressed experiences that were unique to the hearing sibling. Darla formed a special relationship with her sibling through which they played games that consisted of switching roles to where the sibling who could hear would pretend to be deaf. This turned the younger child’s inability to hear into a fun game that was shared between the two of them and reportedly gave them a special bond. They enjoyed signing with each other and missed getting to do that after the deaf sibling received a cochlear implant.

Question Three

The third question of the study explored what was difficult for the participants after the siblings who are deaf received their cochlear implant.

Common themes. While said differently all the participants reported amazingly similar stories. The most difficult event for the participants was that they had to change their way of communication after the sibling who was deaf received their cochlear implant. The family’s form of communicating transitioned from sign language to speaking only or they constantly had to integrate what the deaf sibling was learning in therapy into the way the family communicated. Some participants stated they missed signing with their sibling.

Other difficult events that the participants were faced with happened prior to the cochlear implant. All participants had to step in and help the parents and their siblings more. In addition,

the participants had to spend more of their time around their sibling and at appointments.

However, this was not something that affected them negatively, nor was it necessarily a difficult event. The participants saw this as something that was needed for the family, and wanted to be a part of everything and help in any way possible. Anne did state she felt as though she needed to become more of a second mom to her sibling. In her life, this was a positive response because she wanted to be a part of everything and it meant a lot to her to attend all appointments.

Overall, there was no big event that was difficult for any of the siblings and any event described above was not reported as having a negative impact.

Discussion

The purpose of this study was to understand the adjustment families undergo when a child is diagnosed with deafness as well as their adjustment to the child hearing after a cochlear implant is in place. The results of this study suggest that while there was a definite change in family dynamics, this was not seen as particularly negative. Family members worked together to meet the needs of the deaf child. This took additional time but led to enhanced bonding and a broader view of the world for the participants of this study. Interestingly, few events were considered difficult and those addressed as possibly difficult tended to happen prior to the younger sibling receiving the cochlear implant.

The consistency of themes across participants suggests that being a female older child with a younger deaf sibling has an identifiable social story. The participants saw this as a positive growth experience in their lives. This is important since this was not predicted from the literature. Specifically, earlier studies report that deafness changes family dynamics and that the hearing siblings lose part of their time with parents due to the needs of the deaf child. As stated in the review of the literature, negative sibling relationships “can be linked to children being more depressed and feel as though they are not worthy” (Verte, Hebbrecht, and Roeyers, 2006, p. 91). Older siblings also state they have “more responsibility around the house and that they cannot bother their parents with their worries” (Raghuraman 2008). However, as shown in the results, the participants reported only positive changes. Although much more time was required from the family to attend appointments and therapy, the family attended together and became more of a cohesive group in order to help. The participants wanted to play a larger role in their siblings’ lives and were excited to be able to help.

In addition, it was thought that the hearing sibling would benefit greatly from cochlear implants because there would be less time required from the parent for the deaf sibling that could now be spent with the hearing sibling. As stated in the review of the literature, “negative reactions were when parents would give differing amounts of attention to the children” (Bat-Chava and Martin, 2002, p. 82). Despite predicted negative reactions, the data suggests that the benefits the hearing siblings had was a better appreciation for cochlear implants; both the technology and what it can do for an individual who is deaf. Participants were able to see improvements in their sibling’s communication and daily life as well as enjoy a different kind of relationship than two hearing siblings.

Lastly, it was predicted that after the cochlear implant was in place, the family would be solely focused on helping the child who is deaf to communicate. This was thought to be a negative event for the sibling because they would feel neglected. However, as shown in the results, there is no negative event. In fact, the most difficult event for the participants was that they had to change the way they communicated with their sibling. The participants had grown used to the deafness and way things were and had a difficult time adjusting. Although parents did need to spend more time with the child who was deaf, the siblings chose to take part in this as well. They wanted to be a part of it just as much as the parents and were happy to spend their time helping.

Limitations of the Study

As participants were sought for this study, it became apparent that finding these individuals was much more difficult than what was originally thought. Nominations were sought through individuals who were known to be in the cochlear implant community and as many were from out of state, it was too far of a distance for participants to travel for a face-to-face interview.

In addition, the time needed from each participant ended up a limiting factor as most participants could not commit to that amount of time. Because of the distance and time factors, none of the interviews were done face to face. This study would perhaps have yielded more and/or richer information and the researcher would have been able to acquire more details from each participant had it been given face to face. This study had no male participants and only four female participants. More participants may have been better as to continue to validate the results. Furthermore, additional males would have changed the dynamic of the study as males would offer a much different view than females.

Future Directions

In the future, this study could be performed using the same distribution technique. Nominations would be sought over a longer period of time and through more individuals in order to increase the study's numbers. Most importantly, nominations would be sought for males. In addition, more interviews would be done face to face. Not only would the future study have face to face interviews, the researcher would also lead interviews in focus groups. These focus groups would consist of male/male, male/female, and female/female in order to see what role gender plays in this study.

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Appendix A
Instrument

Initial Interview (Session 1)

Code Name (please make-up a code name for yourself that doesn't include your name):

Age:

Gender:

How many siblings:

Your age when your sibling was implanted:

Siblings age when he/she was implanted:

Birth order of siblings:

Interview

- 1) What's that first thing you remember about your sibling?
- 2) What's the first thing you remember about his/her hearing loss?
- 3) Describe your role in the family before cochlear implantation? What stands out for you?
- 4) What changed for you when your sibling was implanted?
- 5) Did your role in the family change? If so, how?
- 6) What was it like once she/he could hear?

Is there anything else you would like to say?

Follow-up (Session 2)

Themes have been derived from the information that you provided in your interview. These are the points I think you were making. Please read over these and tell me if I correctly understood what you were trying to say. Do any points need to be clarified, expanded, or left out?

Thank you for helping me with this study.

Appendix B
Data

Initial Interview (Session 1)

Code Name: Anne

Age: 18

Gender: female

How many siblings: 1

Your age when your sibling was implanted: 6

Siblings age when he/she was implanted: 2

Birth order of siblings: myself and then my brother

Interview

1) What's the first thing you remember about your sibling?

My brother has the kindest heart and he is very outgoing.

2) What's the first thing you remember about his/her hearing loss?

My brother lost his hearing from contracting meningitis; I remember he was very sick and wasn't supposed to live but my family was thankful he lost his hearing and not his life.

3) Describe your role in the family before cochlear implantation? What stands out for you?

I was a new big sister and a nurturer at heart. I attended almost every audiology appointment and any other appointment that assisted my brother with other healthcare needs resulting from the meningitis and stroke.

4) What changed for you when your sibling was implanted?

As an older sister, I felt the need to become more of a second mom than sibling. Everything changed. Cochlear implants helped my brother achieve goals in every aspect of his life.

5) Did your role in the family change? If so, how?

No. My role was to love, protect and teach my little bub. Why would his hearing effect my duty as a caring sister?

6) What was it like once she/he could hear?

Phenomenal. The look on his face when he heard birds outside and my voice was priceless! I couldn't exactly understand it all at the age of six but I knew his whole world had changed and that nothing could hold him back.

Is there anything else you would like to say?

My brother wouldn't be who he is today without cochlear implants.

Initial Interview (Session 1)

Code Name: Betty

Age: 26

Gender: Female

How many siblings: Three siblings. One implanted sibling.

Your age when your sibling was implanted: Thirteen

Siblings age when he/she was implanted: Two

Birth order of siblings: I am the oldest, my implanted sibling is the youngest

Interview

1) What's the first thing you remember about your sibling?

I am eleven years older than my brother, so I remember him being a baby very well. I remember visiting him in the hospital and I remember thinking that he was actually a lot bigger than I thought he was going to be. Except for his hands. They were so tiny!! I remember him grabbing my finger. Then I remember having to run away because when we got there they didn't have a diaper on him and he peed everywhere.

2) What's the first thing you remember about his/her hearing loss?

I remember that he failed his newborn hearing test but that the nurses said it was no big deal because those tests are not accurate and it is hard to gauge what a baby is doing. I remember my mom trying to test if he was hearing or not. He was really good at reading lips and made lots of sounds so he fooled us for a long time. He would say easy words like "ball." We would do tests like dropping a ball on the ground when he wasn't looking to see if he would react and he always turned around (we later found out it was probably because he felt the vibrations in the floor). Also my mom would have us stand behind

him and call his name and he would turn around (but it was because he could see her look at us and was following her eyes). I remember he never would respond when we turned on the vacuum cleaner. Also he was a terrible sleeper at night (probably because it was dark and he couldn't see). He never wanted to go to sleep.

3) Describe your role in the family before cochlear implantation? What stands out for you?

I am the oldest. Because I am so much older than my brother I was always taking care of him and the whole family gave him lots of attention. We thought he was so cute and everyone wanted to play with him all the time. He really was such a funny cute, active baby. It was really hard to believe he couldn't hear because he was so interactive.

4) What changed for you when your sibling was implanted?

We did a lot of activities relating to hearing skills once he was diagnosed. Before he was implanted we learned some sign language for common things like "ball" and he loved salami so we could use the sign for pig when he wanted salami. We went to speech therapy sessions and workshops and even met with a counselor for siblings with deaf children three or four times a year at one of the workshops.

5) Did your role in the family change? If so, how?

My role didn't really change at all. We all as a family just adjusted to best help him. My mom's life changed a lot because she worked with him all the time. She was determined to make him read as early as possible since he was behind in hearing. She put him in a special needs pre-school right away so that he could have interaction with other kids and was constantly being stimulated.

6) What was it like once she/he could hear?

