Decisions Hispanic Families Make After the Identification of Deafness

Annie Steinberg
University of Pennsylvania School of Medicine

Lisa Bain
Yuelin Li
The Children’s Hospital of Philadelphia

This study examines 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 geographical areas shared their experiences in searching for appropriate interventions and making choices regarding communication and education. We explored the impact of language, culture, minority status, and access to information and services on the decision-making process. The results indicate that the deliberations of Hispanic parents are often complicated by language and cultural barriers and by limited access to information, resources, and a full range of options. The communication method chosen tended to be the one recommended by professionals, usually a combination of spoken English and sign language. Parents frequently expressed the hope that their child would learn Spanish as well. These subjects displayed a higher degree of assertiveness in obtaining services for their children than other studies have suggested.

The diagnosis of a chronic condition in an infant or child can have a profound impact on the family. In the case of deafness, the experience of identification and the period immediately following has been described as one of grief, anger, guilt, helplessness, denial, and above all, confusion (Mindel & Vernon, 1971; Schlesinger, 1972; Steinberg, 1991). Although identification of a child’s deafness is inevitably a highly charged emotional experience, not all families respond in the same way, nor are responses necessarily consistent with the previous description. One factor influencing the response by a family to a child’s disability is the family’s cultural background. Cultural elements such as language, family structure, gender roles, beliefs about health and healing, and acculturative stress play significant roles in the family’s decisions about rehabilitation and treatment of disabilities (Arnold, 1987).

Individuals of Hispanic descent constitute the largest minority group in the United States, accounting for 12.5% of the total population (U.S. Census Bureau, 2001). This rapidly growing U.S. minority group is a heterogeneous community of Americans and immigrants who derive their cultural identity from Mexico, Puerto Rico, Cuba, and Central and South America. 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 in 1990 to 1991, 4.2%, or over 900,000 individuals, had hearing impairments (Ries, 1994).
The extent to which culture influences decision making has not been adequately studied. In one study of Hispanic families with children who are deaf, many families expressed difficulty dealing with their community’s stigmatization and lack of understanding about their children’s deafness and deafness in general, and most identified some problems with communicating with their children. Most families were keenly aware of and valued the higher quality of specialized services generally provided at no cost to families in the United States, compared with the vastly different quality and cost of services to deaf children in their countries of origin, yet they experienced additional stress as a result of separation from familial and community supports (Steinberg, Davila, Collazo, Loew, & Fischgrund, 1997). In another recent study, Hispanics living in the United States were found to experience additional stress originating from a difficulty in communicating with their physicians (Collins et al., 2002).

The process of decision making is a complicated one, influenced by emotions, beliefs, values, and expectations (Eleweke & Rodda, 2000; Steinberg & Bain, 2001; Steinberg, Brainsky, Bain, & Montoya, 1999). In the United States, the majority of parents of newly identified deaf children share the same language as the professionals from whom they seek help. Parents from minority cultures, particularly those whose primary language is not English, may have additional difficulty in coping with and successfully navigating through the decision-making process for their deaf children. Janis and Mann (1977) proposed a decision-making model that requires appraising the challenges and surveying the alternatives as initial steps. These steps require that parents have access to complete and accurate information in order to make decisions for their children.

Even when parents and professionals speak the same language, the information presented may be misunderstood. A difference in the language spoken by professionals rendering care and families receiving the information may exacerbate the chances for misunderstanding, difficulty, and stress. Interpreters may mitigate the communication barrier to some extent but may also introduce additional complications if interpreters are poorly trained (Vasquez & Javier, 1991).

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 face the prospect of learning two new languages: English and 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). Several studies suggest that Hispanic families underutilize support services that are available in the school system (Bennett, 1989). Furthermore, older studies suggest that parents of Hispanic heritage seldom participate in the development of their children’s individual educational plans (Delgado, 1984; Stein, 1983).

In this study, we explored the decisions that Hispanic parents make for their deaf children regarding medical interventions, language, and children’s use of early intervention services and entry into preschool and elementary school. The author’s (A. S.’s) clinical experience with both Hispanic and non-Hispanic families suggests that parents make choices at transitional points that impact long-term outcome. A recent study of non-Hispanic families examined the extent to which the following factors influence choices after identification: accessibility of resources and information; quality and content of professional guidance; the family’s hopes, expectations, and religious beliefs; and the parents’ decision-making style (Li, Bain, & Steinberg, 2002). This study expands this previous work to address the decision-making process of Hispanic families.

Methods

Subject Recruitment

To sample a variety of cultural backgrounds, twenty-nine families of Hispanic descent were recruited from four distinct geographical areas in the United States: Pennsylvania, Texas, central Florida, and northern California. Members of each of these communities were hired to assist in recruitment of subjects, data collection, and translation of interviews. Each of the four communities had one community facilitator and one interviewer. In general, the community facilitators knew the subject families prior to the study and therefore did not conduct the interviews themselves. The researchers traveled to each of the four sites to train the community
facilitators and interviewers in topics such as recruiting and eliminating bias from interviews. The community facilitators were all connected with deaf education in their respective communities and were in charge of recruiting Hispanic families with hearing-impaired children between the ages of 3 and 13.

