Current Topic

**Why Do Parents Who are Deaf Have Their Child
Who is Deaf Fitted With a Cochlear Implant?**

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The first time in Germany that a child who was deaf was fitted with a cochlear implant was in 1988. In the course of that year, cochlear implants were increasingly requested by parents who were mostly people without hearing impairments, because over 90% of children who are deaf have parents without hearing impairments. Nowadays, cochlear implantation is a widely recognized and accepted method of treatment. The situation has been different, however, for of parents who themselves are deaf. Bonded by the Deaf community and culture, the Deaf can communicate with their children from the start via sign language. Nevertheless, more and more Deaf parents are opting for a cochlear implant for their children who are deaf. Background for this decision, based on data from interviews with Deaf parents, is described in this paper.

Key words: cochlear implants, parents who are deaf, Deaf community, children who are deaf and have cochlear implants

Background

In Germany, deaf toddlers have been receiving cochlear implants since 1988. Although the idea of cochlear implants initially met with some reticence, the implants are now regarded as a standard and accepted procedure for children who are congenitally deaf. In cases without other complications, children who are congenitally deaf are fitted with a cochlear implant at around 8-15 months of age. Likewise, bilateral implantation has become a standard procedure. According to the published literature (Krüger, 1991; Große, 2003), at least 90% of children who are congenitally deaf have parents without hearing impairments who perceive cochlear implants as a chance for their children to acquire hearing ability, thereby establishing a closer family bond.

When, in the mid-nineties, all the members of a family of four, that is, parents both of whom were deaf and their two sons (then 6 and 3 years old) who were also deaf, were fitted with cochlear implants at more or less at the same time, a new debate was set in motion (Begall, 1995). Until then, children who

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were deaf and who had parents who were deaf had not been considered likely candidates for cochlear implantation. Hardly any physician or educator had reckoned on parents who were deaf wanting to have their children who were deaf fitted with cochlear implants.

At that time, the adult Deaf were extremely critical of cochlear implants. Even advocates of cochlear implantation for children who were deaf had no idea how hearing and speech development could be organized when the parents themselves were deaf and therefore unable to communicate sufficiently in spoken language.

As the family had expected, the children in the family described above gained great benefit from the cochlear implant procedure. From the outset, however, cochlear implants for their parents were perceived more as a social measure that served to strengthen the family bond or family consciousness. The parents who had received the cochlear implants had limited hope of learning to hear.

Some time later, there was a further example of children of deaf parents receiving cochlear implants. Whereas the first family had had hearing relatives, all the members of this second family were deaf, that is, the grandparents and other relatives were also deaf. In this case the parents who were deaf opted for cochlear implantation for their daughter and son, aged 8 and 6, respectively.

These examples resulted in the initiation of a multiple-study research programme at the Department of Education of the Deaf and Hearing Impaired at the University of Munich. The following report describes the pilot study, conducted from 2001–2004, and designed as field research (Leonhardt, 2004, 2008, 2010).

Preliminary Considerations

The research project was based on the following considerations (cf. Leonhardt [2010] 8–9):

- (1) A majority of Deaf people feel a certain allegiance to the Deaf community and culture. Bonded by a valued sign language, they are able to communicate freely, without any barriers, with other members of the Deaf culture.
- (2) Initially, cochlear implants were vigorously opposed by the Deaf community. This was still the case in the mid-nineties, i.e., at the time of the first cochlear implantation in Germany in children who were deaf whose parents were also deaf.
- (3) Deaf parents have a completely different attitude towards the deafness in their children than do parents without hearing impairments. From their own experience, they know that Deaf people, too, lead a life of fulfilment and enrichment. Using sign language, they can communicate with their children. They are therefore in a different situation from parents without hearing impairments, who, receiving a diagnosis of deafness in their

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children, are initially preoccupied with coming to terms with “deafness” itself and coping with this phenomenon.

- (4) The special situation of children without hearing impairments whose parents are deaf has long been neglected in literature. Only recently, in the framework of Children Of Deaf Adults (CODA), has attention focussed on children without hearing impairments whose parents are deaf. This constellation appears more complex than that of children who are deaf and whose parents are deaf.
- (5) With regard to cochlear implantation for their children who are deaf, deaf parents find themselves in a different situation to that of parents without hearing impairments. While parents without hearing impairments may opt for cochlear implantation for their children as a means of “bringing the family closer together” (enabling a common bond of hearing), parents who are deaf, on the other hand, may feel that they are casting their child into an unknown environment of which they have little experience.

Research Questions and Methods

For the pilot study, first, basic information about the target group was collected. In particular, the following questions formed the basis of interviews:

- What were the motives of parents who are deaf or have severe hearing impairments for having their children fitted with cochlear implants?
- How did the family’s social environment react or behave towards the families who opted for cochlear implantation for their children?
- What form of communication is predominantly used within the family? How is the development of hearing and speech organized?
- What kind of care and special education is provided to these children in their pre-school (nursery school)? Which school system (mainstream or a school for children with hearing impairments) was selected or is planned?
- At the time of the interview, how did the parents evaluate their decision of cochlear implantation for their children?
- What problems arose in the rehabilitation process?

