

A Look at the Decisions Hispanic Families Make After the Diagnosis of Deafness

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An Introduction to the Sharing Results Series

“Sharing Results” is a series of occasional papers that describe the results of work undertaken by the Laurent Clerc National Deaf Education Center in its three priority areas of literacy, family involvement, and transition from school to postsecondary education and employment. The focus of each of these papers is determined through an extensive public input process with parents, educators, service providers, and researchers throughout the country. The Sharing Results series includes three kinds of papers:

1. descriptions of critical needs in the Clerc Center’s priority areas and the processes used to identify those needs,
2. descriptions of the results of collaborations between the Clerc Center and other schools and programs to develop and implement innovative approaches to some of the persistent challenges of the Clerc Center priority areas, and
3. extensive descriptions of the evaluation of selected innovations to provide information to help program planners determine whether an innovation would be appropriate for their program.

It is hoped that the Sharing Results papers will provide valuable information and ideas to parents, educators, service providers, researchers, and others interested in the education of deaf and hard of hearing children.

Note: Copies of the Sharing Results papers can be ordered through the Clerc Center. To order printed copies of these documents, or for a complete listing of other Clerc Center publications, please contact:

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Vivian Ruperto, B.A., was a research assistant at The Deafness & Family Communication Center at the Children's Seashore House of The Children's Hospital of Philadelphia. She contributed to both the data collection and analysis phases of this research.

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Introduction

The diagnosis of a chronic condition in an infant or child can have a profound impact on a family. When a child is diagnosed with a hearing impairment, a family can experience a range of emotions, including grief, anger, guilt, helplessness, and confusion. And the family's response to a child's disability can be influenced by the family's cultural background. Factors such as a culture's language, family structure, and beliefs about health and healing, among other things, can shape the family's decisions regarding a disability.

Since individuals of Hispanic descent constitute the largest minority group in the United States, the authors were interested in how Hispanic parents make decisions for their deaf or hard of hearing child with regard to using early intervention services and entering school. (A previous study with non-Hispanic families indicated that it is at these transitional points that choices are made that will impact the direction of the child's life.)

When a child has a hearing loss, parents need to decide how they will communicate with their child, how the child and the parent will learn to communicate effectively in the chosen modality, whether the child will use hearing aids or other assistive devices, whether the child will get early intervention services, and where the child will go to school. Embedded in the decision about school are other important decisions: whether the child will be in a class with other children with hearing loss or integrated into a mainstream classroom, and whether the child will receive special services to ameliorate the hearing loss. Early intervention and school decisions also often require collaboration between parents and the state, county, or local school system.

This paper is based on a study that examined the decision-making process for Hispanic families living in the United States who have a child with a hearing loss. Twenty-nine families in four different geographical areas shared their experiences in learning about their child's disability, searching for appropriate interventions, and making choices regarding communication and education. The authors explored the impact of language, culture, minority status, and access to information and services on the decision-making process.

As described in the families' own words through semistructured interviews, the decision-making process for a child with a hearing loss is a complex one. It is a process affected by information and resource availability, including the quality of the information provided by professionals and other sources, the parents' ability to acquire information and services, the parents' personal preferences and values, their decision-making style, and their beliefs about the causes and consequences of deafness. In the interviews, parents shared information about their feelings and the information available at the diagnosis of their child's hearing loss, language difficulties and preferences, how they chose communication methods, their outlook on school choices and advocacy, their opinions about cochlear implants, the role of church and faith, and their feelings of satisfaction or dissatisfaction. The interviews were conducted and translated by individuals who are fluent in Spanish and familiar with the Hispanic community.

Although shared decision making between parents and professionals is often seen as the desired model (Charles, Gafni, & Whelan, 1997), this document shows that there are barriers that sometimes prevent parents from participating fully in the decision-making process. The authors

explored to what extent access to information—a requirement for shared decision making—is blocked in the Hispanic community by language and cultural factors, as well as by the limited availability of resources and knowledge of legal rights.

The parents' experiences can heighten service providers' awareness to issues that are important in the Hispanic community. While more specific examples are provided in **Section 3: Implications for Service Providers**, in general it is recommended that professionals consider the language and cultural needs of the Hispanic community and ensure that all available information is provided in a culturally and linguistically accessible form to parents making decisions for their deaf and hard of hearing children.

Throughout this document to ensure anonymity, non-relevant demographic and job information has been changed, and pseudonyms and general terms are used for names, hospitals, schools, and places.

The words (in italics) of eight families are presented. These eight families are representative of the 29 interviews conducted, and they demonstrate the uniqueness of each individual case and the diversity of experiences among Hispanic parents of deaf and hard of hearing children in the United States. The families interviewed in this study resided in Florida, Texas, California, and Pennsylvania, areas chosen to sample the experiences of families who had both emigrated from different countries and settled in different communities throughout the United States. More information about the background and interview process of the study is provided in **Section 4: Background and Additional Information About the Study**.

This document is organized first by topic, and then includes comments from the families. If you would prefer to read the comments in full from each family, please see the **Full Family-by-Family Version of this Document** in the **Appendix**.

Section 1: Descriptions of Families

Family 1

The interview was conducted in Spanish with the mother. F is a 6-year-old boy with a severe-to-profound hearing loss. He lives in Florida with his mother, 14-year-old sibling, and cousin. No other family members have a hearing loss. The mother has completed two years of college and works outside the home. The family speaks primarily Spanish in the home, but mixes in English. The children speak English well, and the mother says that her 14-year-old son, who has normal hearing, speaks Spanish *very poorly ... his first language is English*. The family moved from Puerto Rico when F was born.

Family 2

The mother and father were present for the interview, which was conducted in Spanish. T is a 7-year-old boy with a severe-to-profound hearing loss. He lives in Florida with his parents, brothers, and sisters. The mother is a homemaker and the father works in a blue-collar position. The family moved from Puerto Rico six years ago looking for better services for their child, although at that time hearing loss had not been confirmed.

[Father speaking] [We moved] *primarily, because in Puerto Rico we knew he was going to be marginalized and we knew that here we were going to find better services related to doctors and education.*

The parents suspected deafness because T did not babble and had a high-pitched cry. In addition, as a result of birth complications, he had been in intensive care and had received medication that could have been ototoxic. The parents attributed his hearing loss to this medication, but later learned that he had other congenital problems that suggested he might have been born deaf.

Family 3

Both the mother and father were present for the interview, which was conducted in Spanish. S is an 8-year-old girl with a profound hearing loss. She lives in a small town in Texas with her parents and a 1-year-old sibling. The mother is a homemaker and the father works in a skilled trade. The family moved from a small town in Mexico seven years ago looking for a better life and a better job.

[Mother speaking] *In Mexico there are no possibilities for a good life. There aren't many jobs out there, the pay is very low. It is very difficult to live in Mexico.*

The parents speak only Spanish, but say that S is learning more English than Spanish in school.

Family 4

The mother and father were present for the interview, which was conducted in Spanish. M is a 12-year-old boy with a severe hearing loss. He lives in Texas with his parents and a 17-year-old sibling. Both parents work outside the home. The mother is a bookkeeper and the father is starting a business and currently works in a restaurant. The family moved to the United States from Mexico four years ago.

[Mother speaking] [A son] *should be the priority, right?*

[Father speaking] *We had the option because when we realized that he was not hearing well he was about a year old. Since he was born in [a city in Mexico], we didn't really know if he could hear or not. There the doctors in [that city] are more deficient. They didn't take the precautions to find out. When he was about a year and three months, he entered school. Since that time he has been in school with speech therapists and all those things. He was in a special school for deaf kids.*

The parents speak Spanish in the home, although the mother says she fully understands English, studied English at a community college for one year, and is taking a course at a college. The father said he understands spoken English better than he reads English. *My English is about 50 percent*, he says.

Family 5

The mother and father were present for the interview, which was conducted in Spanish. H is a 6-year-old boy with a severe hearing loss. He lives in California with his parents and a sibling. The mother is a homemaker and the father works in construction. The family moved to the United States from Mexico before H was born.

[Father speaking] *Well, I came here when I was about 18 years old. I came here to work, to help out my family but then later I got married and well I thought that this was the best place to live.*

[Mother speaking] *... for a better future.*

The family speaks Spanish in the home. The father said he speaks *a little bit* of English, but the mother does not.

Family 6

The mother and the community facilitator for this project (who is deaf) were present for the interview, which was conducted in Spanish. P is a 4-year-old girl with a profound hearing loss. She lives in California with her mother and father, an aunt and uncle, and three cousins. The mother is a homemaker and the father works in a skilled trade. The aunt and uncle work in a restaurant. P was born in the United States. Her mother moved from Mexico 10 years ago with her parents, who moved for economic reasons. The mother said she speaks English with P, but Spanish with her husband.

Yes, [my English] isn't that great, but I am able to communicate, and I understand it very well.

Family 7

The interview was with the mother and was conducted in Spanish. B is a 10-year-old boy with a profound hearing loss. He lives in Pennsylvania with his parents and three siblings. The mother is a homemaker and the father is disabled. The family speaks Spanish at home, although the younger children also speak English. The family moved from Puerto Rico two years and five months prior to the interview because of B's hearing loss.

We came to the United States because of the child, because of his disability. He is deaf. For a while I was thinking about coming here because they say that, in the caring for handicapped children, there is a lot of help here and the doctors help a lot where my country is a little behind. Over there the child was in a school where there were a lot of children with different disabilities. So I thought that a lot of children with a lot of disabilities, it couldn't work; it's too limited. They should be, each child should be with children with the same disability because that way the professionals can get to them better.

Family 8

The mother was present for the interview, which was conducted in English. J is a 10-year-old boy with a profound hearing loss. He lives in Pennsylvania with his mother and three siblings. The mother works in a factory and the father works in construction. The mother was born in the United States, and J's father was born in Puerto Rico. The family speaks English in the home. The mother said she speaks, but does not read, Spanish.

Section 2: Study Results—In the Families’ Own Words

(Please note: In the on-line version of this paper, clicking on the bold, underlined **Family Number** will access the description of the family as presented in the **Descriptions of Families** section, as well as a complete dialogue with that family. In the printed version of this paper, please see the **Full Family-by-Family Version of this Document** in the **Appendix**.)

Events and Emotions Surrounding the Diagnosis

The Hispanic parents in this study related many of the same difficulties in obtaining a diagnosis as have been related to the authors by non-Hispanic families, particularly the problem of professionals dismissing parents’ observations without necessary follow-up or attributing the child’s unresponsiveness to something other than hearing loss, such as mental retardation. However, the problems faced by Hispanic parents are often exacerbated by language difficulties and by limited access to health care services.

For most of the families in this study, the diagnosis of hearing loss was obtained in the United States (69 percent), although the primary factor motivating many of the families to leave their home country (in most cases Puerto Rico or Mexico) was either the suspicion or confirmation of hearing loss. The families believed that the opportunities, resources, and services for deaf and hard of hearing children were superior in the United States and that their child would face less discrimination than he or she would in the native country.

Family 1: Shortly after the family moved from Puerto Rico, it became apparent that something was wrong when F slept through a loud fire alarm.

[Mother speaking] I went to the pediatrician, and I told him all what had happened, and that everyone was telling me that there was something wrong with my baby, and that perhaps it was mental retardation, I never thought that it was because of his ears and then I took him to the health center...and the doctor told me that there was nothing wrong. Some time went by. When he was 7 months old I took him again for his medical appointment for his vaccinations and I told the doctor, ‘My baby is not like other babies, something is wrong with him.’ And he told me, ‘I’m the doctor, you are a mother, you are not a doctor.’ But I told him, ‘I have four children, and this baby is not the same.’ And he told me, ‘I am telling you that mothers see things in their children that they do not have. Your son is fine.’

I went to the emergency room and registered him as if he had spent the night very ill and I said to the lady that he had been very ill all night. When I went into the emergency room, the doctor asked me what was wrong with the boy, and I was crying and I told him, ‘I think my baby is deaf because I talk to him and he does not turn around and I give him books that make music and things that make sounds and he does not look at them.’ I had him sleeping on my lap and the doctor clapped his hands and he gave me a referral and sent him [to the hospital], then he told me that he had a problem. I took him there and then that is where they did the evaluations, they checked him and that is where they confirmed to us that he

was deaf. The diagnosis was a severe-to-profound hearing loss in both ears, more in the right than in the left one.

The mother said when she first told F's father that F was deaf, he blamed her and refused to accept the diagnosis. A few months later, F's father came to visit from [another country] and later decided to move to the United States and learn sign language. After some medical testing, the mother was told that F's deafness was due to measles and a high fever that he had contracted when he was 2 months old.

The mother said she felt guilty when she found out her child was deaf.

I felt guilty because ... I don't know why. ... when I had [my older child] I said I would have no more children, but I got married again, and after five years my husband kept on saying that he wanted a baby, a baby, a baby, a baby, a baby. ... I was told that women must have their children when they are young. My own mother was quite old-fashioned and said that older women have children that are born retarded, that they aren't born healthy, that they must have their children in their 20s, and that is how my grandmother and my mother were, and I thought this was the right way to do things. And so I thought, 'Look, I had this child when I was 34 years old, and look, he was born deaf.' So, I felt guilty, because in order to satisfy my husband and have a baby, he [the baby] has to suffer, because I am not the one who is deaf, and although I try, and do everything I can for him, it's his life. He's my son, I'd like to hear for him, or give him my ears, but he's the one who is deaf, not me.

Family 2: Shortly after arriving in the United States, T's hearing was tested and he was found to be deaf. After that, the parents took him to an audiologist where a profound hearing loss was confirmed. T was nearly 2 years old at this point.

[Mother speaking] When I asked the doctor what were the alternatives, she told us there were no alternatives—only the hearing aids that cost almost \$2,000. We did not economically have \$2,000. We were at the mercy of the medical insurance if it would cover it or not because there was no more help.

With the diagnosis, the mother said she felt as if *walls fell down*.

... We had a tendency to think that everything is okay and I thought everything was okay, and then you know how I think, now this.

Family 3: The parents first began to suspect hearing loss when S was 2 years old because she wasn't talking or paying attention to them. Although the family was living in the United States, they lived near the Mexican border and they took her to a doctor in Mexico, who referred them to an ear, nose, and throat doctor (also in Mexico). The doctor told them S was deaf.

[Mother speaking] It was very bad for me because I was not expecting it. All of a sudden he told me that my daughter could not hear anything and that she would never be able to speak ... those were his exact words. He did not even examine her. The first time we went to him, he did not [examine her], he only checked her as he would have for any other illness, such

as a cold, and later he said, 'The child does not hear and that is why she does not talk.' He said, 'She does not hear a thing and if she does not hear a thing, she will not speak a thing.'

After hearing this news, the mother talked to an aunt who lives in another state; the aunt called the school nurse at her son's school, and the school nurse called the school near where S and her family lived. The school contacted the mother, ran some tests, and then referred her to a program, which sent her to a city in a different state for hearing tests. The tests showed that she was *almost completely deaf*. It was about two months after the initial diagnosis that they received the conclusive diagnosis. They also took her to a second doctor in Mexico, who gave similar test results.

Both parents said they felt very sad when they learned of their child's deafness.

[Father speaking] *We think the worst, that she may not be able to speak, that she will not be able to study, that is the first thing that comes to your mind.*

Family 4: The parents first realized M had a hearing problem when he was 1 year old because he was very quiet.

[Mother speaking] *My family is very expressive and shows many expressions of affection, and when we were playing around, I noticed my son made a great effort to laugh. I noticed he wasn't able to make basic sounds, no 'papa,' just 'ab-ab-a.' And he would babble very little. A year later he continued to babble 'aba,' instead of 'agua' [water]. That is why I thought he had no residual hearing back then. Then I took him to his pediatrician and he told me not to worry. ... Another thing he asked was if I had any deaf people in my family and then he said, 'Do not worry, there are some kids that start talking late or maybe they have a problem with their tongue, what they call a tied tongue.'*

The doctor recommended that they see a speech therapist. After four months, there was little progress.

[Mother speaking] *Then [the speech therapist] told me, 'You know your son has a problem. I am going to ask you to take him to a neurologist.' That was when we brought him here [to the doctor], they did an evoke response test and they told us he was deaf. We took him to the doctor, with a neurologist, in [a city in Mexico]... when he gave us the news, it was like a bucket of cold water showered us. 'Your son is deaf. You have to take him to an institute so he will learn to talk.'*

The parents said they were at first disturbed to learn of their child's deafness, but then became optimistic.

[Father speaking] *It was very traumatic, because one sees the problems sometimes with a certain kind of stigma that you will say, 'Oh, what am I going to do?' One thinks that we're just going to draw on our glass of water and sometimes that is not the truth. We have learned how to live and we are very happy with the kids, and we realize that there are many ways and other sources that we can help him with so he can progress and succeed, and I*

think they are doing it right now. There is hope there. We have hope. M is really progressing right now and we're just waiting for something new to come out. This is our hope.

[Mother speaking] We just felt that he was going to suffer a lot. We thought that he was, that it's going to be all right, then at the same time we thought that we have to help him out, we have to do something about it. We are very happy. We have a great family. We are a good couple. We have a great marriage. We talk to our [other] son, and we told him the news that his brother was deaf. We were all very sad because he's a kid that has his limits now, but if you think the positive way and you analyze, one has to be calm in this kind of situation. We have to look for the solution. If a door is closed, we have to go and see if there is another one open and that's the only way that we're going to be able to help him.

In contrast to many of the other families, Families 5, 6, and 7 had relatively little difficulty in obtaining a diagnosis. Family 8 experienced difficulty because of the progressive nature of the child's hearing loss.

Family 5: The mother first suspected hearing loss when H was about 16 months old, and she and her sister noticed that H was not trying to speak. She took him to an ear, nose, and throat specialist in Mexico who told them that H had a hearing loss.

Both parents said they felt very sad upon learning of H's hearing loss.

[Father speaking] Well, first it was very sad and they were in Mexico and I was here working and so I decided that it would be more beneficial for him to be in this country. He was born here so I thought, you know, he could study here and go to school here because the person I knew in Mexico who was deaf, a lot of people ignored him and they didn't have respect for him. So I didn't want that for my son. So that's when I decided that he should come here so he could go to school here.

[Mother speaking] Well, I also felt very sad. Well, I also knew deaf people in Mexico and they don't know how to communicate, they don't know sign language, they don't have any language. They try to speak but you can't understand them. So I thought being here, he would have a better future and everything would be closer to him and, you know, if we stayed there, we wouldn't be able to get into the state he had to go to, to go to school, and really, economically, it would just be too difficult. So I decided that this was the place for him.

Family 6: Hearing loss was first suspected when P was about 6 months old. P's grandmother noticed that she was not reacting to loud noises. The parents took P to the pediatrician who told them she might have a hearing loss.

[Mother speaking] The pediatrician said that she might be deaf. After that came the other tests and everything.

P's hearing loss was confirmed when she was 7 or 8 months old.

The parents said learning about their child's hearing loss was difficult.

Well, at first it was very hard because, you know, we come from a world where we are used to communicating using our words and our voice and we just weren't used to that kind of thing, and it's very hard because now we have to learn a whole different language to be able to communicate with her.

Family 7: The mother learned before B was born that there was a Rh incompatibility and that the baby was likely to have "problems." At birth, he was found to be deaf and have other medical problems.

The mother's feelings about her child's hearing loss were overshadowed by concerns about his overall health and well-being and his other disabilities.

It wasn't easy ... I felt sad. I was crying a lot. I was very worried if his operation was going to leave him crippled because, as they said, the diagnosis of the child was that he was going to stay crippled in the bed and that he wasn't going to be able to do anything. So when they told me that, I got so worried that he would come and that he would stay in the bed and all since a condition like that is very difficult.

Family 8: The mother suspected a hearing loss when J was 1 year old because he *wasn't like my other children*. When he was 6 months old, J was sick with a high fever.

That's not normal for a 6-month-old child. I knew something was not right and that's when I started taking him to the doctors, trying to find out if that fever had caused anything else. And that's how I found out that he was, you know, will not hear. So they started testing him ... they kept testing and testing. That is when they told me that he was, you know, completely deaf.

The mother reports feeling sad when she learned about J's hearing loss and also upset that the doctors had not paid closer attention after he had the high fever.

At first I was sad, but I mean that's my son. I love him. I mean it was harder more for him than it was for me, and all the signs I had to learn, I learned from him because he taught me, but I mean you learn to deal with it. ... [I was thinking] that he wouldn't be able to hear me say I love him because at the time I didn't know sign language, so I didn't think he would ever hear me say 'I love you' or, you know, go, you know, dance and party and, 'I want you to play with me,' you know, stuff like that where music is always involved when it comes to kids. And the birds chirping, because he loves the park. He's a park freak. He loves it, and I mean, I always figured he wasn't going to be able to hear certain things that I wanted him to hear. So I was sad for him, not so much for myself because no matter what, he's my son, I will always love him, but I was sad for him because I would think that he was going to miss out on...so it made me feel sad.

...I feel like it should have never happened. The instant that he had a fever of 110, they should have kept on checking because, I mean, a fever of 110, I mean that causes something, especially on a 6-month-old baby, and they just kept dismissing it as though it was just ear infections, and I feel as though they should have checked a little more deeper into it.

Language Differences at Diagnosis and in School

Language differences presented significant obstacles to many of the Hispanic parents. Hispanic professionals (counselors, audiologists, nurses, teachers) were most effective at reducing the impact of language differences. When Hispanic professionals were not available, interpreters were also useful, although in this study parents seemed to develop more trusting relationships with professionals with whom they could communicate effectively and comfortably. Even parents who spoke English relatively well seemed to benefit from interaction with Hispanic professionals, suggesting that much more than linguistic fluency or comprehension is involved.

The inability to communicate in English affects more than the relationship between professionals and parents. This study indicates that parents who are unable to take full advantage of information and resources in English tend to experience a narrow perspective of the options available and a more limited perspective of prognosis and the future potential of their child. This can be seen from the moment of identification of the hearing loss forward.

One mother's inability to comprehend an English word was perceived by the physician as denial. If he had had access to her primary language and culture, he would have discovered that it was she who aggressively pursued the identification of the hearing loss. From her initial encounters, this mother was misunderstood, and critical opportunities for optimal parent-professional collaboration were lost. Parents' fluency in English lessens this obstacle, but some families prefer important information in their native language regardless of their linguistic fluency. In fact, several of these families residing in the United States traveled back to Mexico to obtain the diagnosis. To underscore the individual nature of the preferences and needs of parents, one of the parents who received the diagnosis in Mexico reported that even though she received the diagnosis in Spanish, she did not understand what she was told until she came to the United States and met with an audiologist with an interpreter present.

While receiving diagnostic and therapeutic information in Spanish was not always necessary, its availability was appreciated and appeared to increase rapport and trust. Most (95 percent) of the families also reported using interpreters. Future investigations may examine how Spanish-speaking staff, particularly native speakers, affect satisfaction with service delivery, parental involvement, and outcomes. One could hypothesize that environments that support accommodations for parental understanding both model and support the acceptance of the child's need for communication adaptations.

Family 1: The mother said she had trouble understanding the doctor at the diagnosis of her child's hearing loss.