Instruments

Families who volunteered to participate were asked to complete a questionnaire (Appendix A) and participate in a 1- to 2-h semistructured interview (Appendix B). The questionnaire was developed in consultation with Kay Meadow-Orlans (Meadow-Orlans, Mertens, Sass-Lehrer, & Scott Olson, 1997). The semistructured, open-ended interview was designed to allow informants to discuss issues of importance to them with guidance from the interviewer but few directed questions that would have elicited yes or no answers. Thus, issues emerged somewhat spontaneously, and not all informants directly addressed the topics we subsequently chose to analyze. This process allows analysis of the study subjects’ experiences as well as their insights, cultural beliefs, and language.

Interviewers and community facilitators assisted families in filling out questionnaires when necessary. Interviews were conducted in either English or Spanish, according to the subject’s preference. With subject’s consent, interviews were audiotaped, videotaped, or both. Interviews that were conducted in Spanish were translated into English. Twenty-seven of 29 interviews were fully translated and transcribed. The translators were native Spanish speakers who were also fluent in English and who had prior translation experience. To the extent possible, translators were also matched to subjects according to dialect of Spanish spoken. Two interviews, both from families in the Texas subgroup, were not translated or transcribed due to technical problems. Thus, the sample size of interviews was reduced from 29 to 27 families, whereas the sample size of the data from the survey questionnaire remained at 29 families. A survey 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. The questionnaire has been included in Appendix A. All instruments used in this study were approved by the institutional review board of the Children’s Hospital of Philadelphia. The institutional review boards of several of the cooperating schools also reviewed and approved the instruments.

Analysis

Demographic items from the survey questionnaire were summarized by tables of frequency counts and percentages (see Table 1). Answers to questions regarding support, utilization of resources, and attitudes and beliefs about deafness were dichotomized, and the percentage of affirmative responses was calculated (e.g., “somewhat supportive” and “very supportive” vs. “not very supportive” and “unsupportive”). Responses to questions regarding the use of resources were dichotomized into “used, found helpful” (coded affirmative) versus “did not use” and “used, did not find helpful” (coded negative). These data are presented in bar graph form (see Figure 1). Analysis of the interviews used qualitative methods (Miles & Huberman, 1994.) Translations of interviews were fully transcribed from audiotapes. Transcripts were coded for themes of interest according to a coding schema developed by the research team. Themes were grouped in five categories of potential influence on parental decision making: guidance provided by professionals (including whether information was available in Spanish), internal factors (e.g., parental expectations, values), external factors (e.g., availability of resources), decisions made, and satisfaction. The codes were then applied to the transcripts using a computer program called Folio Views (Folio VIEWS Infobase Production Kit, 1995), which allows for easy markup of text, followed by compilation of all segments coded with a particular theme. Each interview was coded by at least two researchers. Disagreements between the coders were resolved by the senior research analyst. Through this process, themes emerged that were of particular importance to the respondents in the study, and these themes were further analyzed for this publication.
Results

Respondents

Eighteen of the interviews were conducted with mothers only, one with the father only, and nine with both mother and father. For one of the two interviews not transcribed for technical reasons, it is unclear who participated. Questionnaires were filled out by 28 mothers and one father.

All parents had at least some high school education, and about a third also had some college education. Eleven mothers (39%) and 14 fathers (58%) did not complete high school. Seven mothers (25%) and six fathers (25%) graduated from high school, and another nine mothers (32%) and four fathers (16%) attended college. One mother had achieved a bachelor’s degree.

Seventeen (59%) of the 29 children in the Hispanic group lived with both parents. Six children (21%) lived with their mothers only; two (7%) lived with mothers and stepfathers. The remaining four (14%) lived with family other than parents. Twenty-one parents (72%) reported that they had other children. Three parents (10%) reported that their deaf children had other deaf siblings: One parent had three children, and two parents had two deaf children each. Four parents (14%) reported that there were extended family members (e.g., cousins, uncles, grandparents) who also had hearing losses.

For most of the families in this study, the identification of hearing loss was obtained in the United States (69%). Many of the families left their countries of origin (usually Puerto Rico or Mexico) either when they suspected a hearing loss or after hearing loss was confirmed, believing that the opportunities, resources, and services for deaf children were superior in the United States and that children would face less discrimination there than at home.

