

Editor's Introduction: Programs that assess candidacy for cochlear implantation invariably face discussions of the cultural implications of prosthetic intervention. The application of electrified implants to the auditory pathway over the past 30 years has defined a culture divide for many, and childhood implantation has been a focus of these concerns. There are no correct positions in such controversies. Health care and communication professionals should be guided by the candidate's and their family's perception of how best to participate in an environment that will be meaningful, as defined by them. What is most important is that the decision to pursue implantation should be as fully informed as possible and that factual information flow across the cultural divide. As faculty of Gallaudet University, Christiansen and Leigh offer a unique perspective on implant outcomes as based on extensive survey data from families of children with cochlear implants.

John K. Niparko, MD

Children With Cochlear Implants

Changing Parent and Deaf Community Perspectives

John B. Christiansen, PhD; Irene W. Leigh, PhD

Objective: To examine changing parent and deaf community perspectives related to pediatric cochlear implantation.

Design: This research is based primarily on 2 nonrandom study designs. In the first study, conducted by the Gallaudet University Research Institute, Washington, DC, in the spring of 1999, a 12-page questionnaire was distributed to 1841 parents of children with cochlear implants; 439 questionnaires were returned. In the second study, we conducted 56 interviews with parents of 62 children with implants (and 1 without).

Subjects: Parents of children with cochlear implants; Gallaudet University faculty, staff, students, and alumni.

Results: While parents frequently receive conflicting information about educational and communication options for their child, they generally support signing be-

fore and after implantation. The parents of a child with an implant have a great interest in their child's spoken language development, and most would like to have had their child receive an implant earlier. Children with implants are educated in a variety of educational settings. Mainstreamed children with implants often continue to require classroom support services, and children with implants are frequently not isolated from both deaf and hearing peers. Parents have mixed experiences when getting information from persons in the deaf community.

Comment: Opposition to pediatric cochlear implantation within the deaf community is giving way to the perception that it is one of a continuum of possibilities for parents to consider. To ensure optimal use of the cochlear implant, parents need to remain involved in their child's social and educational development.

Arch Otolaryngol Head Neck Surg. 2004;130:673-677

From the Departments of Sociology (Dr Christiansen) and Psychology (Dr Leigh), Gallaudet University, Washington, DC. The authors have no relevant financial interest in this article.

THE TOPIC OF COCHLEAR implants has received intense scrutiny among deaf and hard-of-hearing persons, educators, parents of deaf children, and others concerned about the welfare and future of deaf persons and the deaf community.^{1,2} When it comes to cochlear implantation in children who are often too young to decide if this technology is something they want for themselves, there has been pronounced disagreement about the appropriateness of the

procedure.³⁻⁵ Most recently, however, there have been signs of changing perceptions, facilitated by the publication of new research data.

Because approximately 90% of parents who have deaf children are themselves hearing, the process of deciding whether to have their child undergo implantation is a particularly intense experience for many parents.⁶ Moreover, most of these hearing parents have had little, if any, contact with deaf persons, or scant knowledge or understanding of deafness,

Table 1. Main Reason for Deciding to Get a Cochlear Implant*

Main Reason Cited by Parents	% of GRI Sample†
Ease in development and use of oral spoken language	52
Child's safety or environmental awareness	25
To gain hearing	8
Child's expressed desire for an implant	6
Convenience in daily activities	3
Better future with more opportunities	3
Concern for child's self-image	1

*Data derived from the 1999 Gallaudet Research Institute (GRI) parent survey.

†Percentages do not add up to 100 owing to rounding.

before learning that their child is deaf.⁷ Many parents thus find themselves in a situation with minimal experience or knowledge on which to rely when they need to start making decisions about how to socialize and educate their child.

We began our research by designing a study to explore (1) how parents perceived their experiences as they navigated the diagnostic phase, (2) the decision-making process regarding cochlear implantation, and (3) the aftermath of implantation, including communication, education, and psychosocial issues. We also were interested in parent perceptions of, and interactions with, the deaf community. Finally, we wanted to see how initial parental perceptions and expectations about the implant were modified by subsequent experiences.