When [the doctor] told me, 'He's deaf,' I did not understand the term 'deaf,' I was not familiar with it, I did not know what 'deaf' was. When he told me it was a 'severe-profound hearing loss,' then I could translate it word-by-word and I understood: severe-to-profound hearing loss, but I did not know what 'deaf' was. And I asked him, 'Is there someone here that speaks Spanish? Because I do not understand.' Then he [took hold of me] by the shoulders and said to me, 'It is not that you do not understand, it is that you do not want to understand.' And I told him, 'I do not understand what deaf is. What does 'deaf' mean?' Then he said to me, 'No hearing.' And I said to him, 'He does not hear?' and he told me, 'No.'

Interviewer: Did they give you an interpreter?

A nurse who spoke Spanish came.

Interviewer: How did you feel talking with an interpreter after just being told?

I felt as if I was 'at home' because she... she ... was a Mexican woman, a very good person, and she said, 'Don't cry, try to calm down so that I can tell you what the doctor has said.'

They explained things to me, but it is very difficult because they explained things to me in English, with medical terminology.

Interviewer: Do you feel that language was an impediment at this moment?

Yes, it was an impediment, because ... if it had been in Spanish, although it was hard to accept anyway, one can ask questions, one is free, one can ask the questions like one wants, but it is hard when one feels like they are trapped by a strange language. The words don't come out, they don't come out. I just asked, 'Why, why, and why?' and 'What can I do? What can I do?' and they said, 'There is nothing we can do, he's deaf.' And this I'll never forget because they always said, 'There is nothing that we can do, there is nothing that I can do, there is nothing that you can do, he's deaf.' And that's how things stood.

Family 2: The diagnosis was given in English, but an audiologist who spoke Spanish was there as well. An interpreter was not needed, according to the mother, *because I understand English well*. She said she understood everything at the diagnosis. The mother also said she would call the Hispanic audiologist when the doctor was away or when she had questions about hearing aids or other things.

[Father speaking] *All the time we talked to her, it was in English. By language, we have never been discriminated nor have we had lack of information. Everything has been clear like in black and white.*

Family 3: At the diagnosis, the parents said that although the doctors and audiologist did not speak Spanish, interpreters were always available.

[Mother speaking] *Also, we never had any difficulties regarding that [language] because they always have people that help us [translate] with the doctors, at the school, with everything. They always have someone who speaks Spanish. One struggles but, well, one wishes that the doctor would explain things. Many times when they are translating they use different words and one can get confused, maybe that is not exactly what the doctor means.*

Nonetheless, the mother said, *We think that we understood everything that we were being told.*

At school, S's current teacher speaks Spanish, although some of her former teachers have not. This has at times created difficulties, with the mother having to seek out someone to translate. Written information was often sent home in English.

[Mother speaking] *I was talking with the teacher a few days ago when we went [to the school] and I told her to send me the messages in Spanish because there are times they are in English, and I just look at them because I don't understand them ... we would like to be able to speak the same language as them, but if, I mean, that would be better, for us to speak the same language, but we do understand each other more or less.*

...Sometimes one struggles, but does it affect us? No, because this is an area in which most people speak the two languages. If she does not speak it, the person next to her probably does; therefore, it is not too difficult.

Family 4: The diagnosis was given to the parents in Spanish. The audiologist who fitted M with hearing aids spoke English and a nurse interpreted. The parents say that for the most part, they can understand the audiologist's English, but sometimes ask the nurse to translate just to be sure they are understanding him correctly.

Most of the time information from the school is given in Spanish, but sometimes, especially outside of school, only English is used.

[Father speaking] *We don't know the English language as we should—we always struggle with it. It has never been, for me and I think for my wife too, it has not been a problem. It is an obstacle, though, because it's been more than just understanding it. Everything that we have been told and/or we have been given an opinion on, and at school, for the child, and about his health—we have understood everything perfectly, I think. When there is a doubt, we look to others to clarify it; we don't keep anything that, I mean, well, no, no, no, we find a way.*

[Mother speaking] *Yes, yes. That is very important. We always ask, always ask. If we don't understand, we will say, 'Listen, lady, we have some questions. We don't understand something. Please help us. We have doubts about this and that.' ... Everybody makes an effort.*

Family 5: Because H was diagnosed in Mexico, the doctor spoke Spanish and there were no language barriers. However, the mother still felt that she didn't understand what she was told. In the United States, the audiologist spoke English and the mother had an interpreter. The mother felt

that the information was clear, and she was able to communicate freely with the audiologist. In school, the teachers speak only English and have an interpreter. Written materials are provided in Spanish. Language differences have become less of a barrier as the mother has learned more sign language, which is the language she uses to communicate with the teachers.

[Mother speaking] *I was happy because I was able to understand everything.*

Family 6: The doctor who delivered the diagnosis spoke Spanish, eliminating the need for an interpreter. The audiologist, however, provided information in English. Although interpreters were available, logistical problems limited their usefulness.

[Mother speaking] *Actually, I don't think I've ever had an interpreter ... usually the first few times, it was because it was difficult waiting on the interpreter to arrive. We would have to wait one or two hours for the interpreter to get there and then sometimes they had to help other people who were there before us because the interpreter was busy. From this point on, a lot of things happened, so we finally decided that it was just easier for us to go on our own and with the English we knew, and it was not a perfect English but one we knew, that we could understand, we're able to communicate and it seems to be good enough. I would have really preferred that it would be in Spanish, but it's just so difficult, so difficult, more than anything to find somebody who speaks Spanish. When you go to the hospital there are just so many people and there's not enough interpreters.*

The mother said she felt that she understood the information provided by the audiologist. To the extent that she did not understand what she was told, it is unclear whether language differences were the reason for misunderstanding or if unfamiliarity with deafness and the terminology used by professionals was a more important factor.

Early intervention services were provided in the home. Using sign language provided a communication bridge for this family.

She had a person that spoke Spanish and English and also signed, and another person who spoke Spanish also knew sign language ... occasionally only the one that spoke Spanish would come. And when the woman who only spoke English would come, then the other woman who spoke Spanish came along.

Family 7: The diagnosis of B's problems at birth took place in Puerto Rico, with a doctor who spoke Spanish.

[Mother speaking] *Yes, I understood everything that the doctor told me and if there was something I didn't understand, I would ask him again. He was very nice and he would respond to me, and tell me, and explain to me again every procedure, everything that he was telling me that he had to do.*

The audiologist in Puerto Rico also spoke Spanish. In Pennsylvania, the doctor who treats B speaks English and uses an interpreter. Sometimes a friend who speaks both languages also acts as an interpreter.

Sometimes it is not good. It is not exactly what I would like to explain to the doctor, because sometimes the interpreter cannot explain to the doctor the same way I would.

The audiologist in Pennsylvania also speaks only English. The mother takes a friend with her to act as an interpreter at those appointments.

She knows everything that I have been through and all. So then she helped me a lot to talk to them.

In the Puerto Rican schools, there were no language problems. However, upon coming to the United States, the mother found it somewhat difficult to interact with the teachers.

In the beginning when I came here, it wasn't easy for me, since I was coming into another language. At school, there is not that many people that speak Spanish, the teachers are Americans, all that my son has, so then we use an interpreter. I am taking sign classes, and I think that for me it has not been easy because it is a translation from English to Spanish. It hasn't been easy for me.

Some of the teachers have tried speaking to her in Spanish.

... but it is very difficult. It is like me speaking to them in English.

Papers that come home from school are generally translated into Spanish.

I can understand what they are into. Every day they are telling me what they do in the classroom in Spanish. They have a person that translates what they do.

Despite the language differences, the mother did not identify any significant barriers to B's education.

It could be a lot easier for me to communicate with them and all of that, but since they already have an interpreter, there hasn't been that much that I could say that we have had problems with.

Family 8: Because the mother's primary language is English, she reports no obstacles caused by language differences. However, the father does not speak English and has learned very little sign language.

[Mother speaking] *He wanted to be involved somehow, but just didn't understand quite where he was going, so I was translating for him.*

I mean [the father] will say 'I love you' in sign language, 'play,' or 'park,' but not too much. No... and sometimes J looks at him like, 'Huh?' like, 'What?' but he won't take classes. He refuses to take classes.... After all these years, I think it's still difficult on him. I mean, that's his firstborn [child].

Information Access and Support

Despite the best intentions of professionals who serve the Hispanic community, there remains a significant divide in access to information. Most parents relied on the professionals who were treating their child to provide information, not only about hearing loss itself, but also about available services, medical assistance, and the rights of the child and parents. Materials written in Spanish were frequently offered, but appeared to be limited to general pamphlets that have been translated from English, rather than materials written to be culturally relevant to Hispanic people.

Moreover, while English-speaking parents frequently can obtain materials from numerous sources, including popular books, magazines, professional literature, and videos, Hispanic parents appear to have far fewer resources at their disposal. Thus while Hispanic families in this study appeared less inclined than non-Hispanic families in other studies to seek out multiple sources of information, this may be attributable to the paucity of appropriate materials as well as language and cultural factors that influence information-seeking behavior.

Family 1: The mother says she was told that there was nothing that could be done for F, no operation. She was given a pamphlet written in English, which she had trouble understanding.

So I began to read, and I came to understand that in addition to hearing aids, there is an operation to connect tubes, as this helps them to alleviate the pressure of the liquid that stays, and I began to call doctors to find who, who could help me, where I could take him, and I got an appointment to take him to [a children's hospital] in [a Florida city]. And that is where they gave me hearing aids, and there they gave me an appointment with an ENT [ear, nose, and throat] doctor. He did an evaluation and referred me to an audiologist and they recommended (he was almost 9 months old now) that I take him, that I register him with the county where we live, to register him in the county and in school.

A Hispanic audiologist explained how the ear works and why F could not hear. The audiologist suggested that the mother register F at school, learn sign language, put hearing aids on him, and show him how to use them all the time. The mother said that this audiologist *took her time with me and with him* and was *very sweet, very human*. She explained that F needed to start school right away so he would not fall behind. Another professional, whom the mother refers to as a nurse (this person appears to be Hispanic), was also helpful.

The woman, the nurse, that helped me and gave me the support I needed on the day that they told me he was deaf, she told me, 'Don't be self-conscious, look for help. Look for help for your son because there is a lot of help. In this country, there is a lot of help. Perhaps not in our countries, but here there is a lot of help for them. They are like any other child. Just look for help, it is there.'

At 11 months of age, F was registered for school and got his first hearing aids. The mother began sign language classes and also received a video that explained how deaf people hear. She found the video to be very helpful.

The mother sought a second opinion from another doctor. This doctor informed her of available government services, such as Social Security Disability Insurance, and also recommended that F begin school right away.

Family 2: T was already in a Head Start program prior to diagnosis because his speech development had been slow. At diagnosis, the parents were told that his hearing loss was severe to profound.

[Mother speaking] ... *My question was what alternatives there are, and how can the child progress with this because that was our concern. She told us that the alternatives that there are now are not that many because the child is one step before being deaf. ...And then when she shows us the hearing aids, she tells us the hearing aids are for him, for his condition, she shows us and tells us, the hearing aids cost a lot, the medical plan does not cover it, but we can do the arrangements and then my husband and I decided, well, we have to do the arrangements because he has to have them and there is no other alternative. There is no other alternative and then after that, she talked to us about the school in [another city].*

At every moment, we look to see if there is another alternative besides the sign language—we want it, we want that alternative. She told us, ‘Everything is going to be clear when the boy has the hearing aids, with the way that he uses his residual hearing, how much he will be able to hear.’ But with the hearing aids there was not much success so that’s when we decided on the operation.

The doctor went on to explain cochlear implants to them at that time. While the parents were satisfied with the medical information they received from the doctor, they understood that other sources were needed to find out about educational alternatives. They also understood the underlying motivations of educators from different school systems.

[Mother speaking] *It depends on the professionals. If the professional is the doctor, they’re going to talk to you in the way of the doctor. If you are in the school, and the professionals of the [county], they get paid by the [county] so they’re going to offer you the alternatives that [the county] has and if you’re in [a city in Florida], you’re going to get the alternatives of [a city in Florida]. So the ones from [the county] are not going to say, ‘You don’t want signs, well then there is a school in [a Florida city] and we’re going to transfer you there.’ You’re never going to hear that. Never.*

Interviewer: So do you think they were giving you the alternatives?

Only in accordance to what they had in the county, not the alternatives that I wanted for my son.

Family 3: S was fitted with hearing aids right after the conclusive diagnosis in a Texas town. She was 3 years old at that time.

[Mother speaking] *They told us that in one ear she is completely deaf, and in the other ear she can hear a little bit.... They only told us that she needed the hearing aids, that she was*

not a candidate for surgery because her problem was in the nerve that is connected to the brain, and that cannot be corrected with surgery, but that with the hearing aid she could speak, maybe broken, that was a possibility if she used the hearing aids all the time. It was a possibility, but it was not something for sure, but maybe she could hear more.

[Father speaking] *The doctor who performed the last hearing evaluation said that there was an operation, maybe it is already being done, but at that time two or three years ago the operation was not available, that maybe when they would start performing that operation she might be able to get it.*

[Mother speaking] *The doctor said to get the hearing aids and to find a special school for her and that was going to help her. That is what he told us to do. ... He told us about a program in New Mexico that helped us a lot, and he told us where the schools were located.*

The mother added that, since they left New Mexico, S no longer has a regular doctor and *therefore we don't know if there is something new that might help her.*

The audiologist gave the parents information about hearing aids.

[Mother speaking] *That they were going to help her hear a little bit more and possibly they could help so that she could talk.*

Family 4: The family obtained information from a school for the deaf.

[Father speaking] *They gave me a lot of literature. It was all about behavior, education, and the school itself, things that he could do here in the school, what was the most convenient thing for him to do. ... It helped us a lot, especially about his education, which is the topic we are talking about. They gave us options that he could have, but then we didn't know exactly what we were going to do. They gave us ideas on where we can go or what we can do. Then they just told us you could go to this school, to this place, to that other school. They told us he was going to learn how to sign, he was going to have his speech-language therapy with him and they told us also that he was going to learn how to read lips and all of that. Now we can see things more clearly.*

The parents felt that the information they received was highly supportive and offered in a spirit of teamwork.

[Mother speaking] *I felt that they were giving us that information and advice because they were inviting us to participate in everything that had to do with M. I thought that we were putting together a nice team to help him out.*

Family 5: The mother said that although the doctor spoke Spanish, she had difficulty understanding the information he gave her.

Well, I tried to understand him, but I really didn't know anything about what happens when a child is born like this, with this type of problem, because I really never knew anybody who

had that problem. But once I got here I learned more about it. And I went from one place to another and got more information, so here's where I've learned most of my information because I've seen and met many deaf people here... well, really, I was very surprised and I didn't ask any questions.

[Father speaking] *He gave her a report that shows the scale of what type of hearing loss he has. It shows where a normal person can hear and then where a person starts to have hearing loss, at what different levels. So he was very low at the level of being able to hear. So then he recommended hearing aids, but we really didn't see any type of benefit in that. But my son did make different types of noises and sounds, so I thought in due time he would be able to speak. I thought maybe if they helped him a little bit he could.*

[Mother speaking] *I do think it was clear, but at that time, I just didn't understand it. Yes, because sometimes even if the information is clear you still can't understand the information ... after he gave me that information, I right away came back to this country and they gave me another evaluation here and that's the way everything started here ... the first thing the doctor told me was he sent me to go to the children's hospital to get another evaluation for my son. So the doctor in the hospital there has all the information on my son.... I felt good because he gave me a lot of confidence and I really felt that somebody was supporting me.*

The father said his attitude toward the doctors changed over time.

Well, we felt that they were giving us suggestions, but later we started to feel and believe that they were telling us what we must do. Because as time went along, they told us that there was technology, advanced technology, that would allow my son to speak. There was some type of implant, but we rejected that. We decided to wait until my son could make the decision for himself and maybe wait for science to have more advancement. To wait and see if maybe later there would be something better....

Family 6: The parents felt that the information they received at diagnosis was clear, appropriate, and helpful.

[Mother speaking] [The doctor] *was very clear in his explanation and I actually learned a lot because I never really knew anything about deafness and I learned that there is different kinds of hearing loss and I learned things about the ear that I never knew before, so I really think it was helpful ...after we saw the first doctor, we went and looked for a second opinion. Actually there has been about four or five different specialists who have seen P. We have looked for the answer to maybe the reason why she's deaf or exactly what the problem is with her hearing loss.*

The audiologist who performed the hearing test was also helpful and, in the mother's words, *not pushy*.

The first thing [the audiologist] told us was that P had to be put in a school and that I also had to start taking some classes ... she gave us the phone number and address of the school

she had to go to and we also started the paperwork on getting my daughter's hearing aids ... really, it was more of a suggestion and she didn't, she wasn't pushy, she didn't force us to go there. She just gave us the name of the school that was closest to us. So really, it was just a suggestion that she was giving us. ... I thought she was very helpful, and I also did my own research. I also went to the school to visit and see what that was about and I did a lot of other things.

Family 7: The therapist advised the family to move to the United States for better services.

[Mother speaking] The therapist that was seeing him told me, 'Think about it in the near future. Get out of Puerto Rico to the United States because there he is going to find a better mechanism of life. The schools are going to be better. The doctors are better prepared, more able than here.'

Family 8: Following the diagnosis, the professionals gave the mother about a week to let the information sink in.

They let me think things through and they just kept calling me, making sure that I got help for him as soon as possible because he needed it and he was very young. So I woke up and I'm like, all right this is what I've got to do for him and I called them up and I went to their office and they scheduled a lot of appointments, but I mean he's doing great now.

They told me that I would have to find a special school for him and so he wouldn't be like regular children, but that he was going to be healthy and whatnot. So they started pointing out schools for me and I started interviewing a few schools and I picked a nice, a good school for him and it was, I love that school, because they helped him a lot since he was little....

I felt as though I needed to know more, so I went to the library and I started to read up on things and started getting some more pamphlets and checking up on what it was I, what [it] was [that] I had to deal with, you know, for the future. So I read up on that and I started to go and apply for classes and things like that. I wanted to prepare myself, but I still couldn't get the hang of it.

The mother was also given pamphlets, referred for family counseling, and set up with early intervention services.

For a whole year they [early intervention specialists] came to my home and I talked it out and it helped me a lot. It really did. I was very young. I was only about 19 years old. So I was really young. I didn't know exactly what I was getting myself into, but I mean they explained as much as they could ... they did give me a lot of information. It was like too much to take on, but it made me go out there and say well this, they've given me all this information, I need to read up on it, he's my son, he's going to be with me always. So I started to read and I started to focus on what needed to be done. So I think it was great—all the information they gave me.

A counselor at a school for the deaf was also helpful.

Information from Deaf Adults and Other Parents

Deaf adults and other parents of deaf children were mentioned as a source of information and support by several of the families in this study. In interviews with non-Hispanic families in a related study, meeting other parents of deaf children is frequently cited as one of the most valuable sources of information and support. The Hispanic families in this study appeared to have significantly less access to other parents of deaf children and to deaf adults, yet in several instances they found interactions with these parents to be highly beneficial.

Family 3: The family realized that their daughter could be successful after discussions with other parents of a deaf child.

Not too long ago we spoke to the parents of a deaf boy and they said that their child is doing great. Also, the mother of an older deaf boy, now a young adult, was telling us that her boy did very well in school and that he is in college now. When we hear that, we tell ourselves that our daughter is going to make it, just like him. Before we would think that our daughter was not going to be able to [learn], she is going to be a nobody; we were traumatized [aggrieved] by that. When we see [positive] things like this, it helps us move forward.

Family 4: Meeting deaf adults has been helpful to the parents.

[Mother speaking] There are a lot of people that we met and they really are the ones who are helping us, intervening with decisions. We were looking for someone to help us with a solution to the problem and there we met a gentleman. He's someone from real estate and he gave us an address that we can go and meet this couple. They have a daughter and both are deaf, but they seem to live a normal life. They communicate pretty well with us. They both work and she doesn't really have a lot of audition, but he does, a little bit, and we thought that if they can do it, we think that M can do that too. That's what everybody tells us.

Family 5: The parents have found it helpful to meet with other parents of deaf children and to talk to deaf adults.

[Father speaking about meeting with parents] We discuss how we feel and really about how we communicate with our children.

[Father speaking about meeting with deaf adults] We can discuss things with an adult and they can tell us what they feel and express their feelings better than a child can. You know they can tell us if they're happy the way they are, or tell us what it is that they feel, so then we think, 'Oh, maybe our son feels the same way or is also going through that.' You know, and we think our son isn't going to have any problems later.

Family 6: The mother has become friends with other parents of children who are deaf, and has found that helpful for sharing information about resources, services, activities, and other things. In addition, in the school P currently attends, the mother has met many deaf adults, which she also feels has been helpful.

The biggest thing that has helped me is to realize that [deaf adults] are just like us, that they have the same type of opportunities that we do.

Family 8: The mother says meeting other parents of deaf children and deaf adults has better prepared her for life with a deaf child.

In the beginning, because I wanted to know how it feels to be with other deaf parents. ...with all that they were talking about and what they were going through and me listening to all the things that they had to say, it helped me to understand what I was going to go through, getting ready for.

I know quite a few [deaf adults] and I visited their church and I've gone on family picnics and things like that, which they do a lot at the school and it's great. I mean, it's nice. ...because I got to understand a lot more of what was going to happen to me. I got ready, in other words. They, I watched them, how they were working with their kids and what they had to go through with their kids and I'm like, well that's going to happen to me.

Family Support

Both the survey data and the interviews suggest that Hispanic mothers shoulder much of the burden of decision making and implementing the choices made for their deaf children. Hispanic fathers appear to be less involved in the decision-making process and less supportive than are non-Hispanic fathers. Further, in comparison with non-Hispanic families, Hispanic parents receive less support from grandparents, relatives, and friends.

The relative lack of support from extended family members coincides with the findings of an earlier pilot study (Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997), but contrasts with the characterization of the Hispanic population as comprising individuals who depend on extended family for support (Alvarez & Bean, 1976). In large part, this appears to be due to the fact that families moving from their country of origin to the United States feel cut off from their extended family, and this may be further exacerbated by prevalent negative attitudes about deafness and disability in the home country.

Choosing a Communication Method

The communication method chosen tended to be the one recommended by the professionals consulted, with little consideration of alternative approaches. Frequently, the only option presented was a combination of sign language and speech, or the option of an oral approach was presented but discouraged. Approaches such as Auditory-Verbal or Cued Speech did not appear to be offered as options. It is not clear whether the professionals guiding the parents presented only those options that were available in the geographical area or if they simply lacked knowledge and information

about alternative approaches. With a few exceptions, the parents tended to accept the recommendation of the professionals and to express high levels of satisfaction with their communication choice.

Family 1: The mother received conflicting advice about communication methods. The family developed a good relationship with the early intervention teacher, who advocated total communication.

I had to decide what type of communication we would use, sign language or...whatever we would do. The teacher contributed a lot, she helped us a lot, because she explained the advantages of total communication, which is what we use with him. If he goes out and has contact with other people, if I had taken the advice of 'only sign language,' when my son goes out to play, those children that are outside will not understand him. And she explained these things to us. Well, she is in favor of 'total communication.' And there are other teachers that are not, but I had the good fortune to have her help me with this. And I believe this was the most difficult decision of all that I have done with my son. The biggest thing I have done is to decide how to establish communication with him.

The audiologist also influenced the mother's decision.