Table 1  Child demographics (N = 29)*

<table>
<thead>
<tr>
<th>Demographic variable</th>
<th>Demographic category</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who child lives with</td>
<td>Mother and father</td>
<td>17</td>
<td>(59%)</td>
</tr>
<tr>
<td></td>
<td>Mother only</td>
<td>6</td>
<td>(21%)</td>
</tr>
<tr>
<td></td>
<td>Mother and stepfather</td>
<td>2</td>
<td>(7%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>4</td>
<td>(14%)</td>
</tr>
<tr>
<td>Gender of child with hearing loss</td>
<td>Male</td>
<td>14</td>
<td>(48%)</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>15</td>
<td>(52%)</td>
</tr>
<tr>
<td>Level of hearing loss</td>
<td>Profound</td>
<td>15</td>
<td>(52%)</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>8</td>
<td>(28%)</td>
</tr>
<tr>
<td></td>
<td>Moderate</td>
<td>3</td>
<td>(10%)</td>
</tr>
<tr>
<td></td>
<td>Mild</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>2</td>
<td>(7%)</td>
</tr>
<tr>
<td>Cause of hearing loss</td>
<td>Unknown</td>
<td>15</td>
<td>(52%)</td>
</tr>
<tr>
<td></td>
<td>Heredity</td>
<td>3</td>
<td>(10%)</td>
</tr>
<tr>
<td></td>
<td>Prematurity</td>
<td>2</td>
<td>(7%)</td>
</tr>
<tr>
<td></td>
<td>Meningitis</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td></td>
<td>Prenatal infections</td>
<td>1</td>
<td>(3%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>7</td>
<td>(24%)</td>
</tr>
<tr>
<td>Age at loss</td>
<td>Unknown</td>
<td>9</td>
<td>(32%)</td>
</tr>
<tr>
<td></td>
<td>Birth or earlier</td>
<td>15</td>
<td>(54%)</td>
</tr>
<tr>
<td></td>
<td>No answer</td>
<td>5</td>
<td>(17%)</td>
</tr>
<tr>
<td>Other disabilities</td>
<td>Children with cochlear implant</td>
<td>8</td>
<td>(28%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>4</td>
<td>(14%)</td>
</tr>
</tbody>
</table>

* Ages of children in the sample ranged from 4 years, 5 months to 13 years, 11 months, with a mean of 8 years, 7 months.
Table 1 summarizes the demographic information of the children in our sample. The children ranged in age from 4 years, 5 months to 13 years, 12 months. The mean age was 8 years, 7 months. The majority of children (23, or 79%) had profound or severe hearing loss. Three children had hereditary deafness, and about half of the parents (n = 15) did not know the etiology of their children’s deafness. The average age that hearing loss was confirmed was 24 months (SD = 16), and the average age that the parents suspected that their children had hearing loss was at 14 months. (SD = 10.7). Twelve parents (41%) considered the cochlear implant as an option for their children. Of these twelve, six parents had their children evaluated for the implant. Four children (14%), two in Texas and one each in Florida and Pennsylvania, underwent cochlear implant surgery. Of those four parents, three reported that their insurance covered more than 75% of the cost for the cochlear implant. The figure shows the involvement in decision making, the importance of decision factors, important characteristics of advisors, attitude/knowledge about deafness, and use of resources. The figure includes a bar chart with 95% binomial confidence interval and a percentage of affirmative responses.
fourth parent did not answer this question. All four parents reported that they are very satisfied with the cochlear implant.

Preferred Language in Family

Spanish is the primary language used in most of the homes of the participants (n = 16, 55%). Three parents (10%) cited Spanish and some sign language as their primary means of communication. Two parents (7%) stated that they communicate through a combination of Spanish, English, and signing or gestures. One parent (3%) responded that the children speak English and the parents speak Spanish. Four parents (17%) use English and some sign language to communicate with their children. One parent (3%) 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 (ASL) is the primary language used in the home. Further exploration of preferred language occurred during the interviews with respondents and is discussed later in this article.

Decision Factors

Figure 1 summarizes the data about factors that influenced the decisions made by respondents. The factors analyzed include: the amount of involvement in decision making for parents, grandparents, friends, and the family doctor; the importance of five decision factors; which characteristics of influential people were most important; attitudes and knowledge about deafness; and the use of resources.

The results showed that mothers were most involved (100%) in decision making. Fathers were somewhat less involved (64%), followed by the family doctor, grandparents, and friends. The most important factors in the parents’ deliberations were the recommendations of professionals (96%) and the services provided by the local school district (86%). The parents thought that the most important characteristic of influential people was that they “listened to my concerns.” The availability of services close to home, cost of services, and recommendations of friends were somewhat less important.

Attitudes and beliefs about deafness were assessed by asking respondents about their agreement with six statements. Ninety-six percent of the Hispanic families agreed (strongly agreed or agreed somewhat) with the statement, “Children should be taught sign language so they can talk to deaf people.”

At the same time, only 25% agreed with the statement, “Although sign language may be useful, it isn’t really a proper language.” This positive attitude toward sign language was also accompanied by the belief that “All deaf children can learn to speak if enough time and effort were put into teaching them” and that “As a society, we push out deaf people.” Less than half (46%) agreed with the statement that “Deaf children should go to ordinary schools.”