METHODS

This article is based primarily on 2 research projects approved by the institutional review board of Gallaudet University, Washington, DC. In the first project, which was conducted by the Gallaudet Research Institute (GRI) in the spring of 1999, a 12-page questionnaire entitled "Survey of Parents of Pediatric Cochlear Implantees" was distributed to 1841 parents of children with cochlear implants around the United States; 439 of these questionnaires were returned (24% response rate). About 95% of the parents who received the questionnaire had been identified as the parent of a child with a cochlear implant in a previous (1997-1998) GRI annual survey. (These annual surveys are short questionnaires designed to gather general information about educational services received by deaf and hard-of-hearing children and youth in the United States.) A small number of other parents who received the GRI parent survey were identified from other sources such as parent listservs. This comprehensive survey focused on such issues as preimplant hearing aid use, reasons for getting a cochlear implant, relationship with the implant center, insurance, education and communication, and postimplant therapy, progress, and satisfaction.

In addition to the GRI research, in the summer and fall of 1999 the authors conducted 56 interviews with parents of 62 children with implants (and 1 without) in 15 states and Australia, most of whom responded to a request for permission to interview that was included at the end of the 1999 GRI parent survey. The rest were primarily recruited through parent listservs. All but one of the parents we talked with in this second research project were hearing. The interviews with the parents lasted, on average, 90 minutes, were semistructured, and covered a variety of topics, including the initial reactions of the

parents to their child's deafness, communication modalities, their child's educational experiences, reasons for implantation, and retrospective observations. While we attempted to discuss the same general issues with all the families, because of time constraints and other factors it was not always possible to do so. Interviews were usually conducted in the interviewee's home and were audiotaped. All the audiotapes were transcribed, except for 2 cases in which respondents replied to the interview questions in writing because an in-person interview could not be arranged. In both studies, standard qualitative and quantitative software programs were used to analyze the data.

RESULTS

The children represented in our interviews ranged in age from 2 to 20 years, and the age at implantation ranged from 15 months to 17 years. Also, the "typical" child had received the implant at 4 years of age and had used the device for about 4 years at the time of the interview.

The parents of the deaf children we interviewed often had a difficult time determining whether their child was deaf. Of the parents who discussed this issue with us, about a third of them became aware of their child's deafness before the child was 12 months old, and about half learned of their child's hearing loss between 12 and 24 months. Only a small minority learned of their child's deafness after the child was 2 years old. As parents reported, part of the reason for the delay is because hearing parents do not usually expect to have a deaf baby, are not sure how much a child is "supposed" to hear in the first year of life, or even how a hearing infant typically reacts to sound. The problem is sometimes compounded by audiologists, pediatricians, educators, and others who may not always provide parents with the information they need.

Of the 26 parents who discussed their exploration of preimplant communication modalities (signing or speaking) with us, 15 said they received conflicting advice about which method of communication they should use. Parents are also confused by the need to choose education, including preschool, settings (segregated [deaf only] or integrated environments). They report that these choices are often presented by advocates of one approach or another in a way that makes it appear that no compromises are possible.

Once parents accept or otherwise become resigned to the fact that their child is deaf, they must begin sorting through the confusion and choices. Preimplant communication is very important to the parents with whom we talked, and getting hearing aids for the child and learning to sign are common first steps. According to the GRI study, 76% of the children used their hearing aids all day, every day, before implantation, and half (52%) of the children used some signing (not including cued speech) before getting the implant.

In the GRI survey, parents reported a number of reasons for choosing to have their child undergo implantation, as shown in **Table 1**. A desire to facilitate the development and use of spoken language, as well as safety and environmental awareness, is clearly the most important reason for implantation.

After deciding that a cochlear implant is appropriate, parents again have to make communication deci-

sions. Approximately 50% of the children sign after getting the implant, both at home and at school, indicating that their parents have no strong objection to their signing after implantation. According to the GRI survey, 47% of the children use signs, or signs with speech, in school. While some of these children may eventually stop signing as their ability to understand family members' spoken language increases (which was reported by a few parents), the parents of the signing children feel that signing is a vital part of their child's communication needs (along with speech and listening therapy).

One important area in which parents need to make a decision after implantation is the type of educational setting that is appropriate for their child. Based on the GRI data, parents enroll their children in different types of programs (oral and signing), as shown in **Table 2**. Mainstreaming with hearing students is the most frequent educational placement, but virtually all of these mainstreamed children continue to require services of some type.

Table 3 lists some of the support services that children with implants currently receive in school. The percentages in this table add up to considerably more than 100%, which indicates that many children use a variety of services in school after implantation. Parents note that receiving such services is particularly important because 59% of the children are judged by their parents to be behind their hearing peers in reading, and 37% are seen as being behind in mathematics (according to the GRI study). Therefore, it is not surprising that more than 50% of the parents we interviewed reported active involvement in the annual Individualized Education Plan meetings. Some parents elaborated on how they had to fight for appropriate educational support services for their child.