The audiologist told me, 'If you put him in school, if you put him in speech therapy, if you always are sure to have him use his hearing aids, when he goes to school, he will be able to go to a regular school.' And she told me, 'I cannot guarantee this, but as a result of my experience, I can assure you that this will occur, because the children that are cared for in time receive good training, they overcome, they excel, and it is true.' My son is now in a regular classroom, in a regular kindergarten class, and he has an interpreter. But he is in a regular classroom.

The audiologist was the mother's chief source of information. She also considered other programs: a private school, which she rejected because she didn't have the resources and it was far away and an in-home program. The audiologist said the school program would be better because the materials available there weren't available in the home. The mother also observed some home visits and felt there would be too many interruptions in her home. The school program she chose uses total communication and was *fantastic*.

Family 4: The teacher at the school for the deaf apparently presented the parents with only one option, sign language combined with speech. The parents expressed satisfaction with this option.

[Father speaking] They [the teachers] told us that it's a system that goes together for him to better express his ideas and to better understand other people and for him to also express his ideas in a better way. They [signs and speech] were always used together. They always have to go together for support...At the beginning, I didn't agree with the sign language because I thought that he first needed to learn how to talk. He has a teacher that is also deaf, but she can talk ...When she talks, she does signs and she moves her lips at the same time and one can understand the word and that is one of the things that made me think

sometimes that one day my son is going to be able to talk like her or at least to make himself be understood.

Family 5: The parents immediately began learning sign language on the advice of the teachers.

[Mother speaking] *They told us that we needed to learn sign language so that we would be able to communicate with him. For example, if he were to get sick, we wouldn't know what was wrong with him. So we've learned really basically what he's learned so if he's ever sick you know he could tell me what's wrong. If his ear hurts or 'my head hurts.' So I'm not just here wondering what's wrong with him...I accepted it because I had to learn.*

Family 6: The early intervention teachers advised the mother about communicating with P.

Well, they [the early intervention teachers] told me that I would need to speak to her and that I would need to speak to her and sign at the same time and that it would probably be best for me to speak English to her because it would be easier for her. They said I could speak to her in Spanish, but that it would probably be easier for her to communicate in English. ...I knew I had to go and learn sign language. So we have been going to take some classes and up until now, we're still taking the classes and learning day by day.

Not all parents relied on the advice of professionals. Some actively pursued other options, such as oral communication, because of their own personal beliefs and preferences.

Family 2: At first the family began using some signs with T *to reduce his anxiety with communication*, but dropped them after about six months. The parents favored an oral approach.

[Mother speaking] *The people in the county were offering us sign language ... we had to look for other alternatives because we don't want to limit him.*

[Father speaking about visiting two schools] *We didn't like it because they were using only signs and they were not speaking clearly, they only made noises. We went to the other school where there were children with the same condition and they were talking. So from that moment on, that's when I said, 'This is what I want for my son.'*

Language Preferences

While most parents cited English and/or sign language as the language that was most important for their child to learn, many hoped and expected that their child would and could acquire English, American Sign Language, and Spanish. This put them in direct conflict with the majority of professionals encountered, who recommended a single language emphasis or bilingual approach, but never addressed the issue of trilingualism or options to achieve their goals. The parents' perspectives and wishes may also have limited the options explored with or offered to them after the identification of the hearing loss, such as cochlear implantation.

Most parents wanted their children to learn English or American Sign Language first and often expressed their *certainty* that their child could eventually learn Spanish, yet few spontaneously reported having discussed this with professionals. Some expressed negative feelings about the insensitivity of professionals to their native language and the right of the child to be supported in his or her “native” language (the language of the family into which the child was born). Parents understand the complexity of the task and acknowledge that Spanish confused their child in the past, but their native language had unique value with respect to family communication.

It is difficult to assess the degree to which this is dissimilar from typical assimilation struggles of first-generation immigrant families, although one might hypothesize that hearing loss magnifies this issue greatly. For example, one mother was proud that her daughter could write in English but sad that no one in the family could understand written English. She hoped that her daughter could ultimately learn Spanish to communicate with all family members. Another mother reported that she interprets directly from sign language into Spanish for her husband; she had no strong language preference for her son.

Family 1: The mother expressed some regret that her older (hearing) son does not speak Spanish.

We are trying to avoid the error we made with the older boy, so that later he will follow his culture and language, which is Spanish. We want them also to speak in English. But with them, with the three little boys, we are trying to educate them to be trilingual, that they will be able to speak Spanish, English, and know sign language.

However, she was discouraged from using Spanish with F.

They told me only to use signs, or if we would use signs with Spanish or English. They have always been against my using Spanish. The teachers have always been opposed to this. They want it to be English, and that it is English in signs. But they say that Spanish will confuse him, because it is hard for him...but [laughing] he understands Spanish perfectly.

Interviewer: How do you feel about this advice they gave you?

They are mistaken. They think professionally; they are not part of our culture. And they have no idea how important it is for us that our children preserve their language—that they dominate and perfect English, but that they also dominate and perfect their own language. This is very important to me. He has a family, he has his grandparents and aunts and uncles that speak no English, and know absolutely no sign. So if my son does not speak Spanish and understand Spanish, he will be completely lost within his family.

I want him to be trilingual when he is an adult so that he interacts with his family in Spanish, that he obtains a good job, that he is well paid because he can speak three languages, that if someday he finds himself in a group situation where everyone is deaf, he will be able to communicate with them on an equal basis, that he does not feel apart from the Hispanic group because he is Hispanic, that he does not feel as an outsider with deaf people because he is deaf, and that he does not feel as an outsider with English because he lives here, it is the language of this country and he must be fluent. I think he will have more

advantages than other people. And for this reason, I want him to be able to communicate in the three languages.

Family 3: S's first language is sign language, but the mother thinks it is important that she also learn both English and Spanish.

We were discussing that with the teacher when we went to talk with her. I thought that it was too much for S because she was learning sign language and English, and I wanted to teach her Spanish. I asked the teacher if it was too much for her to teach her the three languages and the teacher said that she could do it. I told her she is learning to read and write, but she writes in English. My relatives tell me how great it is that she knows how to read and write, that way they can write to her, but [she reads and writes] in English and nobody in my family knows how to read or write in English. I would like for her to learn Spanish because that would make it easier for us to communicate with her. I believe that all three languages are important. Because the family speaks Spanish, at school she needs to communicate in English, and she needs the sign language if she is not able to speak.

The mother also said she speaks to S in Spanish and S seems to understand. She doesn't feel this has affected S's progress in school.

Family 4: The parents communicate with their son primarily through English-based sign language.

[Father speaking] *We removed the Spanish completely because Spanish and English, both together, it was too much to mix for him. We definitely said no more sign language in Spanish. If he forgets his signs in Spanish, well, what are we going to do?*

I wish he could learn both, but it's very hard for him, and the most important thing is that he learns how to sign in English in order to communicate. That's the reason that we are here. That is the option that we made and he can learn English now, and maybe later he will be able to do sign language in Spanish.

[Mother speaking] *Before he used to sign both English and Spanish and he was getting confused.*

[Father speaking] *We would like for M to continue his sign language in English because it's what he knows more right now and it's his future. We are not planning to come back to Mexico, so first it's the English, and then maybe Spanish, if he can.*

Family 5: The parents feel that it is most important that H learns sign language. Since they also have a hearing child at home, they speak in Spanish at the same time they are signing.

[Mother speaking] *It's not important for him to speak in Spanish, but I would like him to be able to understand it maybe when he gets a little older. What's important for me is for him to learn sign language because that's who he is really going to be communicating around most of the time.*

[Father speaking] *I believe the best thing is for people to learn the language of their children so that the parents are able to interact and stay close to their children. Because I do believe that the children become distant when the parents don't know their language.*

Family 6: The mother primarily communicates with P through spoken English and sign language.

Sometimes it's English. Sometimes it's Spanish. It's really whatever comes to mind first. Sometimes I don't even realize it and I'm already speaking to her in English, and then there's other times when I don't realize it, and I'm speaking to her in Spanish. But, for the most part, it's usually in English.

I think it's important for her to understand and speak English. Well, I think it really doesn't make much of a difference to me whether she chooses to use sign language or to speak in order for her to communicate. ...I think it's important for her to learn English because of the country we're in now.... I actually hope that she's able to communicate with everybody using all three, English, Spanish, and sign language.

I do believe that [speaking Spanish to her] has affected her negatively, because I think it has maybe held her back a little bit. I think she's supposed to know more signs than she does already. I hope she learns eventually, but for right now what is really important for me is for her to learn sign language and understand it.

Family 7: The mother feels it is important for B to learn sign language, Spanish, and English.

I want him to be using his sign language since that is his language, but also he's being taught how to talk to hearing people.

Family 8: The mother feels that J communicates well with people whether they sign or not. She said she did not feel that one language, English, Spanish, or sign language, was more important than another.

School Choice, Personal Style, and Advocacy

Decision-making styles varied among the parents in this study, ranging from reliance on professional recommendations to the vigorous pursuit of alternatives. In contrast to stereotypical representations of passive and uninvolved or avoidant Hispanic parents, the authors encountered parents at all four sites who recruited lawyer friends to teach them about the educational rights of their child, who were positive and upbeat, hearty collaborators, and active decision makers. As one parent said, *you have to grab the bull by the horns....*

Family 1: F has attended five different schools. At age 6, he is in a regular kindergarten class with a sign language interpreter. He is the only child with a hearing loss in the class and goes to a hard of hearing class in the afternoon. The mother has had to fight hard to get what she felt was appropriate for F, and she was assisted by a program specialist for the school district's deaf and hard of hearing program.

The school where he is now I did not choose, I didn't want it. But the county said that there is no other one, and they assigned him to this school. I made them change, because there, there was no voice used in the class because they are deaf. I communicated with people that helped me. There is a woman that works for the county...she helped me a lot. Thanks to her, I basically got what I wanted, which is to have an interpreter in F's class, and that the teacher of the class is oral because she is not non-oral, she is oral and can talk. I spoke with the superintendent of the schools, of all the schools in the county. I explained all that was happening with him, with my son, what I wanted for my son, and the things to which he has a right. I read a lot. And...I knew that even though they told me that they had an interpreter, they really didn't have one, and they had to look for one. ...I suppose that they didn't have the money, but they got it and assigned one, an interpreter. The school, the school itself is okay. It has a good program, it's just that if you don't pay attention, the program is not handled appropriately. But now, for F, well, it's super.

The mother has also demonstrated the importance of advocacy for her child through her interactions with other parents.

I've made friends with the mothers of children that have been with him. And from there, with another mother, I'm in the process of organizing a support group for the parents of deaf children...for Hispanics and Americans also, because it's incredible, this summer we went to a camp organized by [the school]. And in this county, as big as it is, there is nothing, there is nothing. We are like this, just as you see us, nobody knows anything, and from there came the idea to form a group...of parents, of mothers...that are trying to obtain that which they [the deaf children] have a right to have, that which the law says they're entitled to have. And if I have to force them to change the law, they'll have to change it. [laughter] ...when I can't express myself in English, I speak in Spanish and let them look for someone to explain it to them because they must hear me out.

I have learned things. Yes, I at least, I think, that I need to investigate more, and know someone who knows more, and gain more information. I have learned from the experience of other parents, situations different than mine, or ones that are similar. And these, and these experiences about which I have been told, when they happen to me, as is what has happened, I know the consequences of the things that can be done. I have studied the law, the law IDEA [Individuals with Disabilities Education Act], I have studied it. I have studied about the things that are necessary, Total Communication, sign language only, or English only. For example, I met a young man that speaks Spanish and English. It's very hard...his speech isn't clear, perfect like ours. But he speaks Spanish, he speaks English, and he knows sign language. It can be done, it can be done..... There are people, there are young adults I have seen that are fluent in all three languages. I know that it can be done. I know that each case is unique, but I know it can be done.

What has worked for me is that one must sit down and I write down 'pros,' this will work for this, this, and this, and I make two lists. It doesn't work because of this and this. Which one has more? Which can I eliminate of the ones that don't work? What can I eliminate of

those that function when they are related to ones that don't function, in order to make a balance? Because when [one] looks at things [like] this, they appear differently.

Family 2: The family had purchased a home in one town, then learned that a nearby city offered an oral program for children with hearing aids. The parents negotiated with their hometown to pay for their child to go to the nearby city and to transport him there. T began in a class that was for children who were mentally retarded, but the parents objected and managed to get him moved into another class.

[Mother speaking] *We have friends that are lawyers and they help us and they counseled us, 'Tell the county that you want a teacher that is specialized in working with hearing impaired children. And since they don't have it, they have to transfer you automatically because of the law. The child has the right.' And we went to talk with the county and the board and she prepared us with a binder with all the laws and she underlined all the laws with a highlighter very clearly, all the rights that the child had....*

[Father speaking] *Yeah, the rights that we have, but the county is not interested in recognizing....*

[Mother speaking] *One is never told about all the alternatives one has. When we opened the file in the meeting, they saw that the legal part was also there and we expressed our point of view. Of course, we were prepared ahead of time, both of us, what were we going to say, how we were going to talk about it and of course there were problems because there were people that were not in agreement with it, but we were prepared for that. So then finally they transferred our son. So, then the doctor saw that we were pushing for the child's well-being and she realized that we were fighting for our son to succeed, not only for the operation.*

Family 3: The mother said that at first there were no special school programs available so her daughter was attending a regular school program.

[Mother speaking] *... the teachers were trying to teach her and to learn themselves at the same time, it did not help her much. When we moved to this city, that is when she started attending a special school.*

[Father speaking] *The doctor here in [a city] did tell us that if we placed her in a special school she was going to speak, not the same as we do, but with time she would speak.*

Once the family moved to a small town, the local school referred the mother to the school for the deaf in a neighboring city. The mother says it is a good school that uses sign language and speech. She was not given any other options from which to choose and did not visit any school programs.

Family 4: The parents say they never sit still.

[Mother speaking] *You have to grab the bull by the horns or things will go downhill.*

[Father speaking] *We are looking for everything out there. We are trying to push him as much as we can and we are determined to do everything we have to do in order to help him. We never just stay in one place and don't do anything. We need another opinion or other advice. We are always looking for another opinion, always, always, always. We have had that idea, my wife and I. We always have to keep going, looking for what is there, what is next. I remember when that doctor told me that M was deaf, he told us in Spanish. We felt pretty bad, but since then we have never stopped. We also have sought a lot for God's help.*

[Mother speaking] *We know that the future of our son is in our hands, and we have to place him in the right hands, the right people that really are capable of giving him the tools to succeed I see a bigger future for M. I'm not going to cover the sun with my hand, I'm just going to let the sun come out and see him.*

When M was 4 years old, the family moved, and the parents went to a center with an early intervention program for special education children.

[Mother speaking] [What] *they told us was that they were going to study M's case and they were going to see what they can do. They really tell, they really told us what they already have prepared. These are the resources that we have and we trust them, we trust what they were telling us and they gave us all the information and written papers. So we analyze what they give us, and it looks good for us, we believe that that is okay for him. But they didn't mention to us about other things outside of what they offer. ...When they talked to us about their programs, we said that is fine, it's okay.*

They didn't give us options. They gave us that option, and we saw that obviously M is not talking. He is going to use the signs and the lipreading. I think that that is the best for him. If they give me another option, and we can take it, we can go ahead. We are very open. But, up until now, this is the best option we have. The best and the most important thing they told us is that M was going to go up to wherever he wants to go and they told us that they were going to help us in every way. What I like about the program is that they told us that M was going to go farther. They didn't tell us, 'Okay, M is going to be in this program and he's going to get up to here, up to this point, and that's it.'

The parents have found it necessary to advocate for their child in a range of situations.

One of the things that has bothered me is the transportation, where I have not obtained a good answer. Last year we had a problem with the person that used to take care of him in the bus that brings him home. Every time the bus would come he would start crying, he said he didn't want to go to the school anymore in that bus and I was wondering, what is happening, what is going on now. Then I spoke with the bus driver assistant and I asked her, 'What happened?' And she said to me, 'What happened is that he stands up on the bus and he cannot do that.' So I asked her, 'Do you know how to sign?' And she said, 'No.' And I said, 'Did you explain to him? The only thing that he is seeing is your body language. He can see and he can feel that you're angry, that you're upset, and he paid a lot of attention to your body language and if you scream at him and you don't explain anything, the kid doesn't understand. If you have to tell him something, you have to tell me so I will explain

to him or you can tell the other teachers in the school. If you cannot explain to him, someone has to do it. Someone has to tell him that when he's in the bus, he has to be seated and he has to have his safety belt on.'

Family 5: A teacher from a school district in California helped the parents in their search for the right school. The parents visited five schools in three different cities in California. The mother said the schools offered different types of communication.

[Mother speaking] I did go to a school where they did try to speak, but it seemed that they were forcing the children too much to do something that they weren't able to do. And I didn't really like it there, so I decided that I wanted him to learn sign language and if later in the future he can speak, that's fine, or if not, you know I just accept him that way.

At first I felt that he was the only child who was like that, but after seeing so many children who were like that, I realized it wasn't only him, there were a lot of children like him. And I realized he will have somebody to communicate with, because he's not alone.

I liked it because they always used sign language. So that's what I liked about that school. And in the other schools I did not like them because they spoke to the children and sometimes they would use sign language, and sometimes they wouldn't use signs. So I decided for him, the best thing would be to have somebody that would always sign to him.

H has attended four schools. The parents chose only the preschool he attended after early intervention.

[Mother speaking] They really didn't allow us to choose a school. The only one we chose was the one in [a city in California]. So really, they've been transferring him to different schools.

Currently, H is in a hearing impaired classroom within a mainstream school. The parents would like to send him to the school for the deaf.

[Father speaking] We've always liked for him to be able to interact with more children and there's a school here where all the children, all of them, they are deaf. We would like him to feel more comfortable. Because you know when there are hearing children, sometimes they say bad words or they make bad gestures and then our son learns them and we tell him that he can't do that because it's bad, but he doesn't understand why it's bad.

Family 6: The mother visited different schools with various educational approaches.

The audiologists gave us the address of the school that would best fit her educational needs. So we went to the school. They started to speak to us and they saw P. That was the way it started. Going there ... then we started to look for a school that was closer to us or that was better.

As I did start visiting different schools, I started to notice that at some schools they would only speak to the children, other schools they would speak and sign to the children, and there were yet other schools that they only sign to the children so I did start to notice these differences, but nobody ever gave me complete information about that.

I have done some research about other schools to see if there are other options for me. I would like a school that offers maybe speech therapy for P. There is some speech therapy there in the school, but it doesn't seem to be enough, so we're looking to see where we could get the speech therapy that we need for P. We're just looking into other resources right now. We're looking to see if maybe she could get the speech therapy maybe in the hospital or somewhere else because I would really like for her to stay in that school, the school she's in now.

... I was never given an option. They would always tell me what they offered at that school. Basically, they have told me, 'Here we have oral and signs,' and in the other one, they only had oral communication.

P started to receive early intervention services at about 1 year of age. P remained in this program for only five or six months. Because the school was far from home, she was moved to a school in another city.

Actually, I didn't choose that school. Well, really the reason was that that was the only school available and one of the only schools that did sign and speak. There was another school in [another city], but that was just an oral school. I wanted to be sure that P was exposed to both speech and signing. It always worried me that maybe P wouldn't be able to use her voice, so I wanted to be sure that she did have sign language available to her.

...I wasn't given the option. I did some research about other schools better or closer, but I could not find them. Only this one and the oral one. After that, we came here, and the school she is in now was the one that was recommended to us. The doctor we have now has also given us two other options for schools, but those schools seem to be too far away from us.

The doctor that we're seeing now doesn't seem to agree with the fact that P is going to the school in [a city]. She feels that it is more important for P to go to a school where they offer speech as well as sign language. She feels that it's the best thing for P.

Family 7: The mother was told that B had a right to receive educational services (in Puerto Rico) at 2 years of age. He started school between the ages of 2 and 2 ½ years. It was first recommended that B receive therapy individually, but the mother wanted him placed in a classroom with other children, and that is ultimately what happened. The mother visited two schools; one was a day school for children who are deaf and the other was for deaf and blind children. She chose the school for the deaf.

I liked it since the first day I visited it. I liked what I saw them doing in the classroom. So that's what I like, and I thought that it would be good for me because I saw that the teacher

knew how to get through to the children and his mechanism of work was excellent. The teacher was excellent and professional in helping children that have this problem.

Upon moving to Pennsylvania, they chose a school based on the doctor's recommendation.

That school, I choose it because the doctor told me that it was the very school for him and I went to see it too, and because all the children have the same condition as he does, and they are professionals that work very well, very well with the children, and that was what I was looking for for him.... They have offered me everything and to see if I want him to participate or not and usually when they have new programs for him, I go to the school and see what they do and everything that they're going to do, they inform me.

Family 8: A meeting with the doctor and a school representative guided the mother in choosing a school.

...They gave me a few schools to pick out for him. That's mainly why I went for [a school for the deaf] because they really got involved with my case and they didn't have to, and they helped me a lot. I mean there was nothing they would not do for my son. Until this day, they still, you know, if there's a problem or if he gets into any trouble, they're there, they're on it, and they don't wait. So they help, they've helped me a lot. I give them a lot of credit.

The mother was also told about another school that J could attend, but rejected it without visiting it.

I heard that when a child signs there, they tap him on the hand with a ruler and I mean they weren't allowed to sign, everything was vocally, but I didn't want, I didn't want my son to be put through any pain, and he already at that age was already teaching me sign...and since [a school for the deaf] was already there for me, and they had extended their arm out for me. They didn't have to. I mean, they had just led me, they didn't have to go through all the things that I went through, they didn't have to be there for me and they were.

The Impact of Culture

Cultural knowledge clearly impacts the design and implementation of appropriate services for these families. After a particularly grim experience with the identification of a child's hearing loss, a Hispanic audiologist reassured the mother from within a more culturally relevant context by saying:

... Perhaps in our countries this is not true, but here there is a lot of help for them. They are like any other child. You just need to look for help, it is there.

Knowing the level of services in Puerto Rico, what the diagnosis typically meant for educational options, and the level of stigma and ostracism within families and communities, the audiologist was able to use her knowledge to be extremely supportive, informative, and effective in her work with this mother. She also understood the vital importance of hope in the life of the family.

The Role of Church and Faith

Many parents cite their religious beliefs and their faith in God as providing sustenance, hope, and guidance through the diagnostic period and as their child develops. Clergy, however, were infrequently mentioned as a source of support. Often a cogent decision-making style and analysis of cost-benefit ratios coexisted peacefully with trust that their faith in God would guide them to the best opportunities for their child; this was often closely related to their hope for their child's future.

Several parents said they believed it was God's will that their child was deaf, and even that they themselves were chosen to be the parents of a deaf child. A few attributed the progress that their child had made to God's intervention or suggested that, at some point, God would make their child hear again.

Family 1: The mother says she put everything in God's hands.

I talk a lot with my pastor. I ask God to give me the wisdom to make proper decisions for him [F], not just what I want. ...I took him to healing service at a church that is about two or three hours away from here when he was 2 years old.... I believe, I am sure that God helped his ears, even though he needs the hearing aids. But God has a purpose for F ... and when F is a man, we'll see.

Family 2: The mother says belief in God gave her strength, but the family does not attend church.