We studied six aspects of resource utilization: whether the parents had been given written and videotaped information about different approaches or instructions for sign language or cued speech, whether they participated in parent meetings or individual counseling, and whether they had used interpreters. Sign instruction was the most widely used resource, followed by parent meetings and use of interpreters. We did not distinguish Spanish language from sign language interpreters; however, the interviews suggest that parents were referring to Spanish language interpreters. Individual counseling was used by more than half of respondents. Somewhat surprising was the finding that only 52% of the Hispanic families were given written materials about different options. Videotaped information was even less widely used.

Results

Interview Data

Two interviews were not translated and transcribed because of technical problems. Therefore, the analysis of the interview data includes only 27 subjects. We refer to the subjects as “families” although as we noted earlier, in some cases only one parent was interviewed. In the semistructured interview, we examined how parents go about making important decisions for their children. When a child has a hearing loss, parents need to decide how they will communicate with their child, how the
child and parent both 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. Early intervention and school decisions also often require collaboration between parents and the state, county, or local school system.

We found that the decision-making process for children with hearing loss is a complex one, affected by information and resource availability, including the quality of the information imparted 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. Although shared decision making between parents and professionals is often seen as the desired model (Charles, Gafni, & Whelan, 1997), we found that there were barriers that sometimes prevented parents from participating fully in the decision-making process. We explored the extent to which access to information that is 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 interviews demonstrate the uniqueness of each individual case and the diversity of experiences among Hispanic parents of deaf children in the United States. Several common themes emerged in the interviews, including language differences, language preferences, choice of communication method, decision-making style, and religious beliefs.

Language Differences
Eight families reported that they experienced language difficulties that interfered with their acquisition of complete information. Four of these families reported that language differences presented barriers in some situations but that in other situations, interpreters, Spanish-speaking professionals, or the parents’ own English-speaking ability mitigated these problems. It is especially noteworthy that 19 families, a majority of our respondents, reported that language differences were not a barrier to information access because interpreters were available and effective, Spanish-speaking professionals were available, one or both parents spoke English, or a combination of the above factors.

One Florida mother who felt language was a barrier said, “If it had been in Spanish, although it was hard to accept . . . one is free, one can ask the questions one wants to ask as he or she wishes. But it is hard when one feels trapped [by the language]. In a foreign language, the words don’t come out.”

Only one parent (in California) reported a problem with getting interpreters. She said, “Usually it was because the interpreter took a long time to arrive. We would have to wait one or two hours . . . so we finally decided that it was just easier for us to go in to the appointment on our own and talk to the doctor.”

Three families said interpreters were available but ineffective. In one case, the audiologist provided information in English to the teacher and the mother; when the teacher and mother returned to school, the teacher would tell the interpreter what had been said, and the interpreter would translate for the mother. As a result, the mother was unable to pose questions directly to the audiologist. Parents also reported that the translations were not good or that the interpreter was difficult for the parent to understand. One parent stated that

One of the terms that he used was used in a wrong way, and that made the whole translation different. . . . when they had the interpreter that was Puerto Rican, I understood a lot better. . . . It was not convenient for me to have Mexican interpreters because they do not interpret the same. . . . We have the same culture, but we don’t have the same language.

Twelve families said that written materials were provided in both Spanish and English. Four families said they were available in English only, and the remaining 11 families did not address this issue. Most of the Spanish written materials appear to have been translations from English. Many of the parents said that written documents were provided with English on one side of the sheet and Spanish on the other. One parent said:

They send them to me in English, also in Spanish, but I prefer in English, because the Spanish, they really kill it. I feel bad but I have told them that when they send something to me, send it to me in English
because you have a problem with translations, that they kill my Spanish, oh my God! And it’s better understood in English, because of the terminology and the translations are incoherent.

Language Preferences

Of the 27 families included in this analysis, 17 (63%) expressed the hope that their children would be bilingual (English and Spanish) or trilingual (English, Spanish, and sign language). Of the ten families (37%) who did not express a preference for bi- or trilingualism, four indicated that English was the most important language, five indicated that sign language was most important, and one indicated no preference.

Parents who expressed a preference for trilingualism cited the importance of access to Hispanic culture. Said a mother in Florida, “We are trying to avoid the error we made with the older boy, so that later he will have access to his culture and language which is Spanish, and also that he has complete use of English.” Another mother said, “I want her to know both... because I do want her to know her background.”

Retaining the ability to communicate with extended family members was frequently mentioned as a primary reason for learning Spanish. A mother in Texas said, “I believe that all three languages are important. Because the family speaks Spanish, at schools she needs to communicate in English, and she needs the sign language if she is not able to speak.”