To answer these questions, parents who were deaf or who had severe hearing impairments, whose children had undergone cochlear implantation, were interviewed, following interview guidelines compiled in the run-up.

Study Participants

Eighteen families were interviewed in the pilot study. In four of these families, there were two children with cochlear implants; and the remaining 14 families had one child each with a cochlear implant. In other words, the findings covered a total of 22 recipients of cochlear implants.

The age of the children at the time of implantation varied widely: the young-

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est and oldest recipients were 8½ months and 8½ years respectively. At the time of the interviews, the children were between 1 year 8 months and 15 years 10 months old.

The duration of the children's experience with their cochlear implants also varied hugely: the shortest period was 5 months, and the longest, 9 years 2 months.

The families were selected according to the following criteria:

- Both parents were deaf or severely hard-of-hearing.
- One or more children in the family had been fitted with a cochlear implant.
- The family's residence was in Germany, Austria, or the German part of Switzerland.

If the parents so desired, the interviews were conducted in spoken German or in German sign language in the presence of a sign language interpreter. In a few cases, at the request of the parents, a family member without hearing impairments was present.

Results

All of the parents demonstrated a strong attachment to the Deaf community (Leonhardt [2010] 10). The following findings and discussion should be considered against this background.

Catalyst for Discussion

At the time of the pilot study, discussion about the possibility of a cochlear implant for the child in question had been triggered either by a physician who had diagnosed the child's hearing impairment, or by one of the child's teachers. The latter included nursery school teachers of children with hearing impairments and a few primary school teachers or educational therapists. (In the subsequent study, it was found that the possibility of a cochlear implant had been raised exclusively by educational therapists in early child intervention centers.)

In the initial stage of cochlear implantation in children of parents who were deaf, it was often the grandparents without hearing impairments (usually the grandmother) who urged the parents to consider the possibility of a cochlear implant for their child, because, in the grandparents' opinion, that would facilitate access to hearing, speech, and comprehension.

In several of the families, the cochlear implantation was the child's wish. These children were either older nursery school children or younger primary school children. They were familiar with the cochlear device from their peers at nursery/primary school who had cochlear implants, and they wanted the same thing. In these cases, the parents who were deaf or had severe hearing impairments granted their child's wish.

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Attitude Towards the Cochlear Implant

All the parents interviewed admitted to having been initially opposed to cochlear implants, for various reasons. For example, they knew of cases in which a cochlear implant did not change the child's ability to hear, they feared medical intervention, or they felt that the technology was still in its infancy and so could not be trusted to be safe and effective. An additional point that they made was that because the whole family was deaf, the child's deafness was something that they could live with.

The parents were particularly negative towards the cochlear device if they had had the feeling that they were being pressured into a decision by doctors or educators. This feeling stimulated rejection, rather than acceptance. The parents interviewed in the pilot study also expressed concern as to whether or not a cochlear implant would help their child to hear. This argument was not expressed in the interviews in the subsequent study, however.

The fact that the parents questioned in the pilot study finally opted for cochlear implantation for their children, despite their initial rejection and uncertainty, raises the question of the motives governing their decision. Here, the diversity of rationales is particularly significant. One important aspect was the parents' desire to enhance the quality of life and future prospects for their child. The parents hoped that the cochlear implant would facilitate hearing and speech development in their children, with the result that they would be better equipped to cope with life.

A further point expressed by the parents concerned the decreased number of children who were deaf at schools for children with hearing impairments. This is occurring in Germany as more and more parents opt for cochlear implants for their children. A consequence of the decreased number of pupils means that classes for children who are deaf, if they exist at all, have to accommodate a wider range of age groups or include children who have other disabilities. The parents with hearing impairments very much doubted that their children would thrive in such conditions. Some of them were concerned about whether the hearing and communication situation of their children would develop if the children were in a classroom where all the students had hearing impairments and no cochlear implants.

The parents' decision to get a cochlear implant for their children was nevertheless combined with high expectations. Due to their own experience of having to attend boarding school because of the long distance between their home and the special school for children with hearing impairments, the parents who were deaf or had severe hearing impairments hoped that the cochlear implant would solve this problem, because it would enable integrative schooling for their children that would be close to their home.

Hearing was also perceived by these parents as something valuable that could enrich one's life (e.g., listening to music, communication with people without hearing impairments, and experiencing an acoustic world). The parents'

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main rationale, however, focused on their children's acquisition of simple speech that could be facilitated by a cochlear implant. Statements such as "our child should have it better than we did" were typical.

The parents also expressed concern that in later life they might be accused of depriving their child of the opportunity to get a cochlear implant.

Family Situation

At the beginning of the research, the families could be categorized in one of two constellations:

Constellation 1. In these families, family members without hearing impairments, or close contacts of the family, insisted on cochlear implantation for the children, and were instrumental in the preparation for and organization of the procedure. The family member without hearing impairments (most typically the grandmother) also accompanied the child to the operating room. In these families, an opportunity for development of spoken language was the driving force; the cochlear implantation was typically performed at nursery school or primary school age.