[Mother speaking] Not the church, not a pastor, not a priest, not the church itself, but yes, God, in his totality, the belief of the Powerful God, that is the one who guides us, that who opens the doors and gives us the strength, but to tell you that we went to a church? No, no, no, no. It was God and us. And, yes, he opened the doors for us, he has enlightened our path, which hasn't been easier. The decision about the operation was deciding the future for him. If he wants to learn signs later, fine, I don't have a problem with that, but at least I can say that I did not limit him. We looked at all the alternatives.

Family 3: The parents felt that their religious beliefs have helped guide them in what to do for their daughter.

[Mother speaking] We have always had faith that God is going to help us to move forward.

Family 4: The father says a religious belief provides support.

We all have faith in God. That is the important point, and faith helps us 100 percent, I think.

[Mother speaking] We have this thing we repeat to ourselves, 'God helps us, God will give us strength.' And that has happened, yes, God has given us strength.

Family 5: Although the parents say they are religious, they do not feel that their religious beliefs have been helpful in making decisions.

[Mother speaking] *Well, we really don't look for any type of help. So when we were in Mexico, we didn't go looking for help there and here as well, we really haven't looked for help. We're really waiting for my son, we're waiting to find a church that has sign language for him, so he can go to church.*

Family 6: The mother said she was not influenced *in any way* by the church or religious beliefs.

Family 7: The mother feels that her belief in God has been influential.

I have always belonged to a Christian evangelic religion since I was little, and that has been a big help too.... The church helped me. They told me that there was nothing impossible that could not be done with God's help, and that's the way it has been and thanks to God's help, the child has improved a lot, and I have seen how he is better now.

Family 8: Religion has been a source of some support for the mother.

I prayed a lot. I prayed a lot. I was hoping that the doctors were trying something and say, 'Look, we were wrong. He's still going to be able to hear,' or 'There is something that we can just implant in his ear, don't worry, he's going to be fine,' but I had to accept it. It took me a while, but I had to accept that my son was deaf. I had no choice.

Information and Feelings About Cochlear Implants

Parents in this study were frequently dissuaded from getting a cochlear implant for their child because of the risks involved in surgery and because the benefits of implantation were described as insignificant. Few parents appear to have been presented with the options in a knowledge-based manner, and only a few of the parents in this study had met a child with a cochlear implant. Given the fact that there is now considerable data on both the risks and benefits of cochlear implantation, it appears that parents in this study were not provided with the balanced and comprehensive information they would need to make a decision on this procedure.

For those families who choose cochlear implantation, rehabilitative therapy is essential to maximize benefits, yet in this study there is little mention by the families of the intensive follow-up therapy and processor tuning that are typically required. Thus, it is unclear whether families fully understand the extent to which, with appropriate follow-up, the cochlear implant may assist the child in acquisition of receptive and expressive language.

Family 1: F's mother was told that he would not qualify for a cochlear implant because of the amount of hearing he has and because he speaks clearly. She did not pursue this further, although she has seen other children who have benefited greatly. *If it could work for my son, F would be there* [getting an implant], she said.

Family 2: When T was 3 ½, the doctor brought up the subject of cochlear implantation.

[Mother speaking] *She talked to us about the implants, but she didn't give us a lot of information. She did not insist. It was like, 'This is an alternative for the child and the result*

has been good.’ Because at that moment she had given us that information, the operation was not being performed in small children, in very small children.

At first the parents dismissed the idea, partly because they were told it was an extremely expensive operation (\$45,000 was *way out of our reach*), which their medical plan would not cover, and partly because T was still very young. Then, about a year and a half later, the doctor brought it up again.

[Father speaking] *She told us that doing the operation to children like him...the clinical outlook is perfect for him, for T. The possibilities of improvement for T...not to tell you that it’s going to be 100 percent, but 95 percent. So she said what we will have to deal with is the medical insurance.*

Their medical plan approved the surgery. These parents decided to get a cochlear implant for their child in part because of the information they received from the doctor who diagnosed the hearing loss. They clearly articulated their desire for T to speak and hear. They also investigated the implant option at great length by talking to teachers and to parents of children who had received implants.

[Father speaking] *We started talking with parents that had the operation, looking at the students with the operation, looking at children with the operation, talking with teachers. The teacher gave us names of children we could see that had had the operation.*

[Mother speaking] *And she showed us a child with the operation that was poorly done. So we saw everything. We saw the operation badly done by a doctor. That means it is a responsibility, it’s our responsibility, because we are choosing the future for T.*

T was 5 years old when he had the surgery and at the time of the interview, he had been implanted for nearly two years. The parents are thrilled with the changes they see in him:

[Mother speaking] *From the Earth to the sky! I recommend it to any person if the doctor says that the child is a good candidate and if the parents ask me my opinion. I will recommend it 100 percent....*

Family 3: The parents have received some information about cochlear implants through the news media:

[Mother speaking] *We heard about them after S had stopped seeing her regular doctor, we heard in the news in a TV program, but have not taken her to see if that operation would work for her...what we saw on TV is the only information we have about cochlear implants.*

The mother said she would like to get an implant for S, but has not pursued it further.

[Mother speaking] *A girl that goes to school with our child, she lives close by, we found out that she had a surgery done, but I have not spoken with the mother and I don’t know if that is exactly the type of surgery she had, but we think it was a cochlear implant. We don’t*

know if it has helped her, I don't have any information. S told me that the child had ear surgery but I don't know exactly what....

...We do want to [get an implant for S], but since she does not have medical assistance we would need a lot of money. We are willing to do it, but that has kept us from deciding. Also, I don't know exactly what the surgery is and who can benefit from that surgery.

Family 4: The parents first heard about cochlear implants from a family member who had seen a program on television. The information they received about the cochlear implant came mainly from physicians and focused mainly on the risks, minimizing possible benefits.

[Mother speaking] An article, a device that they put inside of them, what was its name? It is like a cochlear implant; we found out that they were doing that in [a city] so we came here to talk with the doctor, the pediatrician—I do not remember his name. He called and told me, 'You know, ma'am, there is an operation, let me find out more information' and at the time the operation was very popular. They told us the operation is going to be okay, but it was not the recipe [solution]. Then we talked to another doctor, and he told us, 'You know, ma'am, the child will be like this anyway, and this is a risky operation.'

I talked to the teachers and they said, 'The child is going to be exposed to a high-risk procedure and even though the surgery might be a success, he still will not be able to discriminate between sounds. The only thing, the only difference in the surgery is that instead of having his aids outside, he's going to have it inside now.' So we found no reason to expose him to that procedure.

We talked about this with his teacher and she told us, 'I have had some implanted students and they remain the same. There is no change.'

The father added that some of the doctors also indicated that no change in M's audition was likely.

We talked with another doctor and he told us that they recommend the surgery only for people who don't have any residual hearing at all. For them, yes, it is very good. They can improve their hearing and at least they know that there are noises in the outside world, but for M, M can hear noises, like when a dog barks or there is a car, he can really hear that because he starts running right away from it. So we thought it was nonsense to put him through that [the surgery].

The parents chose not to pursue a cochlear implant. However, they indicated a willingness to reconsider.

[Mother speaking] According to the information we were given, we put on a scale the things that we could have after the operation and the things we could not have. That was the most important factor influencing our decision.

[Father speaking] *To do such a thing, we would only need one more thing to convince us, which is reasonable, right? But, until now we have not seen anybody with that surgery. ...If I would have known someone who has it, I would go and ask him.*

Family 5: The parents received information about cochlear implantation from several sources, including a deaf adult, teachers, and medical professionals.

[Father speaking] *We did meet some people who did have the implant done, and we spoke to teachers who are in charge of those children who did have the implants. And we spoke to a deaf adult and asked her if she were able to have the implant, if she would get it done, but she told us that she was happy in the way she was, she was just very happy and satisfied. So we thought about that, and we thought that maybe our son, you know, could be just as happy as he is. So we decided not to make any decisions for him.*

...At the children's hospital was where they told us about it. There was an ear, nose, throat specialist there and he told us about it. He recommended the implant to us and he did tell us what risks there were and we just thought it was a very risky surgery, so we decided against it. Because we thought maybe later he may be in a worse situation. Because even now, even though he's deaf, he still has no type of pain or anything. But if we did go with the implant and if it did cause some type of paralysis of some kind, maybe hitting some type of nerve or something; so I think he would have some type of pain later or headaches, or something, I don't know. So we decided against it.

[Mother speaking] *Well, we see that he's happy this way. He plays, he runs around. But I think that if he would have the implant then there would be some type of risks.*

Teachers also dissuaded the parents from choosing cochlear implantation.

[Father speaking] *Yes, well at the school he was at, there was a teacher there that we discussed this with. There was a boy there at the school who had an implant, so we asked his teacher what type of response did this child have with this cochlear implant and the teacher said he did make sounds, but he did not speak. So we decided that it wasn't as effective as they had originally told us. They had told us that it wasn't going to function the same with each child, so we decided not to do anything with that.*

Family 6: The parents received information about cochlear implants from two doctors, one of whom spoke Spanish and gave the family a lot of information, including books and Internet resources. The parents were told that the implant might improve P's hearing. Ultimately the parents chose not to get an implant.

Well, there were many reasons. First of all, the biggest reason was because they didn't promise us that P could speak or hear with it. The second reason was because the surgery was a little risky, and the other reasons were that they told us there were many things she could no longer do once she got the implant, and I thought it would probably just be best for her to grow up the way she is now, not having any restrictions.

Family 7: The mother said she has heard about cochlear implants from *women in [her son's] school*, although it is not clear if these people are teachers or mothers. She has not met anyone with an implant and has not made a decision about an implant for her son.

They said that it was only for people that have profound loss of hearing or bilateral and that it is good, and that in other children it gives good results.... In reality, I have not thought about whether that operation would be a benefit for him.

Family 8: The mother has gotten little information about the possibility of cochlear implants for J.

As a matter of fact, last year during the summer I went to take J to a new doctor in [a city]. ...They asked me, would I like for my son to have that surgery and that it was very rare, you know, it's new. And I told them that I would think about it. They told me that they would give me a call again, but I never heard from them again.

I was hopeful, but I didn't want to put my son through all that pain. I didn't know exactly what he had to go through in order to get those implants in his ear. So I didn't want to put him through any suffering.

The mother said she has seen a few children at J's school with implants, but doesn't know how well they work.

I just don't want to put him through any pain. I mean he's a healthy boy. He's, I mean, he's very healthy, and when I mean healthy, I mean he's big, he's chunky, runs around, he plays. He does everything that a normal kid would do, it's just that he can't hear and I don't want to put him through any pain that he doesn't need to be in. I mean I would love, I would love to be able to hear him say 'Mom, I love you' without him having to sign it to me, but I don't want to put him through any suffering. I don't want to.

Families' Satisfaction

The parents in this study were more satisfied with the options presented to them than were non-Hispanic parents. The authors hypothesize that with less information transmission, there is less confusion, and the heightened satisfaction may be illusory. However, differences in the expectations of professionals and the future potential of their child may impact on this as well. The impact on these and other factors may be strongest for those families who have come to the United States to obtain audiological and educational services, at least in the initial period of acculturation. This was confirmed by the presence of increased expectations for information from parents who are more fluent in English, have resided in the United States for a period of time, have a network of professional friends and colleagues, and understand the availability of informational resources in the United States.

Family 3: The mother said she is happy right now because her daughter can read and write.

[Father speaking] Yesterday we went to a meeting and they gave us very good news. She is one of the most advanced students in her class and for next year they want her to attend

certain regular classes, with hearing children, along with her interpreter because she is very advanced.

[Mother speaking] *Right now she is learning everything that a hearing child of the same age is learning, because we have compared her with a nephew who is in the same grade as S. He knows how to read, she knows how to read; she knows how to add, how to subtract, we could say that she is at the same level as a hearing child because they are teaching her everything.*

Family 4: The parents expressed satisfaction with M's progress in school. They are active participants.

[Father speaking] *We help with his homework. When they tell us that there is an activity, we are there. They only need to let us know where and when. We're always paying attention to everything they tell us. Communication is constant and continuous. We don't have any doubts about that.*

Above all, the greatest satisfaction we have are the grades he brings home. It also makes us happy when we receive reports detailing all the different things he is doing fine. If there is a low grade, we know we have to help him, but we are on his side.

Family 5: The parents express dissatisfaction with their ability to communicate with H because they need to learn more sign language. They express a moderate degree of satisfaction with H's current school placement.

[Mother speaking] *... Because the teacher he's with now, she's fine.*

[Father speaking] *... [However] we're not satisfied because he's in a class with children that can speak.*

Family 6: The mother feels that she and other members of the family need to learn more sign language. She has been satisfied with her ability to obtain information to make decisions and is happy with the school her daughter attends.

Her principal concern at this time is with regard to education.

This is exactly what we want, for her to have the best education possible. Really my biggest concern with her is her school achievement, we want for her to have the best possible. I hope that academically we've made the right choice and that we've chosen the best school, you know, the school that she's at now.

Family 7: The mother feels satisfied with the school and with her choice to come to the United States. She expressed dissatisfaction with her ability to communicate with her son through sign language, recognizing that she needs more classes.

Family 8: The mother is very satisfied with the school her son attends. She feels that she and her other children communicate well with J, although other family members, such as her sisters, do not.

I felt sad because they don't know what they are missing.

She is also concerned about the difficulty J is having in learning to read and is trying to find answers.

I don't want to dismiss it and have it be something that comes up later on, like what happened when he was deaf, when I found out that he was deaf. I don't want to dismiss it and just, you know, I don't want to. When it comes to J, I made a mistake once, keep dismissing it, oh yes, ear infection, ear infection. It could have been resolved then and he probably wouldn't have been deaf.... But I dismissed it and oh, just let it be, oh it was just ear infections, and now I sit down and I wonder, what if, what if I could have taken more action then.

The mother also said she feels that now that her son is 10 years old, he should be involved in decision making.

I've made a lot of decisions for him, but lately I've had him choose what he wants to do too, because it's important, now that he's 10 years old, that he has to also make decisions. So he's made quite a few decisions for himself too.

Section 3: Implications for Service Providers

Language Difficulties

While there is much that isn't known about the interplay of language with factors such as client characteristics, acculturation, and fluency levels, the recognition of the importance of culture and respect for language preference applies not only to American Sign Language and Deaf culture, but also to Spanish and Hispanic culture. The families interviewed greatly valued the opportunity to converse in Spanish with a member of the community. It may be concluded that:

- cultural matching may ultimately prove to be the critical variable in interventions; and
- trilingual interpreters would be well-equipped to address the complexity of translation and interpretation, and should be very involved in innovating future linguistic solutions for Hispanic families with a child who is deaf or hard of hearing.

Information—Family Demographics

Some 58 percent of the fathers and 39 percent of the mothers enrolled in this study had not completed high school. Although the authors did not inquire about perceived literacy, significantly fewer (55 percent) Hispanic parents were given written materials for review than non-Hispanic parents (92 percent). With the limited access to health care for this community (one-third of Hispanic families in the United States do not have health insurance), informational channels are significantly reduced for many families, making the direct service provider communication and relationship even more vital. Some suggestions:

- Further investigation in the areas of resource material development, building informational telephone networks, and computer utilization for Hispanic families with a child who is deaf or hard of hearing is clearly needed in order to ensure equal access to information.
- Hispanic families need all available information regarding communication methods; this study demonstrated that information provided reliably affected how the families' decisions were made.
- Because Hispanic families have significantly less access to other parents of deaf children, they may benefit greatly from peer support. Facilitated parent groups based in the community (e.g., homes, churches) could serve to connect families and provide needed support.

Choices in Language, Communication Modes, and Educational Approaches

Second language learning is a challenge for many children. Of course, it is affected by language exposure and positive associated emotions, to name just two variables. But to master the first and second language requires full access to rich and continuous language. Forty percent of children in English as a second language (ESL) programs don't master their second language, let alone a third language. Hard choices may need to be made. How should choices be made for these children? Should they be taught in the language of their family of origin, or should a choice be made to give them primary access to the language of the community with which they will most likely affiliate? How much of a role should professionals play in this decision making and how? If the decision is

made to emphasize the language of the child's presumed future community, how can home communication be supported?

There is little knowledge base here. The authors realize that Hispanic families are presented with fewer options, such as cochlear implants. It also appears that Cued Speech is rarely considered as an option, although it's not clear if this is due to a lack of knowledge within the Hispanic community about Cued Speech or if Cued Speech is not thought to be a good choice for families who are struggling with English in the home. If a Hispanic family is presented with the news that their child is deaf or hard of hearing and can learn a manual representation of their language, parents may wish to try to begin to offer their language to their child. Some suggestions:

- Literacy and shared reading programs with reading role models need to be offered to families with cultural matching for families from different cultural backgrounds.
- Further elucidation of parental preference of language is needed on an individual, clinical, and community level.
- When presenting information to Hispanic families, it should be acknowledged that the limits of what is known (e.g., the relative merits of speechreading, auditory training, etc., for children who must negotiate at least two spoken languages daily) are not identified.
- An international collaboration may be very helpful in understanding the balance between the benefits of seeking services in the United States and the challenges of trilingualism. The families came to the United States seeking a new and better life. Would they have achieved the same general well-being (and satisfaction) if they had remained in their country of origin? Is it the hope and striving for a better life that helps in sustaining the added stress?
- Hispanic families should be told about all educational options.

Culture and Faith

Cultural knowledge clearly is important in the design and implementation of appropriate services for Hispanic families. This includes an understanding and appreciation of the importance of religion and faith as well as other aspects of Hispanic culture. Some suggestions:

- A significantly greater presence of Hispanic professionals, educators, and peers (on every level, including summer youth employees, volunteers, parent-to-peer, etc.) is needed.
- Programs must be responsive to the unique nature of communities and their needs. Hispanic Americans have a higher level of religious values affecting their caregiving.
- Heightened understanding of religious values should be an important training component in deaf services programs.

Section 4: Background and Additional Information About the Study

The Hispanic American Population and Deafness

Individuals of Hispanic descent constitute the largest minority group in the United States, accounting for 12.5 percent of the total population (U.S. Census Bureau, 2000). This rapidly growing United States minority group is a heterogeneous community of Americans and immigrants who derive their cultural identity from Mexico, Puerto Rico, Cuba, and other countries in Central and South America and the Caribbean Islands. Individuals in these groups share certain cultural traits, such as the Spanish language, emphasis on the importance of family, and many unique cultural traditions, but differ in other characteristics (Becerra & Zambrana, 1985; Seligman & Darling, 1989). Among individuals of Hispanic descent living in the United States, 4.2 percent, or more than 900,000 individuals, have hearing impairments, according to the National Center for Health Statistics (1994).

The extent to which culture influences decision making has not been adequately studied. The authors completed a pilot study of Hispanic families with a deaf child in which the families' perceptions, attitudes, and beliefs about deafness were explored, as well as their experiences in adjusting to the child's hearing loss and their perceptions about the accessibility of services (Steinberg et al., 1997). Families reported feeling shocked, sad, and frustrated at the time of diagnosis. Many of the Hispanic families interviewed attributed the cause of their child's deafness to "an act of God." Many expressed difficulty dealing with their community's stigmatization and lack of understanding about their child's deafness and deafness in general. Although most identified some problems with communicating with their child, most Hispanic parents rated their communication with their child as adequate via speaking and speechreading in Spanish and/or English, home made gestures, and nonverbal expressions of love and acceptance.

Most families were keenly aware of and valued the higher quality of specialized services that are generally provided at no cost to families in the United States when compared to the vastly different quality and cost of services to deaf and hard of hearing children in their countries of origin. Some families admitted to remaining in the United States, separating themselves from their country of origin and extended family, in order that their child may receive a wider array of services. Thus, they experienced the additional stress of separation from familial and community supports. Although these experiences are not unique to families of Hispanic origin, the ability of the families to deal successfully with the strain at diagnosis may be influenced by cultural and cross-cultural factors of the family, community, and professionals rendering care.

The Decisions of Hispanic Parents of Children with Hearing Losses

The decision-making process is a complicated one, influenced by emotions, beliefs, values, and expectations. In the United States, the majority of parents of newly diagnosed deaf and hard of hearing children share the same language and culture as the professionals from whom they seek help. Nevertheless, the frustration can be daunting, as is articulated by this mother:

...It was like someone put this 18-month-old baby on my lap and said, 'We want you to raise this baby in his native tongue, culture, and educate him in a different kind of way—by the

way, we want you to learn language, but the experts are still arguing what is right.... But you have to know now and make decisions now! And this is during the most upsetting year of your life anyway! I wanted someone to take care of my child and me and show me the right thing to do. (Luterman, 1987)

Considering this experience, one can easily imagine the increased difficulty parents from minority cultures, particularly those whose primary language is not English, may have in coping with and successfully navigating the decision-making process for their deaf or hard of hearing child.

Janis and Mann (1977) proposed a model that requires the initial steps of appraising the challenge and surveying the alternatives. These steps require that parents have access to complete and accurate information in order to make decisions for their child. The first decision-making point faced by parents is at the time of diagnosis. Even when parents and professionals speak the same language, the information presented at diagnosis may be misunderstood. A difference in the language spoken by professionals rendering care and families receiving the information may increase the chances for misunderstanding, difficulty, and stress. Further, in a more recent survey, Hispanic parents reported a more negative impact of deafness compared to white, non-Hispanic parents (Meadow-Orlans, Mertens, Sass-Lehrer, & Scott-Olson, 1997).

For Hispanic families, the choice of communication mode may become even more difficult if the spoken language used in the home is different from the spoken language used in school. Families in this situation thus face the prospect of learning two new languages: English and a sign language.

In addition, the issue of educational mainstreaming takes on added complexity when the family itself does not communicate in the language of the majority culture (Cohen, Fischgrund, & Redding, 1990). Further, several studies suggest that Hispanic families underutilize support services that are available in the school system (Bennett, 1989). In the special education setting, parents of Hispanic heritage seldom participate in the development of their child's Individualized Education Programs (Stein, 1983; Delgado, 1984).

This document is based on a study that is built on two other decision-making studies:

1. an ongoing study of parental decision making among families from the Philadelphia area, including two Hispanic families; and
2. a previous study, "The Hispanic Deaf Child and Family: Cultural Perceptions About Deafness" (Steinberg et al., 1997), which included nine Hispanic families.

The studies have been shaped in large part by information gathered from parents of deaf children; the parents themselves have pointed to areas where cultural differences can lead to misunderstandings and stress.

The authors were interested primarily in the decisions parents make for their deaf child regarding the child's use of early intervention services and entry into preschool and elementary school. A previous study with non-Hispanic families indicated that it is at these transitional points that choices are made that will impact the direction of the child's life. A focus of this study was the

extent to which choices were influenced by differences in the availability of various options, the family's capacity to access services, and the family's expectations.

Research Methods

To represent a variety of cultural backgrounds, 29 families of Hispanic descent were recruited from these four geographical areas in the United States:

1. Florida
2. Texas
3. California
4. Pennsylvania

Members of each of these communities were hired to assist in the recruitment of subjects, the collection of data, and the translation of interviews. Families who volunteered to participate were asked to complete two questionnaires and participate in a one- to two-hour, semistructured interview. Interviewers and/or community facilitators helped the families fill out questionnaires when necessary.

The instruments (the interviews, surveys, and preference studies) of the study were adapted from the authors' existing study of parental decision making and modified to be culturally and linguistically appropriate for individuals of Hispanic descent.