Parents who expressed a preference for sign language often hoped that their children would also learn English, Spanish, or both but indicated that sign language was the more accessible and useful language. A mother in California said, “Well I really think the best thing would be that she learned to communicate in English, but she can’t speak so I guess she’s going to have to use sign language. I think that would be for the rest of her life.” Many of the parents who cited the importance of sign language nonetheless said they hoped their children would eventually learn Spanish as well. Said a mother in Pennsylvania, “The loss of hearing that my son has makes me think that it’s more important for me that he knows how to communicate with people that use sign languages. Now culturally... I would like that he would be able to speak Spanish, but we live in the United States.”

Parents who expressed a preference for English cited the use of English in the schools as a determining factor. A mother in Texas said, “I think it’s more important that he learns and understands English because at the school where he is, the teachers speak only English. It is better for him to understand English than Spanish.” Parents who stressed the importance of English also often hoped for Spanish fluency as well. Said a mother in Florida,

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.

Choice of Communication Method

According to 17 of the 27 families included in this analysis (63%), the only communication option offered by the school or county in which they live was total communication; these families accepted that option without exploring other methods. Five families (19%), all of them from Pennsylvania, were offered multiple options, and all of these families chose total communication. Another five families (19%) sought alternatives beyond those initially presented to them and made choices that differed from professional recommendations.

Parents indicated that different communication modes were rarely discussed or presented as possible options. For example, one parent said, “They didn’t really... tell me much about communication, just that she needs to learn sign language.” Another said, “They told me that he had to go to a special school and learn sign language.” In one case, the parent was told about two options: “The only option they did give me was oral versus total communication, but it was mostly total communication because of the quality of my child’s hearing, because what my child could hear, it wasn’t enough for them to be put in an oral program.”

Only in Pennsylvania were the different options presented. Said one mother, “They gave me two options, sign language only or sign language with voice.” Another mother said, “They gave me a list of, you know, different places to call, different people to meet, make interviews, see the different schools and everything.” All of the fam-
ilies in the Pennsylvania cohort spoke highly of the guidance they received from early intervention specialists at the school for the deaf. Said one mother, “I love that school because they helped him a lot since he was little.”

Decision-Making Style

Previous studies (e.g., Young & Klinge, 1996) have indicated cultural differences for assertiveness in the medical encounter. We explored the extent to which parents played an active or passive role in seeking medical, audiological, or educational services for their children. Of the 27 families included in this analysis, 14 (52%) were rated “active” and 10 (37%) “passive” (Table 2). We were unable to classify the decision-making style of three families. Families were rated active when they described their efforts in words such as inquire, explore, investigate, challenge, fight, and organize. Families were rated passive when they made statements indicating acceptance of guidance without question or followup. Table 2 summarizes the statements of these two groups.

Religious Beliefs and Faith

Seventeen of the 27 families (63%) indicated that their religious beliefs and faith influenced their decision-making process. Seven families (26%) said their decisions were not influenced by religious beliefs, faith, or the Church. One mother answered, “I don’t know, I don’t know if that’s anything that has helped us.” Two families did not address the questions.

For some families, faith and prayer were cited as key factors in the decision-making process. For example, a mother in Florida said, “I put everything in God’s hands. . . I ask God to give me the wisdom to make proper decisions for him.” A father in Pennsylvania said, “We were praying to God that everything would be okay, and God listened to our prayers.”

Several parents (4; 15%) attributed improvements in the children’s hearing to God or indicated a belief that God would cure their children’s hearing impairment in the future. A mother in Florida said, “I am sure that God helped his ears, even though he needs the hearing aids. In time God will be restoring his hearing.” A mother in California described an experience of praying to Santo Niño about her child, who was born with multiple problems, including deafness. “My husband and I knelt down to pray and at that moment I felt that that saint had helped me to save my child and ever since she has been better off.” Another mother in Pennsylvania remembered, “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 is that the child has improved a lot and I have seen how he is better now.”

Discussion

Upon learning that a child has a hearing loss, parents face a host of confusing options and must quickly evaluate the numerous choices in communication, education, and habilitation in the absence of an evidence base and with only limited information about the expected outcomes of the interventions. This decision-making process is challenging, regardless of cultural background. In this study, we sought to determine the degree to which Hispanic parents who live in the United States and who have children with hearing loss are at a disadvantage relative to their non-Hispanic counterparts in the same situation. The findings we discuss below suggest that Hispanic parents of children who are deaf often make their decisions in the context of language and cultural barriers, and limited access to information, resources, and the full range of options. Special issues such as trilingualism are rarely addressed by professionals, leaving parents to grapple with their questions alone.

Language Barriers Scaled by Hispanic or Bilingual Professionals

Language differences presented significant obstacles to less than a third of our families. The availability of Hispanic or bilingual professionals (counselors, audiologists, nurses, and teachers) reduced the impact of language differences to a great extent in some areas. When bilingual professionals were not available, interpreters were also useful, although parents seemed to benefit from clearer communication with professionals who spoke the same language. Even parents who spoke English relatively well described how the presence of a Hispanic professional added to their comfort and ability to integrate and respond to the information. When inter-
Table 2  Parenting style

Active (n = 14)

DHF03 I made them change. I communicated with people that helped me. I’m the type of mother who shows up unexpectedly to see what they are doing. I’m in the process of organizing a support group for the parents. I need to investigate more and know someone who knows more and gain more information.