It was amazing. The surgery is pretty invasive and he had really bad swelling for several days and you could tell he was in a lot of pain so my mom was good at constantly medicating him. We actually got to be there to watch him get hooked up. We were all in a room sitting around a table. He was very confused as they were setting stuff up but continued to look around and just babble like normal. Then they flipped the signal on and he just stopped moving. His eyes looked up at my mom slowly and he looked like he was trying to process the new "sound." He was implanted at the age of 2 which is the earliest age they did it back then. They do them much earlier now to take advantage of the speech development window. Since he was already two, he had a bunch of catching up to do. He and my mom worked so hard. The implant was great and he was clearly hearing sound but that doesn't translate in to speech. I think it is easy to get frustrated because you think that once you have hearing, speech automatically follows and people underestimate the value of speech therapy. The implant itself is only half the battle. I

remember a few things changed. Like the way we talked to him. We were constantly mimicking speech therapy sessions and took a ton of photos of all the things we did so we could review it with him after the fact and try to incorporate language.

Is there anything else you would like to say?

He got a second implant and having the implant on both sides made a tremendous difference, especially as he entered the school system. His second implant failed and he had to have an additional surgery. That was kind of scary just because he was older and could remember it (versus having an invasive procedure and a baby). I think the cochlear implant is such an amazing thing. I am studying hospital administration and we constantly evaluate new technology. As it turns out, cochlear implants are not at all profitable for a hospital. In fact, in many cases, they are a negative income item. However, I was just in a meeting where the Chief Financial Officer (who is ALWAYS concerned about money) said that there is no way that an administrator could refuse to provide cochlear implant services because no amount of money loss could compete with the chance for someone to hear and the value to a patient's life from gaining the sense of hearing is immeasurable. I completely agree.

Initial Interview (Session 1)

Code Name: Carly

Age: 21

Gender: Female

How many siblings: 3 siblings; 1 with cochlear implant

Your age when your sibling was implanted: 8

Siblings age when he/she was implanted: 2

Birth order of siblings: I am the third eldest and the implanted sibling is the youngest.

Interview

1) What's the first thing you remember about your sibling?

I remember visiting him in the hospital. I remember that he didn't make much babbling noises himself. He just cried the majority of the time.

2) What's the first thing you remember about his/her hearing loss?

I was only six when he was born so I do not remember much. I remember that he would cry all the time, especially when it was dark. We tried fitting him with hearing aids first until he was old enough to be implanted.

3) Describe your role in the family before cochlear implantation? What stands out for you?

Since he was the baby of the family, we took care of him and watched him a lot. We also learned a few words in sign language to communicate with him.

4) What changed for you when your sibling was implanted?

We no longer had to get his attention by physically grabbing him. We didn't sign anymore. We attended several speech therapy sessions and workshops for siblings of deaf children.

5) Did your role in the family change? If so, how?

No, he still is the baby of the family and we all still look after him.

6) What was it like once she/he could hear?

It was definitely a lot easier to communicate with him. He still is really good at reading lips for when he takes the device off. It is really an amazing device. He had to attend speech therapy for several years but now he is completely mainstreamed and hears like any normal person when he has his device on.

Is there anything else you would like to say?

Initial Interview (Session 1)

Code Name: Darla

Age: 19

Gender: F

How many siblings: 1

Your age when your sibling was implanted: 11

Siblings age when he/she was implanted: 8

Birth order of siblings:

Interview

1) What's the first thing you remember about your sibling?

The first thing I remember is my dad bringing me to meet her right after her birth. I don't remember seeing her for the first time, but I remember being in the car and being very excited about a new little sister.

2) What's the first thing you remember about his/her hearing loss?

I don't remember my parents telling me about it. It wasn't really anything that was ever a big deal for either my sister or I because we were both young enough when her hearing loss was discovered that it wasn't really an "issue" to deal with. That's just how it has always been for both of us. One of the things I do remember though is when she was 4 or 5 she would be playing outside or something and her aids would always fall off her head and would whistle a lot so my mom would have to tape them to her head to keep her from losing them. I clearly remember her asking some of her friends for any ideas about what else she could use since my sister's hair would always get stuck in the tape.

3) Describe your role in the family before cochlear implantation? What stands out for you?

Before her implant, I usually signed for her in loud situations or if someone was talking to quickly or slowly. We both liked being able to talk without our parents really knowing what was going on because they were much less fluent than we were.

4) What changed for you when your sibling was implanted?

Afterwards we were told by the audiologists not to sign so I stopped. That's the only thing that really stands out just because we enjoyed signing with each other and missed it for a long time.

5) Did your role in the family change? If so, how?

It really didn't. It changed how my sister and I communicated, helped her a lot in school, and had a huge impact on her personally but our lives didn't revolve around her hearing loss. While the implant made it much more convenient than having to sign all the time, and we were thrilled that she was able to hear so well, it wasn't "life altering" for my parents or I the way it was for her.

6) What was it like once she/he could hear?

She loved her implant and we could tell an immediate difference. Now that she's much older, her speech has improved a lot and unless she wears her hair so that it doesn't cover her processor/aid, most people wouldn't even know without being told.

Is there anything else you would like to say?

One of our favorite games when we were little was switching places so that we were both “deaf”. Sometimes I would even put in her hearing aids and we would walk around a store or something signing. She really would be deaf without her aids, and I would look like I was since I was wearing them. Sometimes when I come home from school for a weekend we still do that and see how many people we can get to talk to us before they realize that we “can’t talk back”.