Interviews

Interviews were conducted in either English or Spanish, according to the families' preference and, with consent, were audiotaped and/or videotaped. Interviews that were conducted in Spanish were translated into English. All interviews were fully transcribed. The interview was designed to gather information about parents' or other involved family members':

- knowledge, attitudes, and beliefs about deafness and disability prior to and after their child's diagnosis;
- experiences during the diagnostic process, including their ability to communicate fully with the professionals giving them information;
- understanding of the information presented, including information about options available;
- perceptions of what is helpful, not helpful, and harmful;
- opinions about the manner in which information was presented;
- thoughts about the influence on their decisions of external factors such as program cost, geographic location, transportation, and available options;
- perception of the influence of family and community support on their choices;

- perceptions of other key factors that have influenced their choices, including their family structure and resources, cultural values, and family stress;
- choices made regarding communication mode, language, early intervention, and school; and
- satisfaction with services available, support received, and choices.

Surveys

A questionnaire gathered basic demographic information (age, gender, family composition, education, ethnic identification, etc.) as well as specific information about the child's hearing loss, interventions that had been used, the child's progress, communication methods used, sources of support and information, parental attitudes about deafness, family stress, and parental satisfaction with options available and guidance received.

Preference Studies

Preference studies assessed the preferences of parents for different possible outcomes for their deaf children. A rating scale was used as the preference assessment method because it was easiest for the families to understand, and it was the easiest method to administer (it can be self-administered).

To capture the variety of long-term outcomes that occur in deaf individuals, a multi-attribute system containing a large number of health states and a wide range of outcomes was developed. For each attribute (which included academic achievement, social life, emotional well-being, and ability to communicate), scenarios of possible outcomes at age 18, ranging from poor to good, were developed. Age 18 was selected because there are standardized academic achievement goals for this age and because, by that age, the major effects of the education and socialization processes have been achieved. Additionally, the preference studies assessed the educational choices and communication modalities (sign language versus lipreading/speaking skills) preferences of the parents.

Data Analysis

Interviews

Interview transcripts were analyzed using qualitative methods described by Miles and Huberman (1994). Thematic codes were developed and applied to the transcripts using a computer program called FolioViews, which allows for easy compilation of all segments coded with a particular theme. Each interview was coded by at least two researchers. The senior research analyst resolved disagreements between the coders.

The semistructured and open-ended interview was designed to allow informants to discuss issues of importance to them, with guidance from the interviewer but with few directed questions that would have elicited yes or no answers. Thus, issues emerge somewhat spontaneously, and not all informants directly addressed the topics that the authors subsequently chose to analyze. This

process allows analysis of the families' experiences as well as their insights, cultural beliefs, and language. Interview segments were compiled according to the themes of interest and then re-sorted into sub-themes if necessary. Compiled segments were then analyzed to extract content relevant for the subject of interest.

Surveys

Most items in the surveys were summarized by tables of frequency counts, percentages, and, whenever appropriate, by transforming the four- to-five-point Likert scales to numeric values for the means and standard deviations. In addition, plots and confidence intervals were used to make comparisons between the Hispanic and non-Hispanic groups.

The comparison group of non-Hispanic subjects includes 78 families from various geographical areas who completed the same survey as part of other investigations.

Preference Studies

In the preference studies, parents were asked to rate their child's and their own quality of life on a linear scale and to consider each attribute separately and rate various choices on a similar linear scale. A multidisciplinary team with expertise in working with deaf and hard of hearing children and adults developed the attributes. The parents were also asked to allocate points among the four attributes (academic achievement, social life, emotional well-being, and ability to communicate) to reflect the relative importance of these attributes.

The preference studies were analyzed by attaching a value to each outcome. The value was determined by dividing the distance on the scale from the worst outcome to the outcome of interest by the distance on the scale from the best to worst outcome.

Results of the Surveys

Subjects (Parents)

Eighteen of the interviews were conducted with mothers only, one with the father only, and nine with both the mother and father. One interview was not transcribed and it is unclear who participated in the interview. Questionnaires were filled out by 28 mothers and one father.

Parent Educational Levels

All parents had at least some high school education and about one-third also had a college education.

Family Life

Seventeen (59 percent) of the 29 children in the Hispanic group live with both their mother and father. Six children (21 percent) live with their mother only, and two (7 percent) live with their mother and stepfather. The remaining four (14 percent) live with family other than parents.

Twenty-one parents (72 percent) report having other children, and the average age of the siblings is 1.7 years. Three parents (10 percent) report that their deaf child has other deaf siblings. Four parents (14 percent) report that there are extended family members (e.g., cousin, uncle, grandparent) who also have a hearing loss.

Description of Children

The group of deaf children consisted of 14 boys (48 percent) and 15 girls (52 percent). Their ages ranged from 53 months to 167 months, with an average of 103 months. Eight children (28 percent) had at least one disability other than deafness (three of these children had two disabilities).

Fifteen children (52 percent) had a profound hearing loss, eight (28 percent) had a severe hearing loss, three (10 percent) had a moderately severe hearing loss, one child (3 percent) had a mild hearing loss, and the remaining two (7 percent) were unknown.

The causes for the children's hearing loss varied from prenatal infection to heredity, and about one-half of the parents did not know the reason for their child's deafness. The average age at which hearing loss was confirmed was 24 months, with standard deviations of 16 months. The average age at which the parents suspected that their child had a hearing loss was 14 months.

Use of Assistive Devices

Twenty-four children had hearing aids (83 percent), and the average age that they received their aids was 32 months. Eight parents reported that their child always wears the hearing aid, eleven said sometimes, and four said that the child rarely or never wears it. More than half of the hearing aids (15 out of 24) were provided by public assistance programs. Two hearing aids were provided by insurance companies, one was purchased by the parents, one was provided by the school, and two were obtained or provided through other means. The remaining three families did not respond to the question.

Twelve parents (41 percent) considered a cochlear implant as an option for their children. Of these 12, six parents had their child evaluated for the implant. Four children (14 percent) underwent cochlear implant surgery. Of those four parents, three reported that their insurance covered more than 75 percent of the cost for the cochlear implant. The fourth parent did not answer this question. All four parents reported that they are very satisfied with the cochlear implant.

Training

All children in the study received training for their hearing losses. Nine children (33 percent) received auditory training, with training starting at ages ranging from 15 months to 72 months. Four parents (14 percent) reported that their child received training in Cued Speech. However, information obtained in the interviews did not support this high percentage of Cued Speech. In fact, most of the parents were not aware of this approach. We suspect that the discrepancy lies in the translation of the forms from English to Spanish or from the parents misunderstanding the meaning of Cued Speech. Twenty-seven children (96 percent) received training in sign language, with

training starting at ages ranging from 3 months to 108 months. Twenty children (71 percent) received speech training, with the age that training began ranging from 12 months to 84 months.

Communication Mode

The way in which the parents usually communicated with the child at home was also surveyed. The largest proportion of parents reported using speech and sign to communicate with the child; an additional two respondents also added Cued Speech, and an additional three added gestures. Two respondents said they use Cued Speech, speech, and sign, plus some gestures. Two use sign alone, with the help of gestures. The rest of the parents generally use a combination of signing, some speech, and gestures to communicate with their child.

Preferred Language in the Family

Spanish is the primary language used in the home (by 55 percent). Three parents (10 percent) cite Spanish and some sign language as their primary means of communication. Two parents (7 percent) state that they communicate through a combination of Spanish, English, and signing or gestures. One parent responded that the children speak English and the parents speak Spanish. Four parents (17 percent) use English and some sign language to communicate with their children. One parent cites English as the family's primary means of communication. One parent uses Signed English as the primary means of communication, and another parent states that American Sign Language is the primary language used in the home.

Educational Intervention

Seventeen parents said their child is enrolled in early intervention or other school program; among all 29 parents, about half said that the school their child goes to uses a combination of speech and sign, but *no* gestures, in their approach. Another three parents said the school adopts speech, sign, *and* gestures. One parent reported that the school uses speech with the help of gestures, but there is no signing. The remaining 10 respondents did not answer these questions.

On the average, parents are satisfied with the services their child and family receive from the schools. Thirteen parents (45 percent) report that services were provided for their child at a center or school. Ten parents report that their child's program has deaf adults on staff, and one parent does not know if deaf adults are on staff. Nine parents (35 percent) report that their child (or their family) receives services at home. Fifteen parents (79 percent) report that their child's program is provided by the local school district.

Eleven parents (38 percent) report that the time they spent in their child's formal program ranged from zero to 40 hours per week. Fourteen parents report that the time their child spends weekly in a formal program ranges from four to 56 hours. Thirteen parents (45 percent) report that the time they spend each week teaching their children at home ranges from one-half hour to 168 hours, and one parent responds about spending "every day" teaching the child at home.

Attitude About and Knowledge of Deafness

Hispanic families are more positive about learning to sign and communicating with deaf people than non-Hispanic families. Ninety-six percent of the Hispanic families agreed to the statement: “Children should be taught sign language so they can talk to deaf people”; only 70 percent of non-Hispanic families agreed. However, Hispanic respondents are marginally less likely to think that sign language is a proper language.

The Hispanic families’ positive attitudes toward sign language are also accompanied by the belief that deaf children can learn to speak. They are also reliably less inclined to favor the mainstream educational settings for deaf children.

Use of Resources

Six aspects of resource utilization were studied: whether or not the parents have been given written or videotaped information about different approaches, sign language or Cued Speech instructions, parent meetings, individual counseling, and use of interpreters. The respondents were also encouraged to report any other forms of information that they have received.

Of the Hispanic and non-Hispanic parents who reported having received the information listed above, Hispanic families utilize the resources differently. They are less likely to have received written or videotaped information about different hearing intervention options. Ninety-two percent of non-Hispanic families received written information about different options, whereas only about 55 percent of the Hispanic families were given written materials about different options. Hispanic families were also marginally less likely to be given videotaped information about various options in helping their child.

On the other hand, Hispanic families are slightly more likely to be given instructions about sign language. Their utilization of interpreters is also reliably more frequent. Approximately 68 percent of the Hispanic parents needed help from an interpreter, whereas only 21 percent of non-Hispanic parents needed an interpreter. However, the questionnaire did not differentiate between use of Spanish language interpreters or sign language interpreters.

The participation in either parental meetings or individual counseling is similar in Hispanic and non-Hispanic families.

Almost every Hispanic parent found the services that were available to be helpful if they were given access to them in the first place. In general, almost all families found the resources helpful. Non-Hispanic families rated some of the resources as slightly less beneficial, including instruction about sign language and Cued Speech, individual counseling, and the use of interpreters.

Feelings as a Parent of a Deaf or Hard of Hearing Child

Parental feelings were measured by 10 items regarding parents’ feelings of control and how adequate they feel about being a parent of a deaf child. The items assess feelings about parent-child communication, decision making, responses to special needs of the child, and competence of being a parent in general. These statements included: “I enjoy being a parent,” “My communication skills are quite adequate for my child’s needs,” and “My child is often left out of family conversations

because of communication problems.” The items give a concise summary of a few important issues in raising a deaf or hard of hearing child. The authors used the average of the 10 items to represent the general feelings about parenting for each respondent. Higher scores represent better general feelings.

Likert-type responses were first transformed into numeric values for calculating the scores. The values are 4, 3, 2, and 1 for “strongly agree,” “agree somewhat,” “disagree somewhat,” and “strongly disagree,” respectively. Coding for negative statements is reversed.

Similar feelings about parenting are found in both groups. The non-Hispanic average scores were slightly higher (with the mean at 3.28, the median at 3.2, and the standard deviation at 0.42) than those of Hispanic parents (with the mean at 3.24, the median at 3.3, and the standard deviation at 0.33). Standard two-sample t-tests indicate that the difference is not statistically reliable.

Respondents generally feel good about their parenting. The average ratings are near the “agree somewhat” response, and most of the responses (for example, within plus or minus one standard deviation of the means) fall between the positive ratings of 2.5 and 3.5. Among all 107 respondents, only three of them had an average lower than 2.5.

Such positive feelings are inconsistent with the interviews. Social desirability may be present or perhaps the items fail to capture parental stress, but the interviews provide better in-depth discussions of their difficulties. The interview transcripts indicate that many parents experienced a tremendous amount of stress. Parents typically described “crying” or feeling “shocked” when hearing loss was confirmed. Denial and disbelief were commonly reported. The difficulty of communicating with the child and financial strain were also frequently mentioned.

Decision Making

The decision-making and support section of the survey included the amount of involvement in decision making by parents, grandparents, other family members, and friends. The involvement of professionals, educators, community, and religious members is also included. The results showed that mothers were most involved in decision making, with a mean rating of 4, or “very involved.” This was followed by fathers, with a mean rating of 2.86 (slightly less than “somewhat involved”); the family doctor, with a mean rating of 2.3 (more than “somewhat uninvolved”); and friends and grandparents, with mean ratings of 1.79 and 1.74 respectively (somewhat less than “somewhat uninvolved”). Teachers, counselors, and spouses were rated as most supportive, followed by specialists, the child’s grandparents, other parents of deaf children, friends, other relatives, the family doctor, and clergy.

The most important factors in the families’ deliberations were the recommendations of professionals and the services provided by the local school district. The parents thought that the most important factor in professional assistance is that the health care professionals are able to “listen to my concerns.” The availability of services close to home, cost of services, and the recommendations of friends are relatively less important.

Differences between the Hispanic and non-Hispanic groups were tested with standard two-sample t-tests. Mothers were the most involved persons in both groups. However, Hispanic fathers were reliably less involved in the decision making. Non-Hispanic families gave higher ratings to almost all other social support; their average ratings were around the “agree somewhat” and “strongly agree” range. Hispanic parents felt somewhat less supported by others; on the average, they rated support from grandparents, relatives, and friends as “disagree somewhat” and “agree somewhat.”

In particular, Hispanic families had significantly less access to other parents of deaf children. Their decision making was primarily affected by the services provided by local school districts, and the cost of the services was somewhat important. Both professional experiences with deafness and the information provided affected reliably strongly how the Hispanic families’ decisions were made. The influence of the clergy was not significantly stronger in the decision making of the Hispanic families. Compared with other social support, the influence of the clergy in their decision making was small. It is true among both Hispanic and non-Hispanic groups that teachers and counselors tended to be the most important, more important than family members such as grandparents and other relatives.

Limitations of This Study

Sample Size

The demographics of the Hispanic community in the United States necessitated sampling individuals from diverse backgrounds and living in very different communities; the demographics also imposed significant restrictions on the number of individuals who could be included. While the small sample size limits our ability to generalize the study, the recruitment from various geographical areas and through different sources minimizes the risk of sampling too narrow a range of respondents. Nevertheless, because of the size and diversity of the Hispanic community, a larger study would be needed to understand fully the barriers that face this community and the efforts that have been made to overcome these obstacles.

It should be noted that the researchers chose not to probe immigration status in the study. The researchers did not wish to assume that the Hispanic subjects might be illegal immigrants, or to add stress to the interview of those who might be in that status.

Selection Bias

In contrast to what has been observed in some previous studies, many of the families in this study appeared to act as strong advocates for their children and to display a high degree of satisfaction. As with any study of this type, in which subjects volunteer to be questioned or interviewed in detail, there is the possibility that families who are less involved or less satisfied will be missed, either because they do not wish to volunteer or because the recruitment effort fails to reach them. Thus, the authors cannot be sure that this study is representative of the full range of experiences and sentiments.

Translations

Translation of the interviews from the families' native tongue into English presented several problems. First, there is the general problem of whether the interpreter fully comprehended and accurately interpreted the context and content of the families' responses to questions. Native Spanish speakers did all of the translations. The authors attempted to minimize translation problems by hiring translators who live in the community in which the interview was conducted. Unfortunately, several of our translators were unable to fulfill their commitments, and because of time and distance constraints, some of the translations were done outside the home community. This created some interpretation problems because the translators were sometimes unfamiliar with the dialects and accents of the families.

There were also translation problems with the written questionnaires and with the semistructured interview questionnaire. These questionnaires were initially translated by a Hispanic health care professional from South America and then reviewed by several other Hispanic professionals and a college student who was fluent in Spanish. The community facilitators also had an opportunity to suggest changes in the questionnaires. Nevertheless, it appears that some of the questions were misunderstood. For example, on the written questionnaire, parents are asked if they have used Cued Speech ("habla mostrando, indicando") and several replied that they had; yet no one mentioned Cued Speech in the interviews. Because the use of Cued Speech is relatively uncommon in the United States, it seems unlikely that any of the parents in this study had any knowledge of or exposure to the method.

There are other examples of misunderstanding between the interviewer and the families. For example, one interviewer asks if the mother knows what the communication and educational philosophies are for this program. The mother responds, *The philosophies, what do you mean?*

Interviewer: *What concept does the program use?*

Mother: *The concept of drawing and computer games for the children, like with the computers.*

Interviewer: *Did you know the school's philosophy about communication?*

Mother: *They have some philosophy because when they know that the kid can pronounce the words, they make him speak until the kid uses his own words, then they call us and let us know that he can speak some words. So we have to make him pronounce it, because at that school there are kids in regular school and others in a hearing impaired program so they can hear the other kids normal. When the teacher knows that they can pronounce the words, he makes him pronounce it.*

It is not clear in this case whether the misunderstanding was language-based or due to different cultural perception. The interviewer intended to ask whether the program advocated a specific approach or point of view, but the responses indicate that the families may have interpreted the question differently.

The interviews that were audiotaped in Spanish were translated and transcribed into English, and this paper is based on these interview transcripts. When the paper was being translated into

Spanish, the authors returned to the original interviews and had them transcribed into Spanish to avoid retranslating the now-English quotes back into Spanish. A review process was used at the Laurent Clerc National Deaf Education Center to ensure that the English and Spanish versions were as close a match as possible. In both versions, every effort was made to maintain the true expressions and emotions, the true spirit, of the families' interviews and of the author's words. The Clerc Center believes that both versions of the paper are as equal as possible and that edits made during the translation process were professional and truthful.

Researchers' Bias

The interviewers and community facilitators were instructed that they were not to espouse their own preferences regarding communication modality, school, or other interventions. This is one of the most difficult parts of conducting this type of research, particularly when the interviewers are familiar with the field or are professionals dedicated to helping parents in these situations. Parents often have misconceptions about the availability of certain services and the risks and benefits of different options, and many interviewers feel they have an ethical obligation to correct such misconceptions. At the same time, the interviewers may have had their own biases or misconceptions that occasionally slipped into the interview discussions. This underscores the need for unbiased, comprehensive, and accessible information for both parents and professionals.

Section 5: Appendix

Full Family-by-Family Version of This Document

(Please note: This full family-by-family version presents the comments in full from each family; it is the same information presented in the rest of the paper, but it is organized differently.)

Family 1

Description of the Family

The interview was conducted in Spanish with the mother. F is a 6-year-old boy with a severe-to-profound hearing loss. He lives in Florida with his mother, 14-year-old sibling, and cousin. No other family members have a hearing loss. The mother has completed two years of college and works outside the home. The family speaks primarily Spanish in the home, but mixes in English. The children speak English well, and the mother says that her 14-year-old son, who has normal hearing, speaks Spanish *very poorly...his first language is English*. The family moved from Puerto Rico when F was born.

Events and Emotions Surrounding the Diagnosis

Shortly after the family moved from Puerto Rico, it became apparent that something was wrong when F slept through a loud fire alarm.

[Mother speaking] I went to the pediatrician, and I told him all what had happened, and that everyone was telling me that there was something wrong with my baby, and that perhaps it was mental retardation, I never thought that it was because of his ears and then I took him to the health center...and the doctor told me that there was nothing wrong. Some time went by. When he was 7 months old I took him again for his medical appointment for his vaccinations and I told the doctor, 'My baby is not like other babies, something is wrong with him.' And he told me, 'I'm the doctor, you are a mother, you are not a doctor.' But I told him, 'I have four children, and this baby is not the same.' And he told me, 'I am telling you that mothers see things in their children that they do not have. Your son is fine.'

I went to the emergency room and registered him as if he had spent the night very ill and I said to the lady that he had been very ill all night. When I went into the emergency room, the doctor asked me what was wrong with the boy, and I was crying and I told him, 'I think my baby is deaf because I talk to him and he does not turn around and I give him books that make music and things that make sounds and he does not look at them.' I had him sleeping on my lap and the doctor clapped his hands and he gave me a referral and sent him [to the hospital], then he told me that he had a problem. I took him there and then that is where they did the evaluations, they checked him and that is where they confirmed to us that he was deaf. The diagnosis was a severe-to-profound hearing loss in both ears, more in the right than in the left one.

The mother said when she first told F's father that F was deaf, he blamed her and refused to accept the diagnosis. A few months later, F's father came to visit from [another country] and later decided to move to the United States and learn sign language. After some medical testing, the mother was told that F's deafness was due to measles and a high fever that he had contracted when he was 2 months old.

The mother said she felt guilty when she found out her child was deaf.

I felt guilty because ... I don't know why. ...when I had [my older child] I said I would have no more children, but I got married again, and after five years my husband kept on saying that he wanted a baby, a baby, a baby, a baby, a baby. ...I was told that women must have their children when they are young. My own mother was quite old-fashioned and said that older women have children that are born retarded, that they aren't born healthy, that they must have their children in their 20s, and that is how my grandmother and my mother were, and I thought this was the right way to do things. And so I thought, 'Look, I had this child when I was 34 years old, and look, he was born deaf.' So, I felt guilty, because in order to satisfy my husband and have a baby, he [the baby] has to suffer, because I am not the one who is deaf, and although I try, and do everything I can for him, it's his life. He's my son, I'd like to hear for him, or give him my ears, but he's the one who is deaf, not me.

Language Differences at Diagnosis and in School

The mother said she had trouble understanding the doctor at the diagnosis of her child's hearing loss.

... When [the doctor] told me, 'He's deaf,' I did not understand the term 'deaf,' I was not familiar with it, I did not know what 'deaf' was. When he told me it was a 'severe-profound hearing loss,' then I could translate it word-by-word and I understood: severe-to-profound hearing loss, but I did not know what 'deaf' was. And I asked him, 'Is there someone here that speaks Spanish? Because I do not understand.' Then he [took hold of me] by the shoulders and said to me, 'It is not that you do not understand, it is that you do not want to understand.' And I told him, 'I do not understand what deaf is. What does 'deaf' mean?' Then he said to me, 'No hearing.' And I said to him, 'He does not hear?' and he told me, 'No.'

Interviewer: Did they give you an interpreter?

A nurse who spoke Spanish came.

Interviewer: How did you feel talking with an interpreter after just being told?

I felt as if I was 'at home' because she... she ... was a Mexican woman, a very good person, and she said, 'Don't cry, try to calm down so that I can tell you what the doctor has said.'

They explained things to me, but it is very difficult because they explained things to me in English, with medical terminology.

Interviewer: Do you feel that language was an impediment at this moment?

Yes, it was an impediment, because...if it had been in Spanish, although it was hard to accept anyway, one can ask questions, one is free, one can ask the questions like one wants, but it is hard when one feels like they are trapped by a strange language. The words don't come out, they don't come out. I just asked, 'Why, why, and why?' and 'What can I do? What can I do?' and they said, 'There is nothing we can do, he's deaf.' And this I'll never forget because they always said, 'There is nothing that we can do, there is nothing that I can do, there is nothing that you can do, he's deaf.' And that's how things stood.

Information Access and Support

The mother says she was told that there was nothing that could be done for F, no operation. She was given a pamphlet written in English, which she had trouble understanding.