DHF04 I was very involved, every situation. I talk to some more people and see what they get out of it . . . see what decisions they made and why they made that decision. I do think about it, I don’t just jump into it.

DHF06 we went to talk with the county and the board and she [lawyer] prepared with a binder with all the laws . . . and she underlined very clearly all the rights that the child had . . . so then finally they transferred us.

DHT15 I told them if you’re putting a barrier or a limit, I am very sorry but I am going to remove my kids from the school and the next day we start terminating all the paperwork. We look for the best school and we try to really get into the school to try and to help. You have to grab the bull by the horns and otherwise you’re going to be wasting your time. We never just stay in one place and don’t do anything.

DHT16 We went totally against what the school wanted.

DHC20 We discuss the options and what we think is best and he [husband] helps me make the decisions. . . . I had done some research about these different schools. We’re just looking into other resources right now.

DHC21 I always try to get help somewhere to help me with the decision. I always ask questions. I make sure I go visit the school first and get information about the school.

DHC22 I decided to get her out of that school so then I transferred her to a regular school and I started to notice that she progressed a lot and that she started to do things right.

DHC23 The thing I learned most was my rights. I would start to notice these other women and mothers that were in these meetings and you know, the American women, they were very aggressive and would ask a lot of questions and I would watch them and study them and think that that’s how I should be behaving. I had to get a lawyer and everything. I also feel that it is my responsibility to get more information about the things they are not telling me.

DHC24 I called an agency for the deaf and I asked them to please send me any information, any paperwork that they had. I sent out about 40 letters to different agencies. I’m a person with a very strong character. I really don’t let anybody tell me anything.

DHP26 Started to analyze and to think that no, I should look for other specialists and that I should look for other tools to give to him. I have always been a person that I never give up.

DHP28 My questions were very hard questions. Other professionals that were around me also said that they didn’t expect that I would be so strong, so strong in my questions, because they thought that it was going to be a lot easier with me.

DHP30 When we found out that she didn’t hear anything, that’s when we make decision. That’s when we call over there and then, when there was no more options in Puerto Rico. So we said if she was born like that, we have to look for her progress.

DHP31 So I woke up and I’m like, all right, this is what I got to do for him and I called them up and I went to their office and they scheduled a lot of appointments. I was very involved in it.

Passive (n = 10)

DHF02 I don’t think that here I have enough information, and also I don’t have enough time.

DHT09 They give us the only option and we just follow up.

DHT10 I did not inquire about any other.

DHT11 I never told them what I had decided. They gave me the information and I went to the school and that was all.

DHT12 We only looked at the school program that we were told about.

DHT13 They would give us options and we knew that if they recommended it to us it was for the well-being of our daughter. We always agreed with what they told us.

DHT14 I have never been a person of asking too many questions. So whatever they say, it’s okay.

DHC16 It [the program child attends] was just given to me. I really didn’t choose it. They really didn’t give me much options.

DHC19 It was their decision. They tell me it’s very important for me to go to be able to communicate with her, but I’ve never gone, and they sent me a notice and I told them that I couldn’t go because I have no form of transportation. Then after that they never said anything.

DHP25 They decided. I accepted them.
preters were necessary and available, parents expressed a preference for those with whom they shared the same dialect of Spanish.

Information Unavailable or Incomplete

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 children to provide information and guidance about not only hearing loss but also available services, medical assistance, and children’s and parents’ rights. The survey results indicate that written materials were used by only slightly more than half of respondents. Materials written in Spanish were frequently offered but appear limited to general pamphlets that have been translated from English, rather than materials written to be culturally relevant to Hispanic people. As a result, some Hispanic parents preferred to receive materials written in English because they felt that the quality of the information they received was compromised by the translation process. Moreover, although English-speaking parents frequently can obtain materials from numerous sources, including popular books, magazines, professional literature, videos, and the Internet, Hispanic parents appear to have far fewer resources at their disposal. Thus, although Hispanic families in this study appeared to be more inclined than non-Hispanic families to heed the advice of the professionals treating their children without seeking multiple sources of information, this may be attributable to the paucity of appropriate materials as well as to language and cultural factors that influence information-seeking behavior.

The author’s (A. S.’s) clinical experience suggests that non-Hispanic parents of deaf children often use and appreciate information and support provided by other parents of deaf children. The data presented in Figure 1 suggest that Hispanic parents also benefit from parent meetings; however in the interviews, parents rarely brought up parent meetings as a valued resource. It may be that in translation the question on the survey took on a meaning different from that which was intended. The interviews suggest that Hispanic parents, particularly those living in communities with small Hispanic populations, may not have access to the type of parent support afforded by structured or unstructured parent meetings. Further investigation is needed to determine whether this is true and whether parent meetings would be helpful to this community.