Based on our interview data, there is no simple, clear-cut relationship between implant-user characteristics and academic success. For example, of those children who are at or above the level where their parents would like them to be academically, some received their implants at a very young age, whereas others did not receive their implants until they were teenagers (and were doing very well academically long before implantation). Others have used sign language for years, whereas some do not sign at all, and some are doing very well academically even though they have stopped using the implant.

Well over half of the parents we talked with say that they still see their child as being deaf after getting the implant. These children are frequently not isolated from their deaf peers, nor are they isolated from hearing peers. Specifically, the GRI study found that 32% of the children with implants have only deaf classmates, 30% have only hearing classmates, and 38% have both deaf and hearing classmates. Moreover, most of the parents we talked with said that they were comfortable with their children socializing with deaf peers in addition to hearing peers. One parent of an 8-year-old girl who had been using her implant for about 3 years at the time of the interview said:

There's [sic] four deaf children in her classroom and 20 hearing kids. What a neat thing we've seen. . . . She can communicate with her peers and they can talk to her. It's wonderful. And

Table 2. Educational Environment Reported by Parent*

Current Educational Environment	% of GRI Sample
Fully mainstreamed with hearing children for all activities	34
Partially mainstreamed with hearing children (certain classes, activities, or times)	24
Self-contained classes of deaf and hard-of-hearing children	13
Commutes to residential school for deaf and hard-of-hearing children	10
Lives in a residential school for deaf and hard-of-hearing children	5
Other (eg, reverse mainstreaming with hearing children in a minority deaf classroom, playgroups, deaf/hard of hearing private school)	14

*Data derived from the 1999 Gallaudet Research Institute (GRI) parent survey.

Table 3. Support Services Reported by Parents*

Support Services	Children Receiving This Service, %
Sign language interpreting	40
Teacher aide in the classroom	37
Resource room help	28
Media captioning (closed/real time)	24
Itinerant teacher support	22
Remedial work/tutoring	17
Classroom amplification	16
Personal assistive device	15
Oral interpreter	13
Notetaker	11

*Data derived from the 1999 Gallaudet Research Institute (GRI) parent survey.

when the teacher is up front lecturing she has the [sign language] interpreter so she knows exactly. You know, she can hear the teacher, but not good enough to catch everything.

Even though the initial decision to get a cochlear implant for their child is generally not easy for the parents we interviewed, most of them said they are pleased with the results, with more than 50% stating that they wish that their child had undergone implantation earlier. According to the GRI survey, 62% of the parents wish that their child had undergone implantation earlier because they believe it would have better facilitated the development of spoken language. One year after implantation, 54% were very satisfied with their child's progress. At the time of the GRI study (1999), 67% said that they were very satisfied. This statement clearly indicates that it takes time to note improvement in the child's ability to communicate using the cochlear implant, although perceptions of satisfaction are also related to what parents initially expect, and to what they later come to define as success with the device. Moreover, most of the parents we interviewed said they would be disappointed, but accepting, if their child stopped using the implant in the future. One father said, "When she becomes 18 she might throw it away. I think I can live with that. Until she's 18, I'm God."

When the parents were asked about whether they had had contact with the deaf community before the decision

regarding implantation was made, according to both the GRI parent survey and our interviews approximately 50% of the parents reported that they had not previously met any deaf adults. The GRI survey found that 29% of the other parents had met deaf adults who opposed implantation of deaf children, 24% had met deaf adults who were supportive, and 16% had met deaf adults who were neutral. Another 6% had met with adults (or parents of deaf children) who had discontinued implant use. (Survey respondents were asked to select all sources of information. Thus, the total exceeds 100%.) Some of the parents with whom we discussed this issue reported positive experiences, while others who met deaf opponents of the procedure felt that their experiences were distinctly unhelpful. As one parent said, "When we spoke to the deaf community about the CI [cochlear implant] . . . certain members of the deaf community . . . their feelings were so angry and so hurtful. I mean, we were called child abusers . . . and butchers." In contrast, another parent reported, "It's important for the voice of the deaf community to keep people cautioned or aware of, wait a minute, slow down this speeding train."

COMMENT

Until recently, there was strong opposition in the deaf community to pediatric implants in contrast to the grudging neutrality expressed with regard to adult implantation. A 1991 position statement of the National Association of the Deaf (NAD)⁸ stated, "[The NAD] deplors the decision of the Food and Drug Administration [to approve implantation in children aged 2-17] which was unsound scientifically, procedurally, and ethically." Also, "The parents who make the decision for the child are often poorly informed about the deaf community, its rich heritage and promising futures. . . ."