So I began to read, and I came to understand that in addition to hearing aids, there is an operation to connect tubes, as this helps them to alleviate the pressure of the liquid that stays, and I began to call doctors to find who, who could help me, where I could take him, and I got an appointment to take him to [a children's hospital] in [a Florida city]. And that is where they gave me hearing aids, and there they gave me an appointment with an ENT [ear, nose, and throat] doctor. He did an evaluation and referred me to an audiologist and they recommended (he was almost 9 months old now) that I take him, that I register him with the county where we live, to register him in the county and in school.

A Hispanic audiologist explained how the ear works and why F could not hear. The audiologist suggested that the mother register F at school, learn sign language, put hearing aids on him, and show him how to use them all the time. The mother said this audiologist *took her time with me and with him* and was *very sweet, very human*. She explained that F needed to start school right away so he would not fall behind. Another professional, whom the mother refers to as a nurse (this person appears to be Hispanic), was also helpful.

The woman, the nurse, that helped me and gave me the support I needed on the day that they told me he was deaf, she told me, 'Don't be self-conscious, look for help. Look for help for your son because there is a lot of help. In this country, there is a lot of help. Perhaps not in our countries, but here there is a lot of help for them. They are like any other child. Just look for help, it is there.'

At 11 months of age, F was registered for school and got his first hearing aids. The mother began sign language classes and also received a video that explained how deaf people hear. She found the video to be very helpful.

The mother sought a second opinion from another doctor. This doctor informed her of available government services, such as Social Security Disability Insurance, and also recommended that F begin school right away.

Choosing a Communication Method

The mother received conflicting advice about communication methods. The family developed a good relationship with the early intervention teacher, who advocated total communication.

I had to decide what type of communication we would use, sign language or...whatever we would do. The teacher contributed a lot, she helped us a lot, because she explained the advantages of total communication, which is what we use with him. If he goes out and has contact with other people, if I had taken the advice of 'only sign language,' when my son goes out to play, those children that are outside will not understand him. And she explained these things to us. Well, she is in favor of 'total communication.' And there are other teachers that are not, but I had the good fortune to have her help me with this. And I believe this was the most difficult decision of all that I have done with my son. The biggest thing I have done is to decide how to establish communication with him.

The teacher in F's pre-kindergarten class, in contrast, did not believe in total communication. The mother asked the county to change his school and they did.

The audiologist also influenced the mother's decision.

The audiologist told me, 'If you put him in school, if you put him in speech therapy, if you always are sure to have him use his hearing aids, when he goes to school, he will be able to go to a regular school.' And she told me, 'I cannot guarantee this, but as a result of my experience, I can assure you that this will occur, because the children that are cared for in time receive good training, they overcome, they excel, and it is true.' My son is now in a regular classroom, in a regular kindergarten class, and he has an interpreter. But he is in a regular classroom.

The audiologist was the mother's chief source of information. She also considered other programs: a private school, which she rejected because she didn't have the resources and it was far away, and an in-home program. The audiologist said the school program would be better because the materials available there weren't available in the home. The mother also observed some home visits and felt there would be too many interruptions in her home. The school program she chose uses total communication and was *fantastic*.

Language Preferences

The mother expressed some regret that her older (hearing) son does not speak Spanish.

We are trying to avoid the error we made with the older boy, so that later he will follow his culture and language, which is Spanish. We want them also to speak in English. But with them, with the three little boys, we are trying to educate them to be trilingual, that they will be able to speak Spanish, English, and know sign language.

However, she was discouraged from using Spanish with F.

They told me only to use signs, or if we would use signs with Spanish or English. They have always been against my using Spanish. The teachers have always been opposed to this. They want it to be English, and that it is English in signs. But they say that Spanish will confuse him, because it is hard for him...but [laughing] he understands Spanish perfectly.

Interviewer: How do you feel about this advice they gave you?

They are mistaken, they think professionally, they are not part of our culture. And they have no idea how important it is for us that our children preserve their language—that they dominate and perfect English, but that they also dominate and perfect their own language. This is very important to me. He has a family, he has his grandparents and aunts and uncles that speak no English, and know absolutely no sign. So if my son does not speak Spanish and understand Spanish, he will be completely lost within his family.

I want him to be trilingual when he is an adult so that he interacts with his family in Spanish, that he obtains a good job, that he is well paid because he can speak three languages, that if someday he finds himself in a group situation where everyone is deaf, he will be able to communicate with them on an equal basis, that he does not feel apart from the Hispanic group because he is Hispanic, that he does not feel as an outsider with deaf people because he is deaf, and that he does not feel as an outsider with English because he lives here, it is the language of this country and he must be fluent. I think he will have more advantages than other people. And for this reason, I want him to be able to communicate in the three languages.

School Choice, Personal Style, and Advocacy

F has attended five different schools. At age 6, he is in a regular kindergarten class with a sign language interpreter. He is the only child with a hearing loss in the class and goes to a hard of hearing class in the afternoon. The mother has had to fight hard to get what she felt was appropriate for F, and she was assisted by a program specialist for the school district's deaf and hard of hearing program.

The school where he is now I did not choose, I didn't want it. But the county said that there is no other one, and they assigned him to this school. I made them change, because there, there was no voice used in the class because they are deaf. I communicated with people that helped me. There is a woman that works for the county ... she helped me a lot. Thanks to her, I basically got what I wanted, which is to have an interpreter in F's class, and that the teacher of the class is oral because she is not non-oral, she is oral and can talk. I spoke with the superintendent of the schools, of all the schools in the county. I explained all that was happening with him, with my son, what I wanted for my son, and the things to which he has a right. I read a lot. And...I knew that even though they told me that they had an interpreter, they really didn't have one, and they had to look for one. ... I suppose that they didn't have the money, but they got it and assigned one, an interpreter. The school, the school itself is okay. It has a good program, it's just that if you don't pay attention, the program is not handled appropriately. But now, for F, well, it's super.

The mother has also demonstrated the importance of advocacy for her child through her interactions with other parents.

I've made friends with the mothers of children that have been with him. And from there, with another mother, I'm in the process of organizing a support group for the parents of deaf children...for Hispanics and Americans also, because it's incredible, this summer we went to a camp organized by [the school]. And in this county, as big as it is, there is nothing, there is nothing. We are like this, just as you see us, nobody knows anything, and from there came the idea to form a group...of parents, of mothers...that are trying to obtain that which they [the deaf children] have a right to have, that which the law says they're entitled to have. And if I have to force them to change the law, they'll have to change it. [laughter] ...when I can't express myself in English, I speak in Spanish and let them look for someone to explain it to them because they must hear me out.

I have learned things. Yes, I at least, I think, that I need to investigate more, and know someone who knows more, and gain more information. I have learned from the experience of other parents, situations different than mine, or ones that are similar. And these, and these experiences about which I have been told, when they happen to me, as is what has happened, I know the consequences of the things that can be done. I have studied the law, the law IDEA [Individuals with Disabilities Education Act], I have studied it. I have studied about the things that are necessary, Total Communication, sign language only, or English only. For example, I met a young man that speaks Spanish and English. It's very hard ... his speech isn't clear, perfect like ours. But he speaks Spanish, he speaks English, and he knows sign language. It can be done...it can be done. ...There are people, there are young adults I have seen that are fluent in all three languages. I know that it can be done. I know that each case is unique, but I know it can be done.

What has worked for me is that one must sit down and I write down 'pros,' this will work for this, this, and this, and I make two lists. It doesn't work because of this and this. Which one has more? Which can I eliminate of the ones that don't work? What can I eliminate of those that function when they are related to ones that don't function, in order to make a balance? Because when [one] looks at things [like] this, they appear differently.

The Role of Church and Faith

The mother says she put everything in God's hands.

I talk a lot with my pastor. I ask God to give me the wisdom to make proper decisions for him [F], not just what I want....I took him to healing service at a church that is about two or three hours away from here when he was 2 years old. ...I believe, I am sure that God helped his ears, even though he needs the hearing aids. But God has a purpose for F...and when F is a man, we'll see.

Information and Feelings About Cochlear Implants

F's mother was told that he would not qualify for a cochlear implant because of the amount of hearing he has and because he speaks clearly. She did not pursue this further, although she has seen other children who have benefited greatly. *If it could work for my son, F would be there* [getting an implant], she said.

Family 2

Description of the Family

The mother and father were present for the interview, which was conducted in Spanish. T is a 7-year-old boy with a severe-to-profound hearing loss. He lives in Florida with his parents, brothers, and sisters. The mother is a homemaker and the father works in a blue-collar position. The family moved from Puerto Rico six years ago looking for better services for their child, although at that time, hearing loss had not been confirmed.

[Father speaking] [We moved] *primarily, because in Puerto Rico we knew he was going to be marginalized and we knew that here we were going to find better services related to doctors and education.*

The parents suspected deafness because T did not babble and had a high-pitched cry. In addition, as a result of birth complications, he had been in intensive care and had received medication that could have been ototoxic. The parents attributed his hearing loss to this medication, but later learned that he had other congenital problems that suggested he might have been born deaf.

Events and Emotions Surrounding the Diagnosis

Shortly after arriving in the United States, T's hearing was tested and he was found to be deaf. After that, the parents took him to an audiologist, where a profound hearing loss was confirmed. T was nearly 2 years old at this point.

[Mother speaking] *When I asked the doctor what were the alternatives, she told us there were no alternatives—only the hearing aids that cost almost \$2,000. We did not economically have \$2,000. We were at the mercy of the medical insurance if it would cover it or not because there was no more help.*

With the diagnosis, the mother said she felt as if *walls fell down*.

... We had a tendency to think that everything is okay and I thought everything was okay, and then you know how I think, now this.

Language Differences at Diagnosis and in School

The diagnosis was given in English, but an audiologist who spoke Spanish was there as well. An interpreter was not needed, according to the mother, *because I understand English well*. She said she understood everything at the diagnosis. The mother also said she would call the Hispanic

audiologist when the doctor was away or when she had questions about hearing aids or other things.

[Father speaking] *All the time we talked to her, it was in English. By language, we have never been discriminated nor have we had lack of information. Everything has been clear like in black and white.*

Information Access and Support

T was already in a Head Start program prior to diagnosis because his speech development had been slow. At diagnosis, the parents were told that his hearing loss was severe to profound.

[Mother speaking] *...My question was what alternatives there are, and how can the child progress with this because that was our concern. She told us that the alternatives that there are now are not that many because the child is one step before being deaf. ...And then when she shows us the hearing aids, she tells us the hearing aids are for him, for his condition, she shows us and tells us, the hearing aids cost a lot, the medical plan does not cover it, but we can do the arrangements and then my husband and I decided, well, we have to do the arrangements because he has to have them and there is no other alternative. There is no other alternative and then after that, she talked to us about the school in [another city].*

At every moment, we look to see if there is another alternative besides the sign language—we want it, we want that alternative. She told us, ‘Everything is going to be clear when the boy has the hearing aids, with the way that he uses his residual hearing, how much he will be able to hear.’ But with the hearing aids there was not much success so that’s when we decided on the operation.

The doctor went on to explain cochlear implants to them at that time. While the parents were satisfied with the medical information they received from the doctor, they understood that other sources were needed to find out about educational alternatives. They also understood the underlying motivations of educators from different school systems.

[Mother speaking] *It depends on the professionals. If the professional is the doctor, they’re going to talk to you in the way of the doctor. If you are in the school, and the professionals of the [county], they get paid by the [county] so they’re going to offer you the alternatives that [the county] has and if you’re in [a city in Florida], you’re going to get the alternatives of [a city in Florida]. So the ones from [the county] are not going to say, ‘You don’t want signs, well then there is a school in [a Florida city] and we’re going to transfer you there.’ You’re never going to hear that. Never.*

Interviewer: So do you think they were giving you the alternatives?

Only in accordance to what they had in the county, not the alternatives that I wanted for my son.

Choosing a Communication Method

At first, the family began using some signs with T, *to reduce his anxiety with communication*, but dropped them after about six months. The parents favored an oral approach.

[Mother speaking] *The people in the county were offering us sign language ... we had to look for other alternatives because we don't want to limit him.*

[Father speaking about visiting two schools] *We didn't like it because they were using only signs and they were not speaking clearly, they only made noises. We went to the other school where there were children with the same condition and they were talking. So from that moment on, that's when I said, 'This is what I want for my son.'*

School Choice, Personal Style, and Advocacy

The family had purchased a home in one town, then learned that a nearby city offered an oral program for children with hearing aids. The parents negotiated with their hometown to pay for their child to go to the nearby city and to transport him there. T began in a class that was for children who were mentally retarded, but the parents objected and managed to get him moved into another class.

[Mother speaking] *We have friends that are lawyers and they help us and they counseled us, 'Tell the county that you want a teacher that is specialized in working with hearing impaired children. And since they don't have it, they have to transfer you automatically because of the law. The child has the right.' And we went to talk with the county and the board and she prepared us with a binder with all the laws and she underlined all the laws with a highlighter very clearly, all the rights that the child had....*

[Father speaking] *Yeah, the rights that we have, but the county is not interested in recognizing....*

[Mother speaking] *One is never told about all the alternatives one has. When we opened the file in the meeting, they saw that the legal part was also there and we expressed our point of view. Of course, we were prepared ahead of time, both of us, what were we going to say, how we were going to talk about it and of course there were problems because there were people that were not in agreement with it, but we were prepared for that. So then finally they transferred our son. So, then the doctor saw that we were pushing for the child's well-being and she realized that we were fighting for our son to succeed, not only for the operation.*

The Role of Church and Faith

The mother says belief in God gave her strength, but the family does not attend church.

[Mother speaking] *Not the church, not a pastor, not a priest, not the church itself, but yes, God, in his totality, the belief of the Powerful God, that is the one who guides us, who opens*

the doors and gives us the strength, but to tell you that we went to a church? No, no, no, no. It was God and us. And, yes, he opened the doors for us, he has enlightened our path, which hasn't been easier. The decision about the operation was deciding the future for him. If he wants to learn signs later, fine, I don't have a problem with that, but at least I can say that I did not limit him. We looked at all the alternatives.

Information and Feelings About Cochlear Implants

When T was 3½, the doctor brought up the subject of cochlear implantation.

[Mother speaking] She talked to us about the implants, but she didn't give us a lot of information. She did not insist. It was like, 'This is an alternative for the child and the result has been good.' Because at that moment she had given us that information, the operation was not being performed in small children, in very small children.

At first the parents dismissed the idea, partly because they were told it was an extremely expensive operation (\$45,000 was *way out of our reach*), which their medical plan would not cover, and partly because T was still very young. Then, about a year and a half later, the doctor brought it up again.

[Father speaking] She told us that doing the operation to children like him...the clinical outlook is perfect for him, for T. The possibilities of improvement for T...not to tell you that it's going to be 100 percent, but 95 percent. So she said what we will have to deal with is the medical insurance.

Their medical plan approved the surgery. These parents decided to get a cochlear implant for their child in part because of the information they received from the doctor who diagnosed the hearing loss. They clearly articulated their desire for T to speak and hear. They also investigated the implant option at great length by talking to teachers and to parents of children who had received implants.

[Father speaking] We started talking with parents that had the operation, looking at the students with the operation, looking at children with the operation, talking with teachers. The teacher gave us names of children we could see that had had the operation.

[Mother speaking] And she showed us a child with the operation that was poorly done. So we saw everything. We saw the operation badly done by a doctor. That means it is a responsibility, it's our responsibility, because we are choosing the future for T.

T was 5 years old when he had the surgery and at the time of the interview, he had been implanted for nearly two years. The parents are thrilled with the changes they see in him:

[Mother speaking] From the Earth to the sky! I recommend it to any person if the doctor says that the child is a good candidate and if the parents ask me my opinion. I will recommend it 100 percent....

Family 3

Description of the Family

Both the mother and father were present for the interview, which was conducted in Spanish. S is an 8-year-old girl with a profound hearing loss. She lives in a small town in Texas with her parents and a 1-year-old sibling. The mother is a homemaker and the father works in a skilled trade. The family moved from a small town in Mexico seven years ago, looking for a better life and a better job.

[Mother speaking] *In Mexico there are no possibilities for a good life. There aren't many jobs out there, the pay is very low. It is very difficult to live in Mexico.*

The parents speak only Spanish, but say that S is learning more English than Spanish in school.

Events and Emotions Surrounding the Diagnosis

The parents first began to suspect hearing loss when S was 2 years old because she wasn't talking or paying attention to them. Although the family was living in the United States, they lived near the Mexican border and they took her to a doctor in Mexico, who referred them to an ear, nose, and throat doctor (also in Mexico). The doctor told them S was deaf.

[Mother speaking] *It was very bad for me because I was not expecting it. All of a sudden he told me that my daughter could not hear anything and that she would never be able to speak...those were his exact words. He did not even examine her. The first time we went to him, he did not [examine her], he only checked her as he would have for any other illness, such as a cold, and later he said, 'The child does not hear and that is why she does not talk.' He said, 'She does not hear a thing and if she does not hear a thing, she will not speak a thing.'*

After hearing this news, the mother talked to an aunt who lives in another state; the aunt called the school nurse at her son's school, and the school nurse called the school near where S and her family lived. The school contacted the mother, ran some tests, and then referred her to a program, which sent her to a city in a different state for hearing tests. The tests showed that she was *almost completely deaf*. It was about two months after the initial diagnosis that they received the conclusive diagnosis. They also took her to a second doctor in Mexico, who gave similar test results.

Both parents said they felt very sad when they learned of their child's deafness.

[Father speaking] *We think the worst, that she may not be able to speak, that she will not be able to study, that is the first thing that comes to your mind.*

Language Differences at Diagnosis and in School

At the diagnosis, the parents said that although the doctors and audiologist did not speak Spanish, interpreters were always available.

[Mother speaking] *Also, we never had any difficulties regarding that [language] because they always have people that help us [translate] with the doctors, at the school, with everything. They always have someone who speaks Spanish. One struggles but, well, one wishes that the doctor would explain things. Many times when they are translating they use different words and one can get confused, maybe that is not exactly what the doctor means.*

Nonetheless, the mother said, *We think that we understood everything that we were being told.*

At school, S's current teacher speaks Spanish, although some of her former teachers have not. This has at times created difficulties, with the mother having to seek out someone to translate. Written information was often sent home in English.

[Mother speaking] *I was talking with the teacher a few days ago when we went [to the school] and I told her to send me the messages in Spanish because there are times they are in English, and I just look at them because I don't understand them...we would like to be able to speak the same language as them, but if, I mean, that would be better, for us to speak the same language, but we do understand each other more or less.*

...Sometimes one struggles, but does it affect us? No, because this is an area in which most people speak the two languages. If she does not speak it, the person next to her probably does; therefore, it is not too difficult.

Information Access and Support

S was fitted with hearing aids right after the conclusive diagnosis in a Texas town. She was 3 years old at that time.

[Mother speaking] *They told us that in one ear she is completely deaf, and in the other ear she can hear a little bit.... They only told us that she needed the hearing aids, that she was not a candidate for surgery because her problem was in the nerve that is connected to the brain, and that cannot be corrected with surgery, but that with the hearing aid she could speak, maybe broken, that was a possibility if she used the hearing aids all the time. It was a possibility, but it was not something for sure, but maybe she could hear more.*

[Father speaking] *The doctor who performed the last hearing evaluation said that there was an operation, maybe it is already being done, but at that time two or three years ago the operation was not available, that maybe when they would start performing that operation she might be able to get it.*

[Mother speaking] *The doctor said to get the hearing aids and to find a special school for her and that was going to help her. That is what he told us to do.... He told us about a program in New Mexico that helped us a lot, and he told us where the schools were located.*

The mother added that since they left New Mexico, S no longer has a regular doctor, and *therefore we don't know if there is something new that might help her.*

The audiologist gave the parents information about hearing aids.

[Mother speaking] *That they were going to help her hear a little bit more and possibly they could help so that she could talk.*

Information from Deaf Adults and Other Parents

The family realized that their daughter could be successful after discussions with other parents of a deaf child.

Not too long ago we spoke to the parents of a deaf boy and they said that their child is doing great. Also, the mother of an older deaf boy, now a young adult, was telling us that her boy did very well in school and that he is in college now. When we hear that, we tell ourselves that our daughter is going to make it, just like him. Before we would think that our daughter was not going to be able to [learn], she is going to be a nobody; we were traumatized [aggrieved] by that. When we see [positive] things like this, it helps us move forward.

Language Preferences

S's first language is sign language, but the mother thinks it is important that she also learn both English and Spanish.

We were discussing that with the teacher when we went to talk with her. I thought that it was too much for S because she was learning sign language and English, and I wanted to teach her Spanish. I asked the teacher if it was too much for her to teach her the three languages and the teacher said that she could do it. I told her she is learning to read and write, but she writes in English. My relatives tell me how great it is that she knows how to read and write, that way they can write to her, but [she reads and writes] in English and nobody in my family knows how to read or write in English. I would like for her to learn Spanish because that would make it easier for us to communicate with her. I believe that all three languages are important. Because the family speaks Spanish, at school she needs to communicate in English, and she needs the sign language if she is not able to speak.

The mother also said she speaks to S in Spanish and S seems to understand. She doesn't feel this has affected S's progress in school.

School Choice, Personal Style, and Advocacy

The mother said that at first there were no special school programs available so her daughter was attending a regular school program.

[Mother speaking] *...the teachers were trying to teach her and to learn themselves at the same time, it did not help her much. When we moved to this city, that is when she started attending a special school.*

[Father speaking] *The doctor here in [a city] did tell us that if we placed her in a special school she was going to speak, not the same as we do, but with time she would speak.*

Once the family moved to a small town, the local school referred the mother to the school for the deaf in a neighboring city. The mother says it is a good school that uses sign language and speech. She was not given any other options from which to choose and did not visit any school programs.

The Role of Church and Faith

The parents felt that their religious beliefs have helped guide them in what to do for their daughter.

[Mother speaking] *We have always had faith that God is going to help us to move forward.*

Information and Feelings About Cochlear Implants

The parents have received some information about cochlear implants through the news media.

[Mother speaking] *We heard about them after S had stopped seeing her regular doctor, we heard in the news in a TV program, but have not taken her to see if that operation would work for her...what we saw on TV is the only information we have about cochlear implants.*

The mother said she would like to get an implant for S, but has not pursued it further.

[Mother speaking] *A girl that goes to school with our child, she lives close by, we found out that she had a surgery done, but I have not spoken with the mother and I don't know if that is exactly the type of surgery she had, but we think it was a cochlear implant. We don't know if it has helped her, I don't have any information. S told me that the child had ear surgery but I don't know exactly what....*

...We do want to [get an implant for S], but since she does not have medical assistance we would need a lot of money. We are willing to do it, but that has kept us from deciding. Also, I don't know exactly what the surgery is and who can benefit from that surgery.

Family's Satisfaction

The mother said she is happy right now because her daughter can read and write.

[Father speaking] *Yesterday we went to a meeting and they gave us very good news. She is one of the most advanced students in her class and for next year they want her to attend certain regular classes, with hearing children, along with her interpreter because she is very advanced.*

[Mother speaking] *Right now she is learning everything that a hearing child of the same age is learning, because we have compared her with a nephew who is in the same grade as S. He knows how to read, she knows how to read; she knows how to add, how to subtract, we could say that she is at the same level as a hearing child because they are teaching her everything.*

Family 4

Description of the Family

The mother and father were present for the interview, which was conducted in Spanish. M is a 12-year-old boy with a severe hearing loss. He lives in Texas with his parents and a 17-year-old sibling. Both parents work outside the home. The mother is a bookkeeper and the father is starting a business and currently works in a restaurant. The family moved to the United States from Mexico four years ago.