Communication Choices Limited

The finding that the recommendation of a professional was the most important decision factor considered correlates with the results obtained in the interview study. The communication method chosen tended to be the one recommended by the professionals consulted, with little consideration of alternative approaches. Usually the only option presented was a combination of sign language and speech; the option of oral communication was presented but discouraged. The subjects’ attitudes and knowledge about deafness suggest that sign language is presented as a positive alternative. Approaches such as bilingual/bicultural, which uses ASL as the main form of communication; auditory/verbal, which emphasizes optimization of residual hearing; or cued speech, which uses handshapes to provide a visual form of phonemes, 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 whether they simply lacked knowledge and information about alternative approaches. However, it does appear that the Hispanic families in this study were rarely confronted with the “oral-manual controversy” that in other studies appears to frustrate and confuse so many parents. Interestingly, none of the families mentioned residential schools for the deaf, which historically have played a significant role in reinforcing Deaf culture in the United States. In part, the lack of knowledge or interest in residential schools may be due to the fact that most parents are receiving information from educators in the public school system. Another factor, however, is that traditionally and culturally, Hispanic parents do not wish to have their children living away from home, especially in the early years. Hence, this population tends to be enrolled in public school systems.

Retaining Native Language and Culture

Although most parents cited English, sign language, or both as the language that was most important for their
children to learn, they also expressed a strong desire for their deaf children to learn and retain Spanish and its related culture. The task before these parents seems daunting, particularly in light of the fact that professionals often recommended a single language or bilingual approach and fail to highlight options that might allow them to achieve their goal of trilingualism.

Moreover, maintaining a connection to the Spanish language is difficult even for Hispanic citizens with normal hearing. In a recent article about the possible disappearance of Spanish in the United States, Rumbaut (2000) stated that “the hope of fluid bilingualism in the third and fourth generations is slight if not non-existent.” If this is true, deaf children of Hispanic parents have even less chance of learning, let alone retaining Spanish. Counteracting the diminution of Spanish in the United States are several factors: Spanish is still the dominant language in a very large part of the world and is tightly integrated with the cognition, literature, conversation, music, foods, and traditions of people who use it. Additionally, immigration from Spanish-speaking countries to the United States continues to be high, with population forecasts indicating that by 2025, 25% of the U.S. population will be Hispanic.

Decision-Making Style in the Hispanic Community

In contrast to previous studies that have cited minimal involvement of Hispanic parents with educational support services (Bennett, 1989; Cohen et al., 1990), the families in this study indicated a remarkably high degree of effort in obtaining appropriate services for their children, particularly those whose parenting style was rated as active (see Table 2).

Conclusions

Although decision-making literature demonstrates that parents have a strong desire for information and involvement in medical decisions, making informed choices involves access to culturally relevant information and resources. A shared language between parents and medical professionals is also necessary to optimize the discussion and exploration of treatment options. This study demonstrated that various factors impact on the decision-making process for Hispanic families living in the United States who have children with hearing loss, including religious beliefs and faith in God as the ultimate guide to the best options and outcome for the children and complications resulting from language and cultural barriers. Included in the latter category are the following factors: paucity of appropriate Spanish language materials about deafness, little offering or consideration of communication options, absence of shared language with professionals with whom decisions are typically explored, and the failure of professionals to address trilingualism as a feasible family goal. Degrees of assimilation into American culture (including the acceptability of advocating aggressively for one’s child) and satisfaction with the United States relative to services and options available in one’s country of origin are additional factors recognized by parents who participated in this study.

Limitations of This Study

Although this small sample size limits the generalizability of this study, recruitment from various geographic regions 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 necessary to understand fully the barriers that face this diverse community and the optimal efforts that can be made to overcome these obstacles.

Additionally, because of the voluntary nature of the subjects, we may have gained access to families with a more active decision-making style and resultant higher degree of satisfaction; thus we cannot be sure that our sample is representative of the full range of experience and sentiments. The problem of a small, self-selected sample group is common to many ethnographies, including this one, and is difficult to escape. However, this type of sample group does not necessarily detract from the validity of the study’s findings as long as one keeps in mind that the findings should not be overgeneralized.

Translation issues also arose during the translation and transcription of the interviews. Although all of the translations for this study were completed by native Spanish speakers, we originally hoped to utilize translators from within the communities in which the interviews were conducted, but we were unable to realize this
goal in all cases. Additionally, although interviewers and community facilitators were instructed not to espouse their own preferences regarding communication modality, school, or other interventions, personal biases or misconceptions may have inadvertently crept into the interview discussions.

One final limitation concerns the relatively broad age range (approximately 4–14 years) of the deaf children whose families we studied. It is likely that parents of the older children may have unintentionally recalled events that occurred early in their children’s lives less accurately than parents of the younger children. This problem was unavoidable from our point of view because we aimed for a broad sample within the diverse Hispanic community rather than, for instance, a sample that included only newly identified deaf children.