Constellation 2. In these families, the parents made the decision to get a cochlear implant for their child. Perhaps this may be the reason that these parents described the decision-making process as "difficult". In the run-up, the pros and cons were weighed seriously. The parents themselves accompanied their child to the operating room. These families insisted on that both sign language and the spoken word be used in the education of their children. The children in these families were mostly younger recipients of cochlear implants.

Reactions of Individual Deaf People and the Deaf Community

The parents were asked if the fitting of a cochlear implant had had any influence on their child's relations with other children who are deaf, and if so to in what way. The answers to question will be reported separately in terms of before and after the implantation.

Before implantation. The attitudes and behavior of Deaf parents and parents with severe hearing impairments before their children received a cochlear implant reflected two main strategies. One was to discuss points in favor of cochlear implants, as well as the parents' misgivings, with other members of the Deaf community. The other strategy was to keep quiet about their misgivings, and avoid discussion or confrontation with people of differing opinions.

After implantation. The picture after implantation was completely uniform. All of the parents interviewed reported breaking off contact with some of the members of the Deaf community. They were also under pressure to show that the implantation had succeeded in enabling their child to hear. Some of them described incidents in which Deaf people made noises behind the newly implanted children to test whether they could really hear.

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Contact with “Cochlear Implant Families”

All of the respondents criticized the lack of contact with other families in a similar situation. Due to the limited number of children in hearing impaired families who had received cochlear implants, the families generally live far apart. This makes contact difficult. Such contact would be valuable, however, because it would probably contribute to stabilization and information exchange.

In general, parents with hearing impairments desire more communication with each other, and their children with hearing impairments desire more social and play contact with their peers in their neighbourhood who do not have hearing impairments. For the parents, the cochlear implants were perceived as enabling an opportunity for their children to experience natural speech on a daily basis. They always insisted on sign language for communication within the family or in the company of other people with hearing impairments.

Communicative Support for the Child

The parents who were interviewed definitely assumed that hearing and speech training would be provided at the Cochlear Implant Center[†], as well as at child intervention centers and schools, since they, themselves, were hardly in a position to do that.

The interviews also revealed that the younger children experienced better support education than the older ones. They benefited from the fact that the scope for individual therapy for a child at the Cochlear Implant Center, child intervention centers, and nurseries was greater than that in the schools. In schools, the scope of individual speech therapy is limited by external conditions, such as curricula, time-tables, and other stringent organizational demands.

The parents perceived it as their duty to organize contacts for their children with children without hearing impairments by, for example, involving their children in play groups or nursery schools, or through encouraging contacts with peers in the neighbourhood who did not have hearing impairments. Weekly visits from relatives were also organized.

Within the families, both sign language and the spoken word were used. The spoken word is preferably acquired through close contacts with people without hearing impairments, whereas signing is often introduced if the situation demands, in order to avoid communication barriers. Sign language remains the “family language,” the parents reported.

Satisfaction With the Cochlear Implant Fitting

Despite their varying degrees of experience with the cochlear implants, all the parents interviewed expressed satisfaction with the device.

At the time of the interview, the parents reported that they were convinced that their decision to have their child fitted with a cochlear device had been correct. After experiencing their children’s daily lives with the device, the parents said that they would do the same thing again. All of the children wore

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their implant or implants (some of the youth were bilaterally implanted) 24 hours a day.

Parents expressed ambivalent views concerning their children's language development. They admitted to not being able to gauge the status of their children's hearing and speech development or the extent of the children's perception of the spoken word. They also revealed their anxiety concerning re-implantation in the event of a complete failure of the device.

Problems During Rehabilitation

Not all cochlear implant centers have managed to involve parents who are deaf in the rehabilitation phase. Some of the parents interviewed complained that they, as parents who were deaf, had too little influence in the therapeutic process at the cochlear implant centers. They also criticized the lack of use of sign language there.

Conclusions and Prospects

The pilot study summarized above has been followed by three further studies (Leonhardt, 2010, p. 8).

The results of the pilot study suggested that many outmoded and partially false assumptions governing cochlear implants exist among the Deaf. The subsequent study thus attempted to address these prejudices and proactively enlighten the Deaf community by means of carefully compiled material. Prior to conducting the study, people in the Deaf community were consulted about the nature of the materials. The majority opted for a brochure in simple language with many pictures and a flyer with a quick overview. The materials were prepared by a team that included scientists, practitioners, and members of the Deaf community (specifically parents of children with cochlear implants). Before the final materials were printed, they were given to a large group of Deaf people to check and evaluate for understandability (Fiocchetta, 2010). The resulting materials have been available since 2009, and are frequently requested by people in other countries.

Future studies will focus on language development in children who have cochlear implants whose parents are deaf, and on integrative nursery and elementary school education.

Endnote[†]

In Germany all children are monitored at the Cochlear Implant Center for 60 days within the first 2 years after cochlear implantation. Thereafter, screening is annual.

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