[Mother speaking] [A son] *should be the priority, right?*

[Father speaking] *We had the option because when we realized that he was not hearing well he was about a year old. Since he was born in [a city in Mexico], we didn't really know if he could hear or not. There the doctors in [that city] are more deficient. They didn't take the precautions to find out. When he was about a year and three months, he entered school. Since that time he has been in school with speech therapists and all those things. He was in a special school for deaf kids.*

The parents speak Spanish in the home, although the mother says she fully understands English, studied English at a community college for one year, and is taking a course at a college. The father said he understands spoken English better than he reads English. *My English is about 50 percent,* he says.

Events and Emotions Surrounding the Diagnosis

The parents first realized M had a hearing problem when he was 1 year old because he was very quiet.

[Mother speaking] *My family is very expressive and shows many expressions of affection, and when we were playing around, I noticed my son made a great effort to laugh. I noticed he wasn't able to make basic sounds, no 'papa,' just 'ab-ab-a.' And he would babble very little. A year later he continued to babble 'aba,' instead of 'agua' [water]. That is why I thought he had no residual hearing back then. Then I took him to his pediatrician and he told me not to worry. ...Another thing he asked was if I had any deaf people in my family and then he said, 'Do not worry, there are some kids that start talking late or maybe they have a problem with their tongue, what they call a tied tongue.'*

The doctor recommended that they see a speech therapist. After four months, there was little progress.

[Mother speaking] *Then [the speech therapist] told me, 'You know your son has a problem. I am going to ask you to take him to a neurologist.' That was when we brought him here [to the doctor], they did an evoke response test and they told us he was deaf. We took him to the doctor, with a neurologist, in [a city in Mexico]...when he gave us the news, it was like a bucket of cold water showered us. 'Your son is deaf. You have to take him to an institute so he will learn to talk.'*

The parents said they were at first disturbed to learn of their child's deafness, but then became optimistic.

[Father speaking] *It was very traumatic, because one sees the problems sometimes with a certain kind of stigma that you will say, 'Oh, what am I going to do?' One thinks that we're just going to draw on our glass of water and sometimes that is not the truth. We have learned how to live and we are very happy with the kids, and we realize that there are many ways and other sources that we can help him with so he can progress and succeed, and I think they are doing it right now. There is hope there. We have hope. M is really progressing right now and we're just waiting for something new to come out. This is our hope.*

[Mother speaking] *We just felt that he was going to suffer a lot. We thought that he was, that it's going to be all right, then at the same time we thought that we have to help him out, we have to do something about it. We are very happy. We have a great family. We are a good couple. We have a great marriage. We talk to our [other] son, and we told him the news that his brother was deaf. We were all very sad because he's a kid that has his limits now, but if you think the positive way and you analyze, one has to be calm in this kind of situation. We have to look for the solution. If a door is closed, we have to go and see if there is another one open and that's the only way that we're going to be able to help him.*

Language Differences at Diagnosis and in School

The diagnosis was given to the parents in Spanish. The audiologist who fitted M with hearing aids spoke English and a nurse interpreted. The parents say that for the most part, they can understand the audiologist's English, but sometimes ask the nurse to translate just to be sure they are understanding him correctly.

Most of the time information from the school is given in Spanish, but sometimes, especially outside of school, only English is used.

[Father speaking] *We don't know the English language as we should—we always struggle with it. It has never been, for me and I think for my wife too, it has not been a problem. It is an obstacle, though, because it's been more than just understanding it. Everything that we have been told and/or we have been given an opinion on, and at school, for the child, and about his health—we have understood everything perfectly, I think. When there is a doubt, we look to others to clarify it; we don't keep anything that, I mean, well, no, no, no, we find a way.*

[Mother speaking] *Yes, yes. That is very important. We always ask, always ask. If we don't understand, we will say, 'Listen, lady, we have some questions. We don't understand something. Please help us. We have doubts about this and that....' Everybody makes an effort.*

Information Access and Support

The family obtained information from a school for the deaf.

[Father speaking] *They gave me a lot of literature. It was all about behavior, education, and the school itself, things that he could do here in the school, what was the most convenient thing for him to do.... It helped us a lot, especially about his education, which is the topic we are talking about. They gave us options that he could have, but then we didn't know exactly what we were going to do. They gave us ideas on where we can go or what we can do. Then they just told us you could go to this school, to this place, to that other school. They told us he was going to learn how to sign, he was going to have his speech-language therapy with him and they told us also that he was going to learn how to read lips and all of that. Now we can see things more clearly.*

The parents felt that the information they received was highly supportive and offered in a spirit of teamwork.

[Mother speaking] *I felt that they were giving us that information and advice because they were inviting us to participate in everything that had to do with M. I thought that we were putting together a nice team to help him out.*

Information from Deaf Adults and Other Parents

Meeting deaf adults has been helpful to the parents.

[Mother speaking] *There are a lot of people that we met and they really are the ones who are helping us, intervening with decisions. We were looking for someone to help us with a solution to the problem and there we met a gentleman. He's someone from real estate and he gave us an address that we can go and meet this couple. They have a daughter and both are deaf, but they seem to live a normal life. They communicate pretty well with us. They both work and she doesn't really have a lot of audition, but he does, a little bit, and we thought that if they can do it, we think that M can do that too. That's what everybody tells us.*

Choosing a Communication Method

The teacher at the school for the deaf apparently presented the parents with only one option, sign language combined with speech. The parents expressed satisfaction with this option.

[Father speaking] *They [the teachers] told us that it's a system that goes together for him to better express his ideas and to better understand other people and for him to also express his ideas in a better way. They [signs and speech] were always used together. They always have to go together for support. ...At the beginning, I didn't agree with the sign language because I thought that he first needed to learn how to talk. He has a teacher that is also deaf, but she can talk.... When she talks, she does signs and she moves her lips at the same time and one can understand the word and that is one of the things that made me think sometimes that one day my son is going to be able to talk like her or at least to make himself be understood.*

Language Preferences

The parents communicate with their son primarily through English-based sign language.

[Father speaking] *We removed the Spanish completely because Spanish and English, both together, it was too much to mix for him. We definitely said no more sign language in Spanish. If he forgets his signs in Spanish, well, what are we going to do?*

I wish he could learn both, but it's very hard for him, and the most important thing is that he learns how to sign in English in order to communicate. That's the reason that we are here. That is the option that we made and he can learn English now, and maybe later he will be able to do sign language in Spanish.

[Mother speaking] *Before he used to sign both English and Spanish and he was getting confused.*

[Father speaking] *We would like for M to continue his sign language in English because it's what he knows more right now and it's his future. We are not planning to come back to Mexico, so first it's the English, and then maybe Spanish, if he can.*

School Choice, Personal Style, and Advocacy

The parents say they never sit still.

[Mother speaking] *You have to grab the bull by the horns or things will go downhill.*

[Father speaking] *We are looking for everything out there. We are trying to push him as much as we can and we are determined to do everything we have to do in order to help him. We never just stay in one place and don't do anything. We need another opinion or other advice. We are always looking for another opinion, always, always, always. We have had that idea, my wife and I. We always have to keep going, looking for what is there, what is next. I remember when that doctor told me that M was deaf, he told us in Spanish. We felt pretty bad, but since then we have never stopped. We also have sought a lot for God's help.*

[Mother speaking] *We know that the future of our son is in our hands, and we have to place him in the right hands, the right people that really are capable of giving him the tools to*

succeed.... I see a bigger future for M. I'm not going to cover the sun with my hand, I'm just going to let the sun come out and see him.

When M was 4 years old, the family moved, and the parents went to a center with an early intervention program for special education children.

[Mother speaking] [What] they told us was that they were going to study M's case and they were going to see what they can do. They really tell, they really told us what they already have prepared. These are the resources that we have and we trust them, we trust what they were telling us and they gave us all the information and written papers. So we analyze what they give us, and it looks good for us, we believe that that is okay for him. But they didn't mention to us about other things outside of what they offer.... When they talked to us about their programs, we said that is fine, it's okay.

They didn't give us options. They gave us that option, and we saw that obviously M is not talking. He is going to use the signs and the lipreading. I think that that is the best for him. If they give me another option, and we can take it, we can go ahead. We are very open. But, up until now, this is the best option we have. The best and the most important thing they told us is that M was going to go up to wherever he wants to go and they told us that they were going to help us in every way. What I like about the program is that they told us that M was going to go farther. They didn't tell us, 'Okay, M is going to be in this program and he's going to get up to here, up to this point, and that's it.'

The parents have found it necessary to advocate for their child in a range of situations.

One of the things that has bothered me is the transportation, where I have not obtained a good answer. Last year we had a problem with the person that used to take care of him in the bus that brings him home. Every time the bus would come he would start crying, he said he didn't want to go to the school anymore in that bus and I was wondering, what is happening, what is going on now. Then I spoke with the bus driver assistant and I asked her, 'What happened?' And she said to me, 'What happened is that he stands up on the bus and he cannot do that.' So I asked her, 'Do you know how to sign?' And she said, 'No.' And I said, 'Did you explain to him? The only thing that he is seeing is your body language. He can see and he can feel that you're angry, that you're upset, and he paid a lot of attention to your body language and if you scream at him and you don't explain anything, the kid doesn't understand. If you have to tell him something, you have to tell me so I will explain to him or you can tell the other teachers in the school. If you cannot explain to him, someone has to do it. Someone has to tell him that when he's in the bus, he has to be seated and he has to have his safety belt on.'

The Role of Church and Faith

The father says a religious belief provides support.

We all have faith in God, that is the important point, and faith helps us 100 percent, I think.

[Mother speaking] *We have this thing we repeat to ourselves, 'God helps us, God will give us strength.' And that has happened, yes, God has given us strength.*

Information and Feelings About Cochlear Implants

The parents first heard about cochlear implants from a family member who had seen a program on television. The information they received about the cochlear implant came mainly from physicians and focused mainly on the risks, minimizing possible benefits.

[Mother speaking] *An article, a device that they put inside of them, what was its name? It is like a cochlear implant; we found out that they were doing that in [a city] so we came here to talk with the doctor, the pediatrician—I do not remember his name. He called and told me, 'You know, ma'am, there is an operation, let me find out more information' and at the time the operation was very popular. They told us the operation is going to be OK, but it was not the recipe [solution]. Then we talked to another doctor, and he told us, 'You know, ma'am, the child will be like this anyway, and this is a risky operation.'*

I talked to the teachers and they said, 'The child is going to be exposed to a high-risk procedure and even though the surgery might be a success, he still will not be able to discriminate between sounds. The only thing, the only difference in the surgery is that instead of having his aids outside, he's going to have it inside now.' So we found no reason to expose him to that procedure.

We talked about this with his teacher and she told us, 'I have had some implanted students and they remain the same. There is no change.'

The father added that some of the doctors also indicated that no change in M's audition was likely.

We talked with another doctor and he told us that they recommend the surgery only for people who don't have any residual hearing at all. For them, yes, it is very good. They can improve their hearing and at least they know that there are noises in the outside world, but for M, M can hear noises, like when a dog barks or there is a car, he can really hear that because he starts running right away from it. So we thought it was nonsense to put him through that [the surgery].

The parents chose not to pursue a cochlear implant. However, they indicated a willingness to reconsider.

[Mother speaking] *According to the information we were given, we put on a scale the things that we could have after the operation and the things we could not have. That was the most important factor influencing our decision.*

[Father speaking] *To do such a thing, we would only need one more thing to convince us, which is reasonable, right? But, until now we have not seen anybody with that surgery.... If I would have known someone who has it, I would go and ask him.*

Family's Satisfaction

The parents expressed satisfaction with M's progress in school. They are active participants.

[Father speaking] *We help with his homework. When they tell us that there is an activity, we are there. They only need to let us know where and when. We're always paying attention to everything they tell us. Communication is constant and continuous. We don't have any doubts about that.*

Above all, the greatest satisfaction we have are the grades he brings home. It also makes us happy when we receive reports detailing all the different things he is doing fine. If there is a low grade, we know we have to help him, but we are on his side.

Family 5

Description of the Family

The mother and father were present for the interview, which was conducted in Spanish. H is a 6-year-old boy with a severe hearing loss. He lives in California with his parents and a sibling. The mother is a homemaker and the father works in construction. The family moved to the United States from Mexico before H was born.

[Father speaking] *Well, I came here when I was about 18 years old. I came here to work, to help out my family but then later I got married and well I thought that this was the best place to live.*

[Mother speaking] *...for a better future.*

The family speaks Spanish in the home. The father said he speaks *a little bit* of English, but the mother does not.

Events and Emotions Surrounding the Diagnosis

The mother first suspected hearing loss when H was about 16 months old and she and her sister noticed that H was not trying to speak. She took him to an ear, nose, and throat specialist in Mexico, who told them that H had a hearing loss.

Both parents said they felt very sad upon learning of H's hearing loss.

[Father speaking] *Well, first it was very sad and they were in Mexico and I was here working and so I decided that it would be more beneficial for him to be in this country. He was born here so I thought you know, he could study here and go to school here because the person I knew in Mexico who was deaf, a lot of people ignored him and they didn't have respect for him. So I didn't want that for my son. So that's when I decided that he should come here so he could go to school here.*

[Mother speaking] *Well, I also felt very sad. Well, I also knew deaf people in Mexico and they don't know how to communicate, they don't know sign language, they don't have any language. They try to speak but you can't understand them. So I thought being here, he would have a better future and everything would be closer to him and, you know, if we stayed there, we wouldn't be able to get into the state he had to go to, to go to school, and really, economically, it would just be too difficult. So I decided that this was the place for him.*

Language Differences at Diagnosis and in School

Because H was diagnosed in Mexico, the doctor spoke Spanish and there were no language barriers. However, the mother still felt that she didn't understand what she was told. In the United States, the audiologist spoke English and the mother had an interpreter. The mother felt that the information was clear, and she was able to communicate freely with the audiologist. In school, the teachers speak only English and have an interpreter. Written materials are provided in Spanish.

[Mother speaking] *I was happy because I was able to understand everything.*

Language differences have become less of a barrier as the mother has learned more sign language, which is the language she uses to communicate with the teachers.

Information Access and Support

The mother said that although the doctor spoke Spanish, she had difficulty understanding the information he gave her.

Well, I tried to understand him, but I really didn't know anything about what happens when a child is born like this, with this type of problem, because I really never knew anybody who had that problem. But once I got here I learned more about it. And I went from one place to another and got more information, so here's where I've learned most of my information because I've seen and met many deaf people here... well, really, I was very surprised and I didn't ask any questions.

[Father speaking] *He gave her a report that shows the scale of what type of hearing loss he has. It shows where a normal person can hear and then where a person starts to have hearing loss, at what different levels. So he was very low at the level of being able to hear. So then he recommended hearing aids, but we really didn't see any type of benefit in that. But my son did make different types of noises and sounds, so I thought in due time he would be able to speak. I thought maybe if they helped him a little bit he could.*

[Mother speaking] *I do think it was clear, but at that time, I just didn't understand it. Yes, because sometimes even if the information is clear you still can't understand the information ... after he gave me that information, I right away came back to this country and they gave me another evaluation here and that's the way everything started here ... the first thing the doctor told me was he sent me to go to the children's hospital to get another evaluation for my son. So the doctor in the hospital there has all the information on my*

son.... I felt good because he gave me a lot of confidence and I really felt that somebody was supporting me.

The father said his attitude toward the doctors changed over time.

Well, we felt that they were giving us suggestions, but later we started to feel and believe that they were telling us what we must do. Because as time went along, they told us that there was technology, advanced technology, that would allow my son to speak. There was some type of implant, but we rejected that. We decided to wait until my son could make the decision for himself and maybe wait for science to have more advancement. To wait and see if maybe later there would be something better....

Information from Deaf Adults and Other Parents

The parents have found it helpful to meet with other parents of deaf children and to talk to deaf adults.

[Father speaking about meeting with parents] *We discuss how we feel and really about how we communicate with our children.*

[Father speaking about meeting with deaf adults] *We can discuss things with an adult and they can tell us what they feel and express their feelings better than a child can. You know they can tell us if they're happy the way they are, or tell us what it is that they feel, so then we think, 'Oh, maybe our son feels the same way or is also going through that.' You know, and we think our son isn't going to have any problems later.*

Choosing a Communication Method

The parents immediately began learning sign language on the advice of the teachers.

[Mother speaking] *They told us that we needed to learn sign language so that we would be able to communicate with him. For example, if he were to get sick, we wouldn't know what was wrong with him. So we've learned really basically what he's learned so if he's ever sick you know he could tell me what's wrong. If his ear hurts or 'my head hurts.' So I'm not just here wondering what's wrong with him. ...I accepted it because I had to learn.*

Language Preferences

The parents feel that it is most important that H learns sign language. Since they also have a hearing child at home, they speak in Spanish at the same time they are signing.

[Mother speaking] *It's not important for him to speak in Spanish, but I would like him to be able to understand it maybe when he gets a little older. What's important for me is for him to learn sign language because that's who he is really going to be communicating around most of the time.*

[Father speaking] *I believe the best thing is for people to learn the language of their children so that the parents are able to interact and stay close to their children. Because I do believe that the children become distant when the parents don't know their language.*

[Mother speaking] *I think it's important, for example, if my husband and I are communicating that we use sign language so my son, H, knows what we're talking about. Because otherwise, he'll look at us and wonder what we're talking about, or what's going on.*

The parents began sign classes but recognize that it will be difficult to keep up with their son's sign language skills.

[Mother speaking] *We started to go to the sign classes so we would advance at the same rate that he was advancing. Because I know that he's really going to advance to a greater level and we won't be able to surpass that level that he will reach. But we want to at least have some type of communication with him... we're going to try to do the best that we can.*

School Choice, Personal Style, and Advocacy

A teacher from a school district in California helped the parents in their search for the right school. The parents visited five schools in three different cities in California. The mother said the schools offered different types of communication.

[Mother speaking] *I did go to a school where they did try to speak, but it seemed that they were forcing the children too much to do something that they weren't able to do. And I didn't really like it there, so I decided that I wanted him to learn sign language and if later in the future he can speak, that's fine, or if not, you know I just accept him that way.*

At first I felt that he was the only child who was like that, but after seeing so many children who were like that, I realized it wasn't only him, there were a lot of children like him. And I realized he will have somebody to communicate with, because he's not alone.

I liked it because they always used sign language. So that's what I liked about that school. And in the other schools I did not like them because they spoke to the children and sometimes they would use sign language, and sometimes they wouldn't use signs. So I decided for him, the best thing would be to have somebody that would always sign to him.

H has attended four schools. The parents chose only the preschool he attended after early intervention.

[Mother speaking] *They really didn't allow us to choose a school. The only one we chose was the one in [a city in California]. So really, they've been transferring him to different schools.*

Currently, H is in a classroom for deaf and hard of hearing students within a mainstream school. The parents would like to send him to the school for the deaf.

[Father speaking] *We've always liked for him to be able to interact with more children and there's a school here where all the children, all of them, they are deaf. We would like him to feel more comfortable. Because you know when there are hearing children, sometimes they say bad words or they make bad gestures and then our son learns them and we tell him that he can't do that because it's bad, but he doesn't understand why it's bad.*

The Role of Church and Faith

Although the parents say they are religious, they do not feel that their religious beliefs have been helpful in making decisions.

[Mother speaking] *Well, we really don't look for any type of help. So when we were in Mexico, we didn't go looking for help there and here as well, we really haven't looked for help. We're really waiting for my son, we're waiting to find a church that has sign language for him, so he can go to church.*

Information and Feelings About Cochlear Implants

The parents received information about cochlear implantation from several sources, including a deaf adult, teachers, and medical professionals.

[Father speaking] *We did meet some people who did have the implant done, and we spoke to teachers who are in charge of those children who did have the implants. And we spoke to a deaf adult and asked her if she were able to have the implant, if she would get it done, but she told us that she was happy in the way she was, she was just very happy and satisfied. So we thought about that, and we thought that maybe our son, you know, could be just as happy as he is. So we decided not to make any decisions for him.*

...At the children's hospital was where they told us about it. There was an ear, nose, throat specialist there and he told us about it. He recommended the implant to us and he did tell us what risks there were and we just thought it was a very risky surgery, so we decided against it. Because we thought maybe later he may be in a worse situation. Because even now, even though he's deaf, he still has no type of pain or anything. But if we did go with the implant and if it did cause some type of paralysis of some kind, maybe hitting some type of nerve or something; so I think he would have some type of pain later or headaches, or something, I don't know. So we decided against it.

[Mother speaking] *Well, we see that he's happy this way. He plays, he runs around. But I think that if he would have the implant then there would be some type of risks.*

Teachers also dissuaded the parents from choosing cochlear implantation.

[Father speaking] *Yes, well at the school he was at, there was a teacher there that we discussed this with. There was a boy there at the school who had an implant, so we asked his teacher what type of response did this child have with this cochlear implant and the*

teacher said he did make sounds, but he did not speak. So we decided that it wasn't as effective as they had originally told us. They had told us that it wasn't going to function the same with each child, so we decided not to do anything with that.

Family's Satisfaction

The parents express dissatisfaction with their ability to communicate with H because they need to learn more sign language. They express a moderate degree of satisfaction with H's current school placement.

[Mother speaking] ... *Because the teacher he's with now, she's fine.*

[Father speaking] ... [However] *we're not satisfied because he's in a class with children that can speak.*

Family 6

Description of the Family

The mother and the community facilitator for this project (who is deaf) were present for the interview, which was conducted in Spanish. P is a 4-year-old girl with a profound hearing loss. She lives in California with her mother and father, an aunt and uncle, and three cousins. The mother is a homemaker and the father works in a skilled trade. The aunt and uncle work in a restaurant. P was born in the United States. Her mother moved from Mexico 10 years ago with her parents, who moved for economic reasons. The mother said she speaks English with P, but Spanish with her husband.

Yes, [my English] isn't that great, but I am able to communicate, and I understand it very well.

Events and Emotions Surrounding the Diagnosis

Hearing loss was first suspected when P was about 6 months old. P's grandmother noticed that she was not reacting to loud noises. The parents took P to the pediatrician who told them she might have a hearing loss.

[Mother speaking] *The pediatrician said that she might be deaf. After that came the other tests and everything.*

P's hearing loss was confirmed when she was 7 or 8 months old.

The parents said learning about their child's hearing loss was difficult.

Well, at first it was very hard because, you know, we come from a world where we are used to communicating using our words and our voice and we just weren't used to that kind of

thing, and it's very hard because now we have to learn a whole different language to be able to communicate with her.

Language Differences at Diagnosis and in School

The doctor who delivered the diagnosis spoke Spanish, eliminating the need for an interpreter. The audiologist, however, provided information in English. Although interpreters were available, logistical problems limited their usefulness.

[Mother speaking] Actually, I don't think I've ever had an interpreter...usually the first few times, it was because it was difficult waiting on the interpreter to arrive. We would have to wait one or two hours for the interpreter to get there and then sometimes they had to help other people who were there before us because the interpreter was busy. From this point on, a lot of things happened, so we finally decided that it was just easier for us to go on our own and with the English we knew, and it was not a perfect English but one we knew, that we could understand, we're able to communicate and it seems to be good enough. I would have really preferred that it would be in Spanish, but it's just so difficult, so difficult, more than anything to find somebody who speaks Spanish. When you go to the hospital there are just so many people and there's not enough interpreters.