Implications of This Study

The implications of this study’s findings for professionals working with Hispanic families who have children with hearing loss are noteworthy for several areas, including the need for a shared language. Although there is much we don’t know 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 ASL and Deaf culture but also to Spanish and Hispanic culture. The families we interviewed greatly valued the opportunity to converse in Spanish with a member of the community, suggesting that cultural matching may ultimately prove to be the critical variable in interventions. Trilingual interpreters would be particularly well equipped to address the complexity of translation and interpretation and should be very involved in innovating future linguistic options and intervention trials for the Hispanic family with a child who is deaf.

Informational channels were significantly reduced for many participating families, making the direct service provider communication and relationship even more vital. Although we did not inquire about perceived literacy, significantly fewer Hispanic parents (55%) were given written materials for review than non-Hispanic parents (92%); more globally, access to health care was most likely reduced for this community, given that a third of Hispanic families in America do not have health insurance. Further investigation in the areas of resource material development, building informational telephone networks, and a heightened understanding of computer utilization and utility for Hispanic families with deaf children are clearly needed in order to ensure equal access to information. Hispanic families need all available information regarding communication methods. Our study demonstrated that information provided reliably affected how the families’ decisions were made, but in the absence of information, reasoned decisions are not possible, and decision making must rely on other actions, such as an act of faith. 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, etc.) would best serve to connect families and provide needed support.

Learning a second language is a challenge for many children. Although it is affected by language exposure and positive associated emotions, mastery of two languages requires full and continuous access to rich language. Many hearing children learning English as a second language do not master it, let alone a third language. Hard but realistic choices may need to be made for children who do not receive significant auditory input. Should they be taught in the family’s language or should a choice be made to give them primary access to the language of the community with which they will most likely affiliate? Should cochlear implantation be recommended earlier to optimize the auditory input necessary to master several languages? Should a focus be put on a single language, and if so, which one? How much of a role should professionals play in this decision making, and how can their involvement be most helpful? If the decision is made to emphasize the language of the child’s presumed future community, how can home communication be supported?

We have learned that Hispanic families are presented with fewer options such as cochlear implantation. It also appears that cued speech is rarely considered as an option, although it is not clear whether this is due to a lack of knowledge within the Hispanic community about cued speech or whether cued speech is not thought to be a good choice for families who are struggling with English in the home. When Hispanic parents are 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 select this option to begin offering the child their language. Further elucidation of parental preference of language is indicated on both the individual clinical and community levels. The limitations of the knowledge base should be shared when presenting information to Hispanic families (e.g., we don’t know the relative merits of lipreading, auditory training, etc. for children who must negotiate at least two spoken languages daily). Multisite and international collaborations may be helpful in understanding the balance between the added benefits of seeking services in the United States and the challenges of trilingualism for the child who is deaf. Our participating families came to the United States seeking better lives for their children. Would they have achieved the same general well-being (and satisfaction) if they had remained in their county of origin? The issues related to trilingualism complicate literacy enhancement and shared reading programs; reading role models culturally matched for families from different backgrounds would offer the most benefit from the intervention effort.

The findings of this study underscore the need for a significantly greater presence of Hispanic professionals, educators, peer-to-peer support, parent liaisons, and so on. This would assure a higher degree of cultural competence in addressing the needs of this unique community. Finally, the religious beliefs and values of Hispanic Americans have great significance to and deeply affect their caregiving. The heightened understanding of religious values should be an important training component in services programs addressing the needs of Hispanic families with deaf children.

Appendix A: Survey Questionnaire

ID #

Date:

Relationship to child of person filling out this form:

Parental Decision-Making Survey (revised June 13, 1996)

Section I: Background Information About Your Child

1. Child’s date of birth: ____________________________
   boy/girl (circle)
2. At what age was it SUSPECTED that child might not hear well? ____________________________
   At what age was hearing impairment CONFIRMED? ____________________________
3. At what age do you think your child lost hearing?
   __ don’t know
   __ before birth
   __ after birth; age: ____________________________
4. Cause of child’s hearing loss:
   __ prenatal infection: type ____________________________
   __ meningitis
   __ heredity
   __ prematurity
   __ trauma
   __ other: ____________________________
   __ unknown
5. What is extent of child’s hearing loss?
   __ profound (hears only loud noises, even with hearing aid: 91 dB plus)
   __ severe (can tell different kinds of noises: 71–90 dB)
Decisions Hispanic Families Make about Deafness

— moderately severe (can hear speech in a quiet room with hearing aid: 56–70 dB)
— moderate (can hear in most situations with hearing aid: 41–55 dB)
— mild (responds like a hearing child when aid is worn: 27–40 dB)
— don’t know

6. Training child has received
   — none at this time
   — speech (age began: ___)
   — auditory training (age began: ___)
   — sign language (age began: ___)
   — cued speech (age began: