

# The Cochlear Implant Center, Surgery, and Short-Term Post-Implant Outcomes

The parents we interviewed reported choosing surgeons in many different hospitals for the cochlear implant procedure.<sup>1</sup> We asked parents what kind of advice and information they received from the implant center, if they felt they were an integral part of the decision-making process, if they felt there was some “pressure” from people at the implant center to go ahead with the surgery despite any misgivings they might have had, and how informed they were about the risks involved in cochlear implant surgery. Several questions on the Gallaudet Research Institute (GRI) survey also dealt with these and other issues related to the implant center.

Following a referral from their pediatrician, or from another physician or health care professional, some of the parents we talked with shopped around for an implant center. Most, however, simply selected a center near their home because it was the

1. These included hospitals in the following states: Alabama, California, Colorado, Florida, Illinois, Indiana, Iowa, Maryland, New York, North Carolina, Oregon, Pennsylvania, Tennessee, Utah, Virginia, and Washington. (One family had the surgery performed in Australia.)

only one available or because they had developed a good relationship with some members of the staff. Several families, particularly in the western part of the country, traveled a considerable distance for their child to get an implant because there were no implant facilities in their vicinity. The need for post-implant follow-up habilitation activities, including mapping and speech therapy, added to the travel burden for a number of these families.

The entire process from referral to surgery is fairly time-consuming, and usually involves an initial consultation at the implant center followed by audiological, psychological, and surgical assessments. Some of these activities may be combined in a single visit to the hospital; but, at a minimum, several months are typically required for the process to run its course. In addition, as will be seen, many parents we talked with had to spend a great deal of time struggling with their insurance carrier or their HMO to get permission to go ahead with the surgery. This was especially true in the late 1980s and early 1990s when pediatric cochlear implants were much less common than they are today.

Most of the parents we interviewed said that one of the things their implant center stressed was that positive results were by no means guaranteed and that there was considerable variability in the amount of success enjoyed by children after an implant, as reflected in current research literature (see chapter 9). Most of the parents also said that both the pros and cons of implantation were presented by the implant center and that they did not perceive themselves to be pressured to go along with the wishes of the center. Parents knew the decision was up to them. Moreover, most of the parents said that implants were not presented by the implant center as a “cure” for deafness. Many parents also said that the implant center made them aware of the position of many people in the deaf community regarding pediatric implants. The following are some of the comments from parents on these issues:

FATHER: [The implant center] would give us options and give us literature and then say, You make up your own mind. And I appreciated that . . . because I think we are intelligent, educated people, and were able to make an informed decision, but they wouldn't give us any real guidance at all. . . . Handing my child over to a surgeon was probably one of the hardest

things I ever had to do. And I don't know that they could have increased that doubt any more.

INTERVIEWER: So you don't feel . . . [the implant center] was forcing anything on you?

FATHER: No, not at all. I mean, it [was] totally the opposite. . . . They . . . really wouldn't give us any guidance, even when we asked them . . . it was frustrating.

MOTHER: I think they realized that it's a decision that you need to make as a parent . . . it's not a decision that anyone can make for you.

*Parents of a 2-year-old boy implanted in 1998*

They [the cochlear implant center] made me no promises. [As] a matter of fact, I really thought, Well, why didn't they try to get me a little more excited about this thing? . . . But they guaranteed me nothing. They did not bring my hopes up at all, . . . they said she will never hear like a normal person. The implant is not a cure. It . . . doesn't restore hearing. When it's off she is still deaf. She is still going to be deaf. And you don't know how her spoken language will be, or how she's going to do with it.

*Mother of a 2-year-old girl implanted in early 1999*

[At] our cochlear implant center, one of their requirements as you go through the evaluation process is that you read the papers of the NAD, the American Academy of Audiology, and the Cochlear Implant Club International, so you get the whole spectrum of opinion by doing that.

*Mother of a 6-year-old girl implanted in 1996 and a 2-year-old boy implanted in 1998*

The mother of a young boy who was implanted in 1996 said that, in the packet of information she received from the cochlear implant center:

MOTHER: There were two or three articles written by the deaf community; there was information from Cochlear, the company. They gave us names of other parents of children who had

the implant, and we were able to meet other children who had the implant and to meet the parents and talk to them.

INTERVIEWER: So [the implant center] encouraged you to talk with deaf people who were not in favor of implants?

MOTHER: They did. They really did. Whether they were in favor or not. They encouraged us to look at everything, they really did.

*Mother of a 4-year-old boy implanted in 1996*

At another point in the interview, however, the following exchange took place:

INTERVIEWER: Do you think the [implant center] was advertising their successes too much and not giving you a really objective picture of what to expect?

MOTHER AND FATHER (together): Yes.

INTERVIEWER: I wonder if their emphasis on the success stories is making it more difficult for parents whose kids are not quite at that level.

MOTHER: Oh, absolutely.

FATHER: Absolutely, that's what we felt. . . . Because of [the implant center] talking about the success stories, we came very close to saying we made the wrong decision . . . I do not think *we* made the wrong decision, but I sure wish we had a little bit more information at the very beginning. I think we still would have gone with the implant, but I think we would have made a few more right moves along the way.

INTERVIEWER: Do you think the [implant center] has changed its approach a little bit . . . their approach to parents?

MOTHER: Yes . . . they've definitely modified [their approach] because I met another mother whose son was trying to be in the candidacy program to get the implant and they wouldn't accept him because he didn't have enough communication.

*Parents of the same 4-year-old boy*

Although most of the parents said that the implant center they dealt with was even-handed in its approach, and that they

felt comfortable with the process, a few parents perceived some pressure or encouragement from the implant center to get the device for their child.

MOTHER: The medical community acted like, almost, we almost felt as though we would be neglecting him if we didn't follow through on the cochlear implant. It was really presented to us as a gift from God: Why wouldn't you do this for your child? Do you know how horrible it is to be deaf? We were given absolutely no negative information about it at all except for the fact that he would need surgery and general anesthesia.

INTERVIEWER: This was at the [implant center]?

MOTHER: Yes.

*Mother of an unimplanted boy*

I'm going to say that [the implant center] was the one who handed out the literature, both sides of it, so that we would be able to read and make the decision on our own. But they were like our parents, they were wanting to get it done, pretty much. You really wanted to think that they were looking towards his welfare, but. . . .

*Father of a 16-year-old boy implanted in 1995*

INTERVIEWER: Did you feel that they were pushing you to get the implant? Or do you feel that they were just giving information, making it possible for you to make the decision?

MOTHER: I think they were doing that. Obviously they were pro-implant. I mean they . . . had seen the results of the implant.

*Mother of a 10-year-old boy implanted in 1995*

Related to parent involvement, one question in the GRI survey asked parents if they felt they were "a vital and valued member of [their] child's CI [cochlear implant] team." Parents were asked to consider "the period from before the implant surgery through the habilitation and educational adjustment after the

**TABLE 5.1**

Professionals Affiliated with the Cochlear Implant Center Involved in Preparing for and Facilitating Child's Use of the Implant

Professionals at the Cochlear Implant Center	Percent of Parents Citing Professional Involvement
Audiologist	95%
Surgeon	86%
Speech pathologist	75%
Psychologist	35%
Teacher of the deaf	34%
Educational consultant	20%
Social worker	10%
Other professionals	3%

surgery” as they answered this question. Of the parents responding to this question, 96% said they either agreed or strongly agreed that they were in fact a vital and valued member of their child’s cochlear implant team. Moreover, more than two-thirds of the parents reported that they were well acquainted, or very well acquainted, with the members of their child’s cochlear implant team. Parents were also asked to identify the professionals affiliated with their child’s cochlear implant center “who were involved in preparing for and facilitating [their] child’s use of the cochlear implant.” Table 5.1 summarizes the responses to this question.

The results reported in table 5.1 are certainly not surprising, since surgeons, audiologists, and speech therapists are the people responsible for implanting and mapping the device, and for making sure that the child benefits from it as much as possible.

The GRI survey also asked if the parents were satisfied with the counseling they received from their child’s implant team before the surgery. Almost 90% reported that they were either satisfied (24%) or very satisfied (65%) with the counseling they received.

## Surgery-Related Issues

Almost all of the parents we talked with said they felt they were well aware of the potential risks of the surgery. Perhaps the most common concern was related to possible damage to the facial nerve, which lies close to the cochlea. If this nerve was damaged, some type of facial paralysis could occur. In addition, parents were generally aware of some of the limitations that would be imposed on their child because of the surgery, particularly the fact that a magnetic resonance imaging (MRI) of the head would not be an option in the future unless the implanted magnet were to be removed. Most of the parents understood that the surgery might not be completely successful. But, because they wanted to do what they could to enable their child to be able to hear as much as possible, parents said again and again that they felt the risks were acceptable.

FATHER: We realized that we were putting him in an operation, and if it wasn't successful he might lose everything. But, we just thought that the results could far outweigh the risk.

INTERVIEWER: What did the hospital tell you about the pros and cons of the implant?

FATHER: Well, they explained what could happen if something went wrong . . . during the operation. . . . And they told us about all [the plastic] playground equipment, about static electricity [that could damage the programs in the speech processor], they went over all that. And we took the steps . . . we gave away all his toys that were plastic and might cause some static. . . . The hospital didn't hide anything, they tried to tell us everything that might happen or could happen.

*Father of a 7-year-old boy implanted in 1997*

The GRI survey also dealt with the question of risk. One question asked: "When the implant surgery (initially) was performed, were you rather unfamiliar, somewhat unfamiliar, or very familiar with various POSSIBLE negative outcomes of receiving a CI [cochlear implant]?" Responses to this question are summarized in table 5.2. It should be noted that the various categories in the first column of table 5.2 were not explained (i.e., were not operationally defined) on the questionnaire. Rather, each respondent was left

**TABLE 5.2**  
Awareness of Possible Negative Outcomes of Implantation

Type of Possible Negative Outcome	Percent "Rather Unfamiliar" with This Outcome	Percent "Somewhat Familiar" with This Outcome	Percent "Very Familiar" with This Outcome
Auditory or audiological	5%	30%	64%
Medical or health-related	3%	26%	69%
Social	11%	38%	49%
Psychological	13%	39%	45%
Language-related	8%	36%	53%

to his or her own interpretation of what a negative auditory, social, psychological, or other outcome might be.

The vast majority of parents who responded to the GRI survey also reported that they were somewhat familiar or very familiar with each of these items as possible positive outcomes of receiving a cochlear implant. In general, parents reported that they were more aware of possible positive outcomes than they were of possible negative outcomes.

Although parents generally felt that the surgery was highly desirable, this is not the same thing as saying that it was invariably seen as necessary.

The mother of a young boy was asked if she saw implant surgery as elective surgery:

Oh yeah, yeah, yeah, yeah, yeah. . . . I mean we never felt that it was something we had to do. And that was probably part of the reason why it was a hard thing to decide, because here you are putting your kid under the knife, and is it something you really need to do? I mean it was really hard.

*Mother of a 13-year-old boy implanted in 1996*

Very few of the parents we talked with felt that implant surgery was absolutely necessary for their child to lead a productive and



satisfying life. Rather, most parents, after considerable thought and discussion, felt that, given their experiences, their assumptions about the role of hearing in the modern world, their family situation, and the opportunities they hoped would be available for their child, the surgery, however traumatic and nerve-racking it might be, was at least worth trying.

The mother of a young boy recalled her pre-implant anxieties in the days leading up to the surgery:

The whole week [before] . . . I really went through a whole reconsideration, like, he's perfect the way he is, why would we cut into his head? He's doing fine with sign language. What are we doing? We're changing him. It was really terrifying.

*Mother of a 5-year-old boy implanted in 1996*

Another mother, whose child was implanted in 1996, said, concerning the surgery:

We're setting [our daughter] up for her life having a medical need. . . . I realize . . . we're doing that, . . . but we thought even [when] she becomes an adult if she doesn't want [the implant] she can have it taken out.

*Mother of an 11-year-old girl implanted in 1996*

An important issue for many of the families we talked with was how they prepared their child for the implant surgery. Some families visited the implant center prior to the surgery, some said they used coloring books or other books provided by the implant center or from another source, and some used a variety of other creative methods to prepare for the surgery.

FATHER: We told [our son] all about what was going to happen. We took him down to the hospital [and they had] dolls and everything down there. They showed him all the gowns that would be used by the doctors and what he would wear. . . . That was explained to him before the operation.

MOTHER: [Our son] still has the coloring books the hospital gave him about the operation and implant and he still reads them occasionally. He knew he would have the same device his school friend . . . had, so that was great to him.

FATHER: [Our son] had very little language at the time [of the implant]. I want to say he understood . . . we were doing

something. But I can't exactly say that he knew exactly what was going to happen. I mean he didn't know down to the last detail what was going on. He just knew we were doing something and it was going to involve an operation because that was explained to him pretty clearly, I thought.

*Parents of a 7-year-old boy implanted in 1997*

One of the more ingenious methods of preparing their child for the implant surgery is described by the parents of a young boy:

FATHER: We tried to tell [our 7-year-old son] what was going to happen and we introduced him to another kid that had a cochlear implant and he was terrified. And . . . then we got him what they call a kid's kit from the Cochlear Corporation. And it was a little book which, of course, he wasn't able to read, but it had pretty pictures of a kid getting a cochlear implant. And it came with a little toy cochlear implant with a processor and headset and Velcro to attach it to whatever the kid's favorite little doll was. [Our son's] favorite thing was a 6-foot-long stuffed snake. . . . We brought this snake into the hospital for his speech therapy and we took the snake into the audiology booth and tested the snake's hearing and I, I am not kidding, we tested, we gave . . . the snake a hearing test. . . . He was supposed to rattle his tail when he heard sound, and he didn't hear anything! And so we reached the conclusion that his ears were broken, like [our son's], and then we went and took the snake to the doctor . . . in the clinic there, and we said, Okay, here's his audiogram, and of course there's nothing. His ears are broken. Can you do anything for him? Can you fix them? And the doctor looked at this and looked at the snake and took out his little otoscope and he said, No, there's nothing we can do. The only thing that might help him to hear is if he gets a cochlear implant. And [our son] was like, Oh, no! And then we told [him] they could do it right away. But his snake was going to have to stay in the hospital to get this done. He was going to have to [stay] overnight. Actually he had to stay over the weekend because speech therapy was . . . Tuesday. And Tuesday came and we went back to the clinic and the snake was waiting for us there with his head all bandaged up. And the doctor took his little bandage scis-

sors and cut the bandage off. And there was the snake's new cochlear implant. . . . We took the snake back to the booth and, lo and behold, the snake could hear.

MOTHER: Then. . . .

FATHER: . . . our son decided he . . .

MOTHER AND FATHER (together): . . . wanted a cochlear implant!  
*Parents of an 11-year-old boy implanted in 1995*

A few of the children in the families we interviewed experienced some complications with the surgery. One of the more serious complications occurred in a girl who was implanted in 1992. Part of the interview with the mother is as follows:

INTERVIEWER: Did you feel pretty apprehensive at the operation?

MOTHER: For the surgery, yeah, . . . and her facial nerve was damaged for probably . . . 8 or 9 weeks. It was horrible, it was just really bad.

INTERVIEWER: What happened?

MOTHER: Her eye wouldn't shut and [her face] drooped down so when she smiled only [one] side went up.

INTERVIEWER: So, what did they say about that? Did they say, Don't worry, it will go away, or what did they say?

MOTHER: No, they were worried. . . . They thought it would be permanent. They did some tests on the nerves, I don't know what you call it . . . and they thought it would be permanent.

INTERVIEWER: Did they tell you at the beginning this was a risk?

MOTHER: They did, but the doctor said, It's never happened to me.

INTERVIEWER: Did it clear up gradually?

MOTHER: Yeah, just kind of quickly [after about 2 months].  
*Mother of a 10-year-old girl implanted at age 3*

A mother of a son who was deafened by meningitis when he was 2 years old said she felt that the implant center was not

completely honest with her when he was implanted in 1990. She said that after the surgery started:

[My son] was in for about 2 hours when the doctor came out and said, We could only put in one channel. And I said, Why? He said, Because the cochlea was ossified. I said, Didn't you see that on the X-ray? And he said, Yes, but I thought that sometimes it's not solid, sometimes it's not hard, a lot of times, most of the time, it's soft . . . but his is just like bone in [the cochlea].

Later in the interview, the mother was asked if she had known that only one electrode could be implanted if she would still have gone ahead with the surgery.

MOTHER: I would not have gone through with it because . . . it's a big surgery to put him through. . . . You know, at least with 7, 15, 21 [electrodes] you have a chance of 1 or 2 or 3 working. But with one, you only have one chance.

INTERVIEWER: Do you feel like the doctor was honest with you about that, or do you think he was not?

MOTHER: I feel, really, that he was so eager to do it that he wasn't honest with me.

*Mother of a teenager implanted in 1990*

Most of the other complications or unexpected outcomes cited by parents were fairly minor and usually disappeared in a day or two. Some of the children experienced nausea, and in one or two cases postsurgical problems appeared to be exacerbated because, in this era of managed care, the hospital was in a rush to discharge the patient. Some parents were not completely prepared for what would happen after the surgery or what their child would look like.

The scar, the actual incision, is so much bigger, there is so much more hair that went, than I ever imagined.

*Mother of a 9-year-old girl implanted in 1994*

Most parents, however, were surprised at how quickly their child bounced back after the surgery. Some children were outside playing the next day and others returned to school within a few days after the surgery.

Most of the parents said that the surgery went smoothly and that all of the electrodes were successfully inserted in the cochlea. In the GRI survey, 95% of the respondents said that the electrodes were successfully inserted. Over time, however, some of the electrodes may stop working, either because they fail internally or because unpredictable interference among them can make it difficult for the user to interpret sound. About a fifth of the respondents in the GRI study said that some of the inserted electrodes were inactive, either through hardware failure or voluntary shut off. Another 10% said they were not sure whether or not any electrodes were inactive.

One issue that many people, including parents of children with implants as well as adult implant users, have concerns about is the question of re-implantation. That is, do the internal components have to be replaced periodically, or is it expected that they will remain implanted in the cochlea for the implantee's entire life? In general, the expectation, both from the implant center's perspective and from the patient or the patient's family, is that the internal components will not need to be replaced even though new developments in implant technology continue to be made. Rather, it is expected that any changes that occur will take place in the external components, particularly the speech (sound) processor. Indeed, many of the parents we talked with hoped that their child would be able to take advantage of new speech processing technology, including behind-the-ear (BTE) models that would make the implant more cosmetically appealing. Many parents said they hoped to purchase this new technology even if their insurance carrier refused to pay for it.

Concerning this issue, the GRI survey asked parents if their child's "device (internal or processing components)" ever had to be "upgraded or replaced." Virtually all of the respondents said that some upgrading or replacement was necessary. The vast majority of these responses focused on upgrading the external components, or even replacing cords that had been broken or lost, rather than replacing the internal equipment. Since parents were also asked to describe the circumstances of each upgrading or replacement, it is possible to estimate the number of devices that had to be replaced internally. There were 438 responses to the GRI survey that indicated a specific type of implant received by

their child.<sup>2</sup> From the comments made by parents, it is apparent that at least 25 (approximately 6%) of these implants had to be replaced internally one time. This is a conservative number since we only counted those comments in which there was clear, unambiguous evidence that it was the internal component that had to be replaced (e.g., comments such as “implant failed, internal failure” or “internally failed, was replaced as outpatient”). If there was any doubt about whether it was an internal or an external piece that needed to be replaced, we assumed that it was an external part. Thus, because of the ambiguity of a number of comments from parents on the GRI survey, it is likely that at least several additional devices needed to be internally replaced. In any case, this is somewhat more than the 1–2% device failure/ replacement rate commonly cited by implant companies, although it is less than the 10% replacement rate cited by one of the parents we talked with whose son was implanted three times.

INTERVIEWER: What percentage of devices fail, do you have any idea?

FATHER: The doctor in [city] who did the third implant said the literature you get from Cochlear and Clarion say they're 99%; he said actually it's like 90%. . . . So that's one in ten [that] will fail.

*Father of a young boy implanted three times*

The GRI survey also asked parents if the device had to be replaced or upgraded more than once. Again, using a very conservative estimate, it is apparent that at least nine (2%) respondents

2. Devices manufactured by Cochlear Corporation (Nucleus) were used by 358 children, implants manufactured by Advanced Bionics (Clarion) were used by 70 children, and implants from other companies (3M/House and Med El) were used by 10 children. One respondent did not specify the type of implant used. Most of the parents of the children we talked with also used Nucleus devices (Nucleus 22 or the newer Nucleus 24 model), which have been available for a considerably longer period of time than Clarion. Among the families we interviewed, the ratio of Nucleus to Clarion users was about 5:1; no implants made by other manufacturers were used by the children in the families we talked with. For many families included in both the GRI study and in our interviews, the Nucleus device was the only one generally available when their child was implanted. When a choice was available, many parents spent a considerable amount of time weighing the pros and cons (both cosmetic and technological) of each model.

needed to replace the internal device twice and at least one (less than 1%) needed to replace the internal unit three times.<sup>3</sup>

Another issue related to implant surgery that is of concern to parents is the question of which ear to implant. Not only must parents decide what type of implant to get for their child, they must frequently decide where to put it. In a few cases, the cochlear implant surgeon made the decision about which ear to implant, but in most of the families we discussed this with it was the parents who made the final choice.

Deciding which ear to implant is still far from an exact science, and the parents we talked with described a variety of reasons why they decided to have the implant surgery on one ear or the other. Many parents said they decided to implant their child's "worst" ear (in terms of decibel loss) so that, if the implant did not work as expected, then the "best" ear would be available for later implantation (or for continued hearing aid use). In recent years, it appears that parents and implant centers have been more willing to implant the "better" ear since the likelihood of implant success, at least to some extent, has increased, and because it may be desirable to implant the ear that has a better history (or memory) of auditory stimulation.

In some cases, major or minor medical reasons governed the choice. For example, in one family, meningitis led to more ossification of the cochlea in one ear, which necessitated implantation in the other ear, whereas in another family a pre-existing scar near one ear made it appealing to have the surgeon "use" the same scar for the implant surgery. In another family, X-rays of the cochlea in both ears revealed that the facial nerve was too close to the cochlea in one ear, and the surgeon wanted to avoid possible complications in that ear. A minor skull fracture on one side of the head resulting from a fall led to implant surgery on the opposite side of the head for a child in one family, and, in another, it was determined that, on one side, the mastoid bone in the skull was not thick enough to support the internal transmitter.

3. On this point, a recent article in the Health section of *The Washington Post* (Colburn, 2000) entitled "Wired for Sound," includes a sidebar with the heading: "Cochlear Implants at a Glance." The following appears as a caveat in the sidebar: "In about 5 percent of cases, reimplantation is necessary because the original device fails." No source is given for this information, but it is interesting that the percentage is very close to what is reported in the GRI study.

Although medical problems and issues were important for some of the families, much of the time they were not the major factors in determining which ear received the implant. Rather, social factors, including concerns about expected speech and language development, frequently entered into the picture.

A few parents said that they decided to have the implant on the right ear because they thought this might facilitate language and speech development, which is centered in the left hemisphere of the brain. Others decided on the right ear because of athletic concerns (such as a child batting right-handed in baseball or softball and having the implant on the right ear, away from the pitcher), or because it was thought that, in the future, if their child were to be driving a car, an implant on the right ear would be more practical for hearing other people in the vehicle. Another parent decided to have an implant on her child's right ear for a very practical reason: *I usually am using my right hand and carrying [my son] around on my left and I thought that his right ear is going to be most available to me.*

Cochlear implant centers now sometimes perform a promontory stimulation test to determine if implantation in one ear might be more desirable than the other. In this test, an electrode is inserted through the eardrum onto the promontory of the cochlea. Then, tests are performed to determine how the auditory nerve responds to an electrical signal. Presumably, if the response is significantly better in one ear, this might be an important reason to do the implant in that ear. But, there is still no one, single, overriding criterion that is used for determining which ear to implant, and parents and surgeons continue to use a combination of aesthetic, practical, and medical reasons when making the decision.

## **Insurance Issues**

A cochlear implant operation is quite expensive, and implantees and their families encounter additional expenses for postsurgical habilitation procedures, including frequent mapping (programming) of the sound processor and speech/auditory-verbal therapy sessions. At the present time in the United States, the cost for the surgery (including the cost of the device itself) is at least \$40,000. Since few families have the resources to pay for implant surgery themselves, the question of how to pay for the device is one that is of great



importance to parents and others contemplating implantation. Clearly, it was of concern to virtually all of the parents we talked with in our interviews.

It appears that about 1 of every 5 or 6 families we interviewed had significant problems getting their insurance carrier to pay for the cochlear implant for their child. Of the 52 families we discussed this with, 10 of them said that their insurance company or other medical provider refused to pay anything at all for the operation or for postsurgical mapping and habilitation (3 families), or would only pay after one or both parents spent a considerable amount of time on the phone, writing letters, making threats, or some combination of all three of these activities. Moreover, even when some of these recalcitrant insurance carriers finally did pay, they often did not cover the entire cost. In fact, several families we talked with said they have paid a great deal of money themselves for the surgery or postsurgery mapping and habilitation (primarily speech and listening therapy) expenses.

As far as the surgery/hospitalization is concerned, it appears that, in about 42 of the families we interviewed, their insurance company (or Medicaid or another public program) eventually paid 90–100% of the costs. In another 4 families, the insurance paid approximately 75–80% of the surgical/hospitalization expenses. Not all of the parents we talked with mentioned specific percentages, and, as noted, some of the insurance companies delayed paying for a considerable amount of time.

We heard some very interesting stories about insurance-related problems from many of the parents we interviewed. One mother said, *We went [to the hospital] that day for the surgery not knowing if they were going to pay for it or not. [And] we were prepared to take a loan out to pay for it. But the doctor's secretary came down into the waiting room and told us that she got the word that they were paying for it.* Another family got their insurance company to pay for everything, but, the father said, *then they promptly rewrote the insurance contract so that they would never have to pay for another. . . . In the paragraph where it says hearing aids are excluded . . . the new version [says] that hearing aids and cochlear implants are excluded.*

Perhaps the most important reason why a number of insurance companies delayed paying for the procedure was because it was

new and because no one had asked them to pay for it before. In a few cases, insurance companies delayed paying for the implant either because the device had not yet been approved by the Food and Drug Administration (FDA) for use in children or because the child was too young to be implanted according to the FDA guidelines (under 18 or 24 months, depending on when the surgery took place). Thus, it is understandable that, in some cases, a considerable amount of time was needed to secure approval for the procedure. To facilitate this process, the major cochlear implant companies, as well as many cochlear implant centers, now have specific offices or positions assigned to handle insurance-related problems and to secure payment from insurance carriers.

As noted, three families we met, in different parts of the country, were unable to secure any support from their insurance carrier for the implant. In all three cases, however, another agency or person, or even an entire community, stepped in and offered to pay for part or all of the cost of the surgery and hospitalization. The first family had to pay for the surgery themselves, whereas the local Lion's Club paid for the speech processor. The mother of the second family recounts her experience as follows:

When they did the implant the doctor explained to me that it was a \$24,000 surgery [about a decade ago]. . . . I didn't have the \$24,000. I said, If you will take my money every month, I will sign whatever it takes, and I will pay you. . . . I didn't have a husband, I didn't have nobody. It was just me and [my daughter] . . . and . . . my son. . . . And I said, If you're willing to let me sign . . . I will pay you a little bit every month. He said there was no problem with that. So I signed the papers. I was responsible for everything that went on at the hospital. After 2, 3, months, I think I made one payment, and the doctor . . . told me that I didn't have to pay [any] more because someone anonymously—I was not allowed to know the name—paid it off.

In the third family, the entire community came together to raise money for the implant surgery:

MOTHER: I called a lady in . . . a small town nearby who had done fund-raisers before and she told me how to go about it. . . . I asked some people in the community to be the administrators, to be the fund-raising committee, and any money that

was brought in, they were to be in charge of it. . . . From that, the church organized fund-raisers. The baseball team, the parents of the ball team that [my son] played on, they organized a softball game between a [city] TV station and a local industrial park softball team. And they played, and charged admission into the ballpark. . . . The local pizza place donated pizzas for them to sell by the slice. Hamburger joints here in town donated hamburgers to be sold at the concession stand. Everything that night, the money was for [my son].

INTERVIEWER: How much did they raise, do you remember?

MOTHER: Yes, I do. Forty thousand dollars . . . in 2 weeks.

Not all of the money was raised at the softball game, but additional community activities, including a carwash, food sales, and extensive media exposure, resulted in funds that are still being used (and anonymously replenished) today, more than a decade after the surgery.

## Post-Implant Expenses

As far as post-implant habilitation expenses are concerned, it is safe to say that, in general, insurance carriers were much less enthusiastic about paying for postsurgery habilitation costs, especially for ongoing speech or auditory therapy, than they were about paying for the surgery. This reluctance caused considerable consternation among a number of parents we talked with. These parents questioned why their insurance would cover the equipment itself, but not the programming and training that would allow their child to benefit from it.

Slightly less than half (between 20 and 25) of the 52 families we talked with about insurance-related issues said or implied that their insurance carrier paid for post-implant mapping and speech/auditory therapy in full (or close to it). In about the same number of cases, insurance companies paid for some, but not all, of the mapping or habilitation expenses. In general, insurance companies appear to be more willing to pay for mapping than for speech and auditory therapy, perhaps because they see the latter as a long-term commitment. Moreover, a number of parents said that

their insurance company would only pay for speech and auditory therapy expenses after a deductible had been met, or would only pay a maximum of several hundred dollars a year; anything beyond that was the parent's responsibility. In any case, it is clear that many of the families we talked with had to pay for much of the post-implant speech and/or auditory-verbal therapy their child received (outside of school) themselves.

[The insurance company] put a limitation on the amount of speech therapy a cochlear recipient can have. It's not adequate to get through the year at all. And we come out-of-pocket literally in the thousands of dollars for speech therapy for our children.

*Father of a 10-year-old girl implanted at age 4 and  
an 8-year-old boy implanted in 1996*

Another family said that, after the surgery, they started paying for speech therapy themselves. However, they soon noticed that their insurance policy stipulated that a maximum of 2 months of therapy would be covered. They subsequently got the company to pay, and, as the mother of the implanted child said, *once they started it I wouldn't let them stop. I said, You can't deny benefits based on services for a disability.* The father argued: *Are you telling me that you're going to pay for a prosthesis [the implant], but you won't pay for the training . . . to learn to use it? . . . Is that your position? And, ultimately, the insurance company that we dealt with didn't really have any experts who knew anything about it, and we went out and hired our own, and they filed reports, and they said, All right, we'll try it for a year and see if she improves.* Not surprisingly, the parents subsequently reported to the insurance company that progress was being made, and payments from the company have continued. Other parents also reported more success in getting their insurance company to pay for post-implant needs when the therapy is called "prosthetic device training" rather than "speech therapy."

As noted, another post-implant issue that is of importance to many of the families we interviewed is paying for upgrading the external speech processor. Most of the children currently use a body-worn processor that is about the size of a deck of cards. The alternative is a BTE processor that is more cosmetically attractive,

**TABLE 5.3**  
Post-Implant Medical Insurance Services

Medical Insurance Service	Percent of Parents Reporting Full Coverage	Percent of Parents Reporting Partial Coverage	Percent of Parents Reporting No Coverage
Implant reprogramming or remapping	58%	29%	13%
Post-implant speech production therapy	41%	34%	25%
Post-implant auditory habilitation training	42%	32%	26%

especially for teenagers, as well as more functional, particularly in sporting events. We asked parents if they have had any upgrades, or if any were anticipated, and, if so, if their insurance company would pay for it. In only a few cases did the insurance company pay for an upgrade or did parents expect them to. Rather, almost invariably, parents expected to have to pay for this significant cost themselves if it was not available from the cochlear implant company at the time their child had the surgery.<sup>4</sup>

The GRI survey asked parents to indicate whether their medical insurance provided full, partial, or no coverage for reprogramming/remapping, post-implant speech production therapy, post-implant auditory habilitation training, or for any other insurance-covered accommodations or services. Table 5.3 summarizes the responses to these questions.

4. Because of rapid changes in cochlear implant technology, some implant companies offer coupons, or other discounts, for new processors that are not ready for distribution at the time a person actually has implant surgery. In addition, if both BTE and a body-worn sound/speech processors are available at the time of the surgery, the implantee may be given both of them as part of the cost of the operation. Each sound/speech processing device must be programmed separately, however.

In addition to these services, a few parents reported that their insurance carrier also paid for such things as batteries, new cables or wires, and summer speech therapy. These findings closely mirror the findings in our interviews in that insurance companies are more willing to pay for mapping expenses than for speech or auditory therapy, and that many families incur significant out-of-pocket post-implant expenses.

The GRI questionnaire also asked parents how long, after the initial “hook up,” their medical insurance covered “CI habilitation services such as speech perception training and speech production therapy.” A little more than two-fifths of the respondents (43%) said that this benefit was provided for 6 months or less, whereas a little more than one-quarter (27%) said that nothing at all had been covered. Only about 30% of the respondents had habilitation services paid for, in whole or in part, by their insurance carrier for more than 6 months.

## **Short-Term Post-Implant Outcomes**

About a month after the surgery, implant patients need to return to the cochlear implant center to have their implant activated. This involves magnetically attaching the external microphone or transmitter to the internal receiver and programming or mapping the speech (or sound) processor so the implanted electrodes will be able to do the job they are designed to do: stimulate the auditory nerve endings in the cochlea and thereby enable the user to perceive sound. For virtually all of the families we talked with this was a very exciting time; the initial mapping session was the first time they would be able to see if the equipment actually worked as they hoped it might. Of course, many families realized that nothing dramatic might occur since the cochlear implant center had cautioned them against being too optimistic about what their child might be able to initially hear with the implant.

As discussed in detail in chapter 2, mapping is a complex process that involves establishing appropriate levels of sound for each of the implanted electrodes and making sure that the electrodes “work together” to enable the user to perceive sounds as clearly as possible. Under ideal conditions, the implantee is able to inform the audiologist doing the mapping when the sounds

(including pure tones at different decibel levels and frequencies) are too soft, too loud, or just right. Of course, there are other ways, such as closed- or open-set word tests or even simple conversations, to determine the extent to which the mapping for the cochlear implant is appropriate.

For a child, it is often difficult to achieve a good initial cochlear implant map because it is sometimes hard for the audiologist to know exactly what the child, especially a very young child, can hear. Many of the parents we talked with said that, although it was clear their child heard *something* at the first mapping session it was not always clear exactly how much was heard. Consequently, it was often necessary for them to return to the implant center quite frequently during the first 6 months or so to “fine-tune” the map.

We asked parents about their child’s first reaction at the initial mapping session. The vast majority of parents said that their child did in fact respond in some way to sound at the first mapping session; only three families said that there was no response at all. The most common initial reaction was crying, and about half of the parents said that their child appeared to be scared or frightened when sounds were first heard with their newly activated implant. A couple of parents said that their child was *overwhelmed* at the initial activation, whereas another parent said that their child signed *weird* when asked to describe what the sound was like. Not all of the children necessarily cried because they were frightened, however; as one parent said, her child cried and, at the same time, apparently *loved it*. About a quarter of the families we talked with said that the initial mapping session was uneventful; there was no dramatic scene at all, although it was clear that their child did perceive at least some sounds with the implant. And about another quarter said that their child was surprised or excited, or even laughing, at their first mapping session after hearing sound with the implant.

Many parents reported that their child heard new sounds very soon after the implant was activated that had not been heard with the hearing aids. Frequent mention was made of hearing doorbells, microwave timers, running water, telephones ringing, birds chirping, distant sirens, and other everyday sounds for the first time with the implant within a day (or less) to a month or two of use.

I took [my son] into the bathroom [halfway through the first mapping session] and he . . . reached up and flushed the toilet and he jumped, he was scared. . . . And then I went and I

flushed the toilet again [and] he was scared. And then he looked up and it was almost like he was afraid of the handle on the toilet, [but] he finally grabbed it and pulled. And it made the same noise and he jumped. Then he grabbed it again and pulled it and he started laughing. And I couldn't get him out of there.

*Father of an 11-year-old boy implanted in the mid-1990s*

What follows is a short sampling of some other "first-day" reactions to implant activation:

I think it was a bit scary, too, because when she got home [the first day] she didn't like the garage door opener when it opened. She cried, said not to open it. But she liked to run water and put my high heels on and click my high heels.

*Mother of a 7-year-old girl implanted at age 4*

On the drive home after the [initial] mapping I was sitting in the back seat and could hear the music and the music was beautiful and I was just going off, This is so awesome, this is so beautiful, and I could carry on a conversation with my mom and she was sitting in the front and I didn't have to read lips.

*Young woman implanted in 1996 at age 17*

I was driving on the freeway [after the first mapping session] and [my daughter] started screaming in the back seat . . . [because] the magnet had fallen off. She was upset [and] I put it back on. She laughed and laughed and laughed; she loved it. From the . . . very first moment she was so upset to have lost it.

*Mother of an 8-year-old girl implanted at age 2*

When I came in with him, and they turned it on, and gave him his first sound, he started saying, I hear that, I hear that. And that day he heard me tell him that I loved him for the first time. And he turned around and he told me back what I had said. . . . The first day it was turned on he understood that.

*Mother of a teenager implanted in the late 1980s*

Many of the parents we talked with said that the stated or unstated policy of the cochlear implant center where the activation occurred was to start slow and try not to overburden the



child with too much sound all at once. This often involved activating only some of the electrodes at the first mapping session and, even for those electrodes that were activated, setting threshold levels that would allow the child to become gradually acclimated to the new sounds. Although parents sometimes expressed frustration with this policy, since they wanted to see more dramatic, immediate, results, they also understood that it would take time for their child to adjust to the implant.

One of the first things that many parents tried to do was to get their child to respond to his or her name.

After 3 days, when I said [her name] she could turn around. . . . And within a week she would turn her back to us and we would say [brother's name] . . . and she would say, [brother's name], you said [brother's name].

*Mother of an 8-year-old girl implanted in 1996*

A few families said that after a while they noticed that their child was able to respond to sounds in another room. Sometimes this occurred within a few months or even sooner, but sometimes it took several years to reach this plateau.

We started with noisemakers [after a month or so]. You know, we would make noise and he would turn one way or the other, and then we started getting further and further away. And I would say within the first 2 months we could go to the bedroom and we would play a game. He would sit in here and listen and we would go to the bedroom and shake it and he would come running in, and my [deaf] mother was like, she was shocked to see that.

*Mother of a 2-year-old boy implanted in 1998*

It often took some time for the child to get used to new voices.

[My daughter's] first reaction, and actually for a long time [after that] was, I'm waiting for it to be a real voice. It's not a real voice yet. To her, I think, the sound that she had gotten from her hearing aids was real voice sound, and this wasn't a real voice yet. And that's what her reaction was.

*Mother of an 11-year-old girl implanted in 1996*

Almost invariably the progression was from hearing something to making an identification of the sound to, months, or sometimes

even years, later, understanding speech. Moreover, this progression usually did not happen naturally. Rather, parents repeatedly acknowledged that hours and hours of work, including regular speech and auditory therapy after the surgery, was necessary for their child to benefit from the implant. As one mother said: *Detection of sound doesn't mean comprehension. So we still had a lot of work to do [after the first day].*

Part of the development of speech discrimination involves the ability to hear high-frequency consonants that the child was usually unable to hear with a hearing aid. For some families, this development came rather quickly after implantation, whereas for others it was delayed for months or even longer.

The difference we see [that] the implant makes are things like, he never heard the 's' sound or 'ts' before and now he not only hears them but he is producing them. And that is a big difference. He now hears up into the 6000 hertz [cycles per second] frequency range whereas before he was only up to 2000 hertz, and he hears better at lower decibels, too.

*Father of a 2-year-old boy implanted in 1998*

MOTHER: One night [2 months after the implant was activated] we turned off all the lights and I was whispering a few words and [my daughter] was receiving everything I was saying.

INTERVIEWER: She was repeating everything?

MOTHER: Everything.

*Mother of a 3-year-old girl implanted in 1998*

[My daughter] could hear nothing for, I would say, for 3 weeks; we went back four times for mappings. This is unheard of . . . they couldn't figure out where she was. . . . She didn't hear tones, she heard nothing. Three or 4 weeks later she thought she discerned a beeping. . . . We've gone from . . . understanding speech and understanding stuff [with a hearing aid] to hearing beeping. . . . I mean, I was just beside myself; she had many, many mappings. . . . [My daughter] was all over the map, literally, in her mapping. Now she is doing quite well with the implant but it required 6 months to a year to differentiate between tones

and, ultimately, understand speech. Now she is functioning better than she did with the hearing aids.

*Mother of a college-age young woman implanted in 1995*

My speech got so bad [after the implant]. I felt totally cut off from everyone. But I never reached the point that I thought it wouldn't get better. I never got to the point where I was really concerned. I said, I'll just give it 3 more weeks . . . then I said, just 4 more weeks. Also, I remember my experience with the transonic [hearing aid] and how difficult it was to adapt to that. It was horrible the first 2 to 3 months, just like the implant, then it got better.

*The same college-age young woman implanted in 1995*

Not all of the children initially liked wearing their implant, perhaps because they did not like the sounds they were hearing or were otherwise uncomfortable with the device. Consequently, sometimes parents had to resort to bribery to encourage their son or daughter to continue to use the implant. As one mother said: *It took a lot of months of bribery and stickers and just [trying] to motivate [my son] to wear [the implant]*. Another mother had to resort to similar tactics to get her daughter to use her implant, which she hated at first. In this case, the carrot was a Barbie doll. Others said that it took some getting used to and that a break was frequently needed. Even the young woman who found music so awesome on the first day said: *Sometimes I just don't like to study with my implant on. I just take it off because it's so extremely quiet. I still . . . like doing that. It's nice to have the freedom to be able to take it off and not have to hear anything*. On the other hand, one child liked her implant so well, she insisted on sleeping with the external equipment attached.

## Conclusions

There seems to be no one dominant type of post-implant outcome among the families we interviewed. Most young children heard some sounds, especially environmental sounds, more or less right away, whereas a few did not hear anything at all for several months. The most common description that parents offered of their child's progress with the implant was that it was quite slow

and gradual, and that considerable post-implant habilitation was needed. It frequently required 6 months or more before the child was able to respond to his or her name, clearly distinguish among voices, and understand at least some speech. After time, though, most of the families we talked with said that their implanted child could clearly hear much more with the implant than they could with a hearing aid.

A lingering problem mentioned by many parents is the fact that it is often difficult for their child to hear in noisy situations, and it is hard for them to interact with strangers, with those whose voices they are not familiar with. Although these limitations are evident during the first 6 months after implantation, they tend to linger, in some cases for years, in many of the families we talked with. Clearly, few implanted children have “normal hearing” with the implant, and most of them continue to rely on lipreading to a considerable extent for communication.