The mother said she felt that she understood the information provided by the audiologist. To the extent that she did not understand what she was told, it is unclear whether language differences were the reason for misunderstanding or if unfamiliarity with deafness and the terminology used by professionals was a more important factor.

Usually when I don't understand something, I ask them to repeat themselves or to try to find another way to explain it to me.... Now that I look back, at that time, I thought I did have all the information and now several years have gone by and I realize that I didn't have a lot of information at that time. I have learned more now and at this time, I have more information about the hearing aids and the different kinds they have and there's just more information out there now.

Early intervention services were provided in the home. Using sign language provided a communication bridge for this family.

She had a person that spoke Spanish and English and also signed, and another person who spoke Spanish also knew sign language ... occasionally only the one that spoke Spanish would come. And when the woman who only spoke English would come, then the other woman who spoke Spanish came along.

Information Access and Support

The parents felt that the information they received at diagnosis was clear, appropriate, and helpful.

[Mother speaking] [The doctor] was very clear in his explanation and I actually learned a lot because I never really knew anything about deafness and I learned that there is different

kinds of hearing loss and I learned things about the ear that I never knew before, so I really think it was helpful...after we saw the first doctor, we went and looked for a second opinion. Actually there has been about four or five different specialists who have seen P. We have looked for the answer to maybe the reason why she's deaf or exactly what the problem is with her hearing loss.

The audiologist who performed the hearing test was also helpful and, in the mother's words, *not pushy*.

The first thing [the audiologist] told us was that P had to be put in a school and that I also had to start taking some classes...she gave us the phone number and address of the school she had to go to and we also started the paperwork on getting my daughter's hearing aids...really, it was more of a suggestion and she didn't, she wasn't pushy, she didn't force us to go there. She just gave us the name of the school that was closest to us. So really, it was just a suggestion that she was giving us.... I thought she was very helpful, and I also did my own research. I also went to the school to visit and see what that was about and I did a lot of other things.

Information from Deaf Adults and Other Parents

The mother has become friends with other parents of children who are deaf, and has found that helpful for sharing information about resources, services, activities, and other things. In addition, in the school P currently attends, the mother has met many deaf adults, which she also feels has been helpful.

The biggest thing that has helped me is to realize that [deaf adults] are just like us, that they have the same type of opportunities that we do.

Choosing a Communication Method

The early intervention teachers advised the mother about communicating with P.

Well, they [the early intervention teachers] told me that I would need to speak to her and that I would need to sign at the same time and that it would probably be best for me to speak English to her because it would be easier for her. They said I could speak to her in Spanish, but that it would probably be easier for her to communicate in English. ...I knew I had to go and learn sign language. So we have been going to take some classes and up until now, we're still taking the classes and learning day by day.

Language Preferences

The mother primarily communicates with P through spoken English and sign language.

Sometimes it's English, sometimes it's Spanish. It's really whatever comes to mind first. Sometimes I don't even realize it and I'm already speaking to her in English, and then

there's other times when I don't realize it, and I'm speaking to her in Spanish. But, for the most part, it's usually in English.

I think it's important for her to understand and speak English. Well, I think it really doesn't make much of a difference to me whether she chooses to use sign language or to speak in order for her to communicate. ...I think it's important for her to learn English because of the country we're in now. ...I actually hope that she's able to communicate with everybody using all three, English, Spanish, and sign language.

I do believe that [speaking Spanish to her] has affected her negatively, because I think it has maybe held her back a little bit. I think she's supposed to know more signs than she does already. I hope she learns eventually, but for right now what is really important for me is for her to learn sign language and understand it.

School Choice, Personal Style, and Advocacy

The mother visited different schools with various educational approaches.

The audiologists gave us the address of the school that would best fit her educational needs. So we went to the school. They started to speak to us and they saw P. That was the way it started. Going there...then we started to look for a school that was closer to us or that was better.

As I did start visiting different schools, I started to notice that at some schools they would only speak to the children, other schools they would speak and sign to the children, and there were yet other schools that they only sign to the children so I did start to notice these differences, but nobody ever gave me complete information about that.

I have done some research about other schools to see if there are other options for me. I would like a school that offers maybe speech therapy for P. There is some speech therapy there in the school, but it doesn't seem to be enough, so we're looking to see where we could get the speech therapy that we need for P. We're just looking into other resources right now. We're looking to see if maybe she could get the speech therapy maybe in the hospital or somewhere else because I would really like for her to stay in that school, the school she's in now.

...I was never given an option. They would always tell me what they offered at that school. Basically, they have told me, 'Here we have oral and signs,' and in the other one, they only had oral communication.

P started to receive early intervention services at about 1 year of age. P remained in this program for only five or six months. Because the school was far from home, she was moved to a school in another city.

Actually, I didn't choose that school. Well, really the reason was that that was the only school available and one of the only schools that did sign and speak. There was another

school in [another city], but that was just an oral school. I wanted to be sure that P was exposed to both speech and signing. It always worried me that maybe P wouldn't be able to use her voice, so I wanted to be sure that she did have sign language available to her.

...I wasn't given the option. I did some research about other schools better or closer, but I could not find them. Only this one and the oral one. After that, we came here, and the school she is in now was the one that was recommended to us. The doctor we have now has also given us two other options for schools, but those schools seem to be too far away from us.

The doctor that we're seeing now doesn't seem to agree with the fact that P is going to the school in [a city]. She feels that it is more important for P to go to a school where they offer speech as well as sign language. She feels that it's the best thing for P.

The Role of Church and Faith

The mother said she was not influenced *in any way* by the church or religious beliefs.

Information and Feelings About Cochlear Implants

The parents received information about cochlear implants from two doctors, one of whom spoke Spanish and gave the family a lot of information, including books and Internet resources. The parents were told that the implant might improve P's hearing. Ultimately the parents chose not to get an implant.

[Mother speaking] Well, there were many reasons. First of all, the biggest reason was because they didn't promise us that P could speak or hear with it. The second reason was because the surgery was a little risky, and the other reasons were that they told us there were many things she could no longer do once she got the implant, and I thought it would probably just be best for her to grow up the way she is now, not having any restrictions.

Family's Satisfaction

The mother feels that she and other members of the family need to learn more sign language. She has been satisfied with her ability to obtain information to make decisions and is happy with the school her daughter attends.

Her principal concern at this time is with regard to education.

This is exactly what we want, for her to have the best education possible. Really my biggest concern with her is her school achievement, we want for her to have the best possible. I hope that academically we've made the right choice and that we've chosen the best school, you know, the school that she's at now.

Family 7

Description of the Family

The interview was with the mother and was conducted in Spanish. B is a 10-year-old boy with a profound hearing loss. He lives in Pennsylvania with his parents and three siblings. The mother is a homemaker and the father is disabled. The family speaks Spanish at home, although the younger children also speak English. The family moved from Puerto Rico two years and five months prior to the interview because of B's hearing loss.

We came to the United States because of the child, because of his disability. He is deaf. For a while I was thinking about coming here because they say that, in the caring for handicapped children, there is a lot of help here and the doctors help a lot where my country is a little behind. Over there the child was in a school where there were a lot of children with different disabilities. So I thought that a lot of children with a lot of disabilities, it couldn't work; it's too limited. They should be, each child should be with children with the same disability because that way the professionals can get to them better.

Events and Emotions Surrounding the Diagnosis

The mother learned before B was born that there was a Rh incompatibility and that the baby was likely to have "problems." At birth, he was found to be deaf and have other medical problems.

The mother's feelings about her child's hearing loss were overshadowed by concerns about his overall health and well-being and his other disabilities.

It wasn't easy...I felt sad. I was crying a lot. I was very worried if his operation was going to leave him crippled because, as they said, the diagnosis of the child was that he was going to stay crippled in the bed and that he wasn't going to be able to do anything. So when they told me that, I got so worried that he would come and that he would stay in the bed and all since a condition like that is very difficult.

Language Differences at Diagnosis and in School

The diagnosis of B's problems at birth took place in Puerto Rico, with a doctor who spoke Spanish.

[Mother speaking] *Yes, I understood everything that the doctor told me and if there was something I didn't understand, I would ask him again. He was very nice and he would respond to me, and tell me, and explain to me again every procedure, everything that he was telling me that he had to do.*

The audiologist in Puerto Rico also spoke Spanish. In Pennsylvania, the doctor who treats B speaks English and uses an interpreter. Sometimes a friend who speaks both languages also acts as an interpreter.

Sometimes it is not good. It is not exactly what I would like to explain to the doctor, because sometimes the interpreter cannot explain to the doctor the same way I would.

The audiologist in Pennsylvania also speaks only English. The mother takes a friend with her to act as an interpreter at those appointments.

She knows everything that I have been through and all. So then she helped me a lot to talk to them.

In the Puerto Rican schools, there were no language problems. However, upon coming to the United States, the mother found it somewhat difficult to interact with the teachers.

In the beginning when I came here, it wasn't easy for me, since I was coming into another language. At school, there is not that many people that speak Spanish, the teachers are Americans, all that my son has, so then we use an interpreter. I am taking sign classes, and I think that for me it has not been easy because it is a translation from English to Spanish. It hasn't been easy for me.

Some of the teachers have tried speaking to her in Spanish.

... but it is very difficult. It is like me speaking to them in English.

Papers that come home from school are generally translated into Spanish.

I can understand what they are into. Every day they are telling me what they do in the classroom in Spanish. They have a person that translates what they do.

Despite the language differences, the mother did not identify any significant barriers to B's education.

It could be a lot easier for me to communicate with them and all of that, but since they already have an interpreter, there hasn't been that much that I could say that we have had problems with.

Information Access and Support

The therapist advised the family to move to the United States for better services.

[Mother speaking] *The therapist that was seeing him told me, 'Think about it in the near future. Get out of Puerto Rico to the United States because there he is going to find a better mechanism of life. The schools are going to be better. The doctors are better prepared, more able than here.'*

Choosing a Communication Method

The teachers at the school for the deaf in the United States told the mother she needed to learn sign language in order to communicate with her son. The mother said she is *learning a little* and said she also speaks to him in Spanish and he reads her lips.

Language Preferences

The mother feels it is important for B to learn sign language, Spanish, and English.

I want him to be using his sign language since that is his language, but also he's being taught how to talk to hearing people.

School Choice, Personal Style, and Advocacy

The mother was told that B had a right to receive educational services (in Puerto Rico) at 2 years of age. He started school between the ages of 2 and 2½. It was first recommended that B receive therapy individually, but the mother wanted him placed in a classroom with other children, and that is ultimately what happened. The mother visited two schools; one was a day school for children who are deaf and the other was for deaf and blind children. She chose the school for the deaf.

I liked it since the first day I visited it. I liked what I saw them doing in the classroom. So that's what I like, and I thought that it would be good for me because I saw that the teacher knew how to get through to the children and his mechanism of work was excellent. The teacher was excellent and professional in helping children that have this problem.

Upon moving to Pennsylvania, they chose a school based on the doctor's recommendation.

That school, I choose it because the doctor told me that it was the very school for him and I went to see it too, and because all the children have the same condition as he does, and they are professionals that work very well, very well with the children, and that was what I was looking for for him.... They have offered me everything and to see if I want him to participate or not and usually when they have new programs for him, I go to the school and see what they do and everything that they're going to do, they inform me.

The Role of Church and Faith

The mother feels that her belief in God has been influential.

I have always belonged to a Christian evangelic religion since I was little, and that has been a big help too.... The church helped me. They told me that there was nothing impossible that could not be done with God's help, and that's the way it has been and thanks to God's help, the child has improved a lot, and I have seen how he is better now.

Information and Feelings About Cochlear Implants

The mother said she has heard about cochlear implants from *women in [her son's] school*, although it is not clear if these people are teachers or mothers. She has not met anyone with an implant and has not made a decision about an implant for her son.

They said that it was only for people that have profound loss of hearing or bilateral and that it is good, and that in other children it gives good results.... In reality, I have not thought about whether that operation would be a benefit for him.

Family's Satisfaction

The mother feels satisfied with the school and with her choice to come to the United States. She expressed dissatisfaction with her ability to communicate with her son through sign language, recognizing that she needs more classes.

Family 8

Description of the Family

The mother was present for the interview, which was conducted in English. J is a 10-year-old boy with a profound hearing loss. He lives in Pennsylvania with his mother and three siblings. The mother works in a factory and the father works in construction. The mother was born in the United States, and the father was born in Puerto Rico. The family speaks English in the home. The mother said she speaks, but does not read, Spanish.

Events and Emotions Surrounding the Diagnosis

The mother suspected a hearing loss when J was 1 year old because he *wasn't like my other children*. When he was 6 months old, J was sick with a high fever.

That's not normal for a 6-month-old child. I knew something was not right and that's when I started taking him to the doctors, trying to find out if that fever had caused anything else. And that's how I found out that he was, you know, will not hear. So they started testing him...they kept testing and testing. That is when they told me that he was, you know, completely deaf.

The mother reports feeling sad when she learned about J's hearing loss and also upset that the doctors had not paid closer attention after he had the high fever.

At first I was sad, but I mean that's my son. I love him. I mean it was harder more for him than it was for me, and all the signs I had to learn, I learned from him because he taught me, but I mean you learn to deal with it.... [I was thinking] that he wouldn't be able to hear me say I love him because at the time I didn't know sign language, so I didn't think he would ever hear me say 'I love you' or, you know, go, you know, dance and party and, 'I want you to play with me,' you know, stuff like that where music is always involved when it comes to kids. And the birds chirping, because he loves the park. He's a park freak. He loves it, and I mean, I always figured he wasn't going to be able to hear certain things that I wanted him to hear. So I was sad for him, not so much for myself because no matter what, he's my son, I will always love him, but I was sad for him because I would think that he was going to miss out on...so it made me feel sad.

...I feel like it should have never happened. The instant that he had a fever of 110, they should have kept on checking because, I mean, a fever of 110, I mean that causes something, especially on a 6-month-old baby, and they just kept dismissing it as though it was just ear infections, and I feel as though they should have checked a little more deeper into it.

Language Differences at Diagnosis and in School

Because the mother's primary language is English, she reports no obstacles caused by language differences. However, the father does not speak English and has learned very little sign language.

[Mother speaking] He wanted to be involved somehow, but just didn't understand quite where he was going, so I was translating for him.

I mean [the father] will say 'I love you' in sign language, 'play,' or 'park,' but not too much. No...and sometimes J looks at him like, 'Huh?' like, 'What?' but he won't take classes. He refuses to take classes.... After all these years, I think it's still difficult on him. I mean, that's his firstborn [child].

Information Access and Support

Following the diagnosis, the professionals gave the mother about a week to let the information sink in.

They let me think things through and they just kept calling me, making sure that I got help for him as soon as possible because he needed it and he was very young. So I woke up and I'm like, all right this is what I've got to do for him and I called them up and I went to their office and they scheduled a lot of appointments, but I mean he's doing great now.

They told me that I would have to find a special school for him and so he wouldn't be like regular children, but that he was going to be healthy and whatnot. So they started pointing out schools for me and I started interviewing a few schools and I picked a nice, a good school for him and it was, I love that school, because they helped him a lot since he was little....

I felt as though I needed to know more, so I went to the library and I started to read up on things and started getting some more pamphlets and checking up on what it was I, what [it] was [that] I had to deal with, you know, for the future. So I read up on that and I started to go and apply for classes and things like that. I wanted to prepare myself, but I still couldn't get the hang of it.

The mother was also given pamphlets, referred for family counseling, and set up with early intervention services.

For a whole year they [early intervention specialists] came to my home and I talked it out and it helped me a lot. It really did. I was very young. I was only about 19 years old. So I

was really young. I didn't know exactly what I was getting myself into, but I mean they explained as much as they could...they did give me a lot of information. It was like too much to take on, but it made me go out there and say well this, they've given me all this information, I need to read up on it, he's my son, he's going to be with me always. So I started to read and I started to focus on what needed to be done. So I think it was great—all the information they gave me.

A counselor at a school for the deaf was also helpful.

Information from Deaf Adults and Other Parents

The mother says meeting other parents of deaf children and deaf adults has better prepared her for life with a deaf child.

In the beginning, because I wanted to know how it feels to be with other deaf parents. ...with all that they were talking about and what they were going through and me listening to all the things that they had to say, it helped me to understand what I was going to go through, getting ready for.

I know quite a few [deaf adults] and I visited their church and I've gone on family picnics and things like that, which they do a lot at the school and it's great. I mean, it's nice. ...because I got to understand a lot more of what was going to happen to me. I got ready, in other words. They, I watched them, how they were working with their kids and what they had to go through with their kids and I'm like, well that's going to happen to me.

Language Preferences

The mother feels that J communicates well with people whether they sign or not. She said she did not feel that one language, English, Spanish, or sign language, was more important than another.

School Choice, Personal Style, and Advocacy

A meeting with the doctor and a school representative guided the mother in choosing a school.

...They gave me a few schools to pick out for him. That's mainly why I went for [a school for the deaf] because they really got involved with my case and they didn't have to, and they helped me a lot. I mean there was nothing they would not do for my son. Until this day, they still, you know, if there's a problem or if he gets into any trouble, they're there, they're on it, and they don't wait. So they help, they've helped me a lot. I give them a lot of credit.

The mother was also told about another school that J could attend, but rejected it without visiting it.

I heard that when a child signs there, they tap him on the hand with a ruler and I mean they weren't allowed to sign, everything was vocally, but I didn't want, I didn't want my son to be put through any pain, and he already at that age was already teaching me sign...and since [a school for the deaf] was already there for me, and they had extended their arm out

for me. They didn't have to. I mean, they had just led me, they didn't have to go through all the things that I went through, they didn't have to be there for me and they were.

The Role of Church and Faith

Religion has been a source of some support for the mother.

I prayed a lot. I prayed a lot. I was hoping that the doctors were trying something and say, 'Look, we were wrong. He's still going to be able to hear,' or 'There is something that we can just implant in his ear, don't worry, he's going to be fine,' but I had to accept it. It took me a while, but I had to accept that my son was deaf. I had no choice.

Information and Feelings About Cochlear Implants

The mother has gotten little information about the possibility of a cochlear implant for J.

As a matter of fact, last year during the summer I went to take J to a new doctor in [a city]. ...They asked me, would I like for my son to have that surgery and that it was very rare, you know, it's new. And I told them that I would think about it. They told me that they would give me a call again, but I never heard from them again.

I was hopeful, but I didn't want to put my son through all that pain. I didn't know exactly what he had to go through in order to get those implants in his ear. So I didn't want to put him through any suffering.

The mother said she has seen a few children at J's school with implants, but doesn't know how well they work.

I just don't want to put him through any pain. I mean he's a healthy boy. He's, I mean, he's very healthy, and when I mean healthy, I mean he's big, he's chunky, runs around, he plays. He does everything that a normal kid would do, it's just that he can't hear and I don't want to put him through any pain that he doesn't need to be in. I mean I would love, I would love to be able to hear him say 'Mom, I love you' without him having to sign it to me, but I don't want to put him through any suffering. I don't want to.

Family's Satisfaction

The mother is very satisfied with the school her son attends. She feels that she and her other children communicate well with J, although other family members, such as her sisters, do not.

I felt sad because they don't know what they are missing.

She is also concerned about the difficulty J is having in learning to read and is trying to find answers.

I don't want to dismiss it and have it be something that comes up later on, like what happened when he was deaf, when I found out that he was deaf. I don't want to dismiss it and just, you know, I don't want to. When it comes to J, I made a mistake once, keep dismissing it, oh yes, ear infection, ear infection. It could have been resolved then and he probably wouldn't have been deaf.... But I dismissed it and oh, just let it be, oh it was just ear infections, and now I sit down and I wonder, what if, what if I could have taken more action then.

The mother also said she feels that now that her son is 10 years old, he should be involved in decision making.

I've made a lot of decisions for him, but lately I've had him choose what he wants to do too, because it's important, now that he's 10 years old, that he has to also make decisions. So he's made quite a few decisions for himself too.

References

- Alvarez, D., & Bean, F. D. (1976). The Mexican-American family. In C. H. Mindel and R. W. Haberstein (Eds.), *Ethnic families in America* (pp. 271-291). New York: Elsevier.
- Arnold, B. R. (Ed.). (1987). *Disability, rehabilitation and the Mexican-American*. Edinburg, TX: Pan American University.
- Becerra, R. M., & Zambrana, R. E. (1985). Methodological approaches to research on Hispanics. *Social Work Research and Abstracts*, 21(2), 42-49.
- Bennett, A. T. (1989). *Hispanic families and children in the special education intake process*. New York: The Lexington Center.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or It takes at least two to tango). *Soc Sci Med*, 44(5), 681-692.
- Cohen, O., Fischgrund, J., & Redding, R. (1990). Deaf children from ethnic, linguistic and racial minority backgrounds: An overview. *American Annals of the Deaf*, 135(2), 67-73.
- Delgado, G. L. (1984). Hearing-impaired children from non-native-language homes. In *The Hispanic deaf: Issues and challenges for bilingual special education*. Washington, DC: Gallaudet College Press.
- Janis, I. L., & Mann, L. (1977). *Decision-making: A psychological analysis of conflict, choice, and commitment*. New York: Free Press.
- Luterman, D. (1987). *Deafness in the family*. Boston: College-Hill Press.
- Meadow-Orlans, K., Mertens, D., Sass-Lehrer, M., & Scott-Olson, K. (1997). *Support services for parents of children who are deaf or hard of hearing*. Presentation at the Convention of the American Instructors of the Deaf (CAID)/Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD) meeting: Pages of the Past...Chapters of the Future, Hartford, CT.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Mindel, E. D., & Vernon, M. (1971). *They grow in silence: The deaf child and his family*. Silver Spring, MD: National Association of the Deaf.
- National Center for Health Statistics. 1994.
- Rodriguez, O., & Santiviago, M. (1991). Hispanic deaf adolescents: A multicultural minority. *The Volta Review*, 93(5), 89-97.

- Schlesinger, H. S. (1972). Diagnostic crisis and its participants. *Deafness Annual*, Volume II. Silver Spring, MD: Professional Rehabilitation Workers with the Adult Deaf.
- Seligman, M., & Darling R. (1989). *Ordinary families, special children: A systems approach to childhood disability*. New York: Guilford Press.
- Stein, R. C. (1983). Hispanic parents' perspectives and participation in their children's special education program: Comparisons by program and race. *Learning Disability Quarterly*, 6, 432-439.
- Steinberg, A. (1991). Issues in providing mental health services to hearing-impaired persons. *Hospital and Community Psychiatry*, 42(4), 380-389.
- Steinberg, A., Davila, J., Collazo, J., Loew, R. C., & Fischgrund, J. E. (1997). "A little sign and a lot of love ...": Attitudes, perceptions, and beliefs of Hispanic families with deaf children. *Qualitative Health Research*, 7(2), 202-222.
- Torrance, G. W. (1986). Measurement of health state utilities for economic appraisal. *Journal of Health Economics*, 5, 1-30.
- U.S. Census Bureau. (2000). *Profile of general demographic characteristics for the United States: 2000*. Washington, DC: Author.