The new NAD position paper on cochlear implants,⁹ issued in October 2000, reads, in part, "Cochlear implantation is a technology that represents a tool to be used in some forms of communication, and not a cure for deafness." Also, "The NAD recognizes all technological advancements with the potential to foster, enhance, and improve the quality of life for all deaf and hard of hearing persons." And finally, "The NAD recognizes the rights of parents to make informed choices for their . . . children, respects their choice to use cochlear implants and all other assistive devices, and strongly supports the development of the whole child and of language and literacy."

In an important way, the views expressed in the new NAD position paper on cochlear implants could make it easier for parents to decide to get a cochlear implant for their child. Why? Because changing views in the deaf community, as reflected in the NAD position paper, suggest that implantation will not irrevocably cut off a child with an implant from the cultural deaf community. Parents will feel less torn and rejected as they assess their decision, since they see themselves as providing additional options for their children in both hearing and deaf worlds.

While parents are not always comfortable about taking advice from deaf persons, it is nonetheless important to keep in mind that adult deaf persons know what

life as a deaf person is like. They have their own unique perceptions of the value of cochlear implantation, perceptions that vary considerably among those who are part of the deaf community, depending on the nature of their backgrounds and experiences. As a consequence, dilemmas faced by parents may be a little less difficult to resolve, because it is increasingly clear that many decisions related to implantation do not have the unavoidable "either-or" quality that many had previously assumed. For example, as noted earlier, having a cochlear implant will not inevitably separate a young child from the deaf community or from deaf friends; it does not automatically mean that a child will never sign and will have only hearing friends, nor does it mean that in classroom settings a child will no longer require support services.

Another example of the changing climate was the establishment of a Cochlear Implant Center at Gallaudet University in 2000 (the Laurent Clerc National Deaf Education Center). One of the purposes of this center is to educate children with implants in an educational setting that emphasizes both visual and auditory learning.

In light of these developments, we distributed a questionnaire to a mostly random sample of faculty, staff, students, and alumni in the spring and summer of 2000 to assess the changing climate at Gallaudet. One of the 9 statements on the questionnaire asked whether "Gallaudet University should do more to encourage students with cochlear implants to attend." Most of the deaf (54%), hearing (71%), and hard-of-hearing (65%) respondents agreed with the statement. Another statement in the questionnaire asked whether "[f]aculty and staff should be encouraged to sign with voice whenever possible in order to make the University more 'user friendly' for students who use voice communication more than sign, as many cochlear implant users do." In comparison to hearing (31%) and hard-of-hearing (24%) respondents who disagreed, a much higher proportion of deaf respondents disagreed (63%). Thus, while there may still be resistance in some areas to making accommodations for students with implants, the trend seems to be moving in the direction of inclusiveness rather than exclusiveness. Some respondents also added comments such as, "More parents are choosing to have their deaf kids implanted. That is their right to choose. Gallaudet needs to prepare to meet the needs of a more diverse student body if it wants to continue to exist." And, "I formerly did not support the cochlear implant as I felt it would destroy the deaf community. But now I respect individual choice and feel the cochlear implant is part of deaf culture, anyway. People's perspectives on deaf culture are different now."

Parents of deaf children are confronted with the need to make choices about issues that they may have seldom thought about before learning of their child's hearing loss. Objective advice and information may be difficult to come by, not only because parents are new to the field and may find it difficult to evaluate the quality of the information but also because the information itself may be presented in way that implies that there is only one "obvious" or "correct" way to proceed. Even though the samples in both the GRI parent survey and in our interviews were clearly biased in favor of implants (owing to the difficulty in recruiting parents with negative experiences),

the parents we interviewed often told us that they would like professionals to be more open about providing information on different options. Based on our research findings, these parents do avail themselves of a variety of communication and educational options. While support services in the mainstream (the most frequent educational placement reported by parents) may be less expensive than traditional residential schools, educating a child with a cochlear implant is by no means cost free. Consequently, educational costs of children with implants (including indirect costs to the family when one parent decides to quit his or her job to work with the child) continue to be an important issue.¹⁰⁻¹²

It is certainly true that implantation will probably make it easier for deaf children, especially those who receive implants before the age of 5 years,^{13,14} to acquire spoken language, depending on their ability to maximize implant use through intensive training. But it is also true that many deaf persons who do not use spoken language are leading very successful and productive lives. Clearly, many persons in the deaf community, including faculty, staff, students, and alumni at Gallaudet University, are much more open minded about cochlear implants today than they were 5 or 10 years ago, although some still question pediatric implants. Has the "cochlear implant community" changed, too, in reflecting more diversity in opinions? Does the cochlear implant community reach out to deaf community members who come seeking information?

What is most important, perhaps, is that we recognize that there are many different avenues to success. It is also important to acknowledge that early identification of hearing loss is crucial, that early communication between the deaf child and his or her parents and family is vital, whatever the communication choice, and that a lot of hard work on everyone's part is necessary to continue to foster the "common ground" that is emerging in the debate about the appropriateness of pediatric cochlear implants. Ongoing, important questions that everyone needs to be concerned about regarding the educational needs of children with cochlear implants are, "To what extent are schools and school systems with implanted children successfully meeting their needs?" "And, if some of the challenges are not being satisfactorily addressed, what policy and/or personnel decisions need to be made in order to enhance the educational experiences of these children?"

Submitted for publication August 4, 2003; final revision received December 15, 2003; accepted February 2, 2004.

We gratefully acknowledge financial support from Gallaudet University, Washington, DC, for research reported in this article.

This article is adapted from John B. Christiansen and Irene W. Leigh, *Cochlear Implants in Children: Ethics and Choices* (Washington, DC: Gallaudet University Press; 2002). Quotations are reprinted by permission of the publisher.

This study was presented at the Ninth Symposium on Cochlear Implants in Children; April 26, 2003; Washington, DC.

Corresponding author: John B. Christiansen, PhD, Department of Sociology, Gallaudet University, 800 Florida Ave NE, Washington, DC 20002 (e-mail: John.Christiansen@Gallaudet.edu).

REFERENCES

1. Nevins ME, Chute PM. *Children With Cochlear Implants in Educational Settings*. San Diego, Calif: Singular Publishing Group; 1996.
2. Niparko JK, Kirk K, Mellon N, Robbins A, Tucci D, Wilson B, eds. *Cochlear Implants: Principles and Practices*. Philadelphia, Pa: Lippincott Williams & Wilkins; 2000.
3. Balkany T, Hodges A, Goodman K. Ethics of cochlear implantation in young children. *Otolaryngol Head Neck Surg*. 1996;114:748-755.
4. Crouch R. Letting the deaf be deaf: reconsidering the use of cochlear implants in prelingually deaf children. *Hastings Cent Rep*. 1997;27:14-21.
5. Lane H, Bahan B. A review and reply from a deaf-world perspective. *Otolaryngol Head Neck Surg*. 1998;119:297-307.
6. Moores DF. *Educating the Deaf: Psychology, Principles, and Practices*. Boston, Mass: Houghton Mifflin; 2001.
7. Andrews J, Leigh IW, Weiner M. *Deaf People: Evolving Perspectives From Psychology, Education, and Sociology*. Boston, Mass: Allyn & Bacon; 2004.
8. National Association of the Deaf (NAD). Report of the task force on childhood cochlear implants. *NAD Broadcaster*. 1991;13:1-2, 6-7.
9. National Association of the Deaf (NAD). NAD position statement on cochlear implants. Available at: <http://www.nad.org/infocenter/newsroom/positions/CochlearImplants.html>. Accessed February 10, 2004.
10. Cheng A, Haya K, Rubin R, et al. Cost-utility analysis of the cochlear implant in children. *JAMA*. 2000;284:850-856.
11. Francis HW, Koch ME, Wyatt JR, Niparko JK. Trends in educational placement and cost-benefit considerations in children with cochlear implants. *Arch Otolaryngol Head Neck Surg*. 1999;125:499-505.
12. Niparko JK, Cheng AK, Francis HW. Outcomes of cochlear implantation: assessment of quality of life implant and economic evaluation of the benefits of the cochlear implant in relation to costs. In: Niparko JK, Kirk K, Mellon N, Robbins A, Tucci D, Wilson B, eds. *Cochlear Implants: Principles and Practices*. Philadelphia, Pa: Lippincott Williams & Wilkins; 2000:269-288.
13. Geers AE, Nicholas JG, Sedey AL. Language skills of children with early cochlear implantation. *Ear Hear*. 2003;24(suppl):46S-58S.
14. Spencer PE. Language development of children with cochlear implants. In: Christiansen JB, Leigh IW. *Cochlear Implants in Children: Ethics and Choices*. 2002: 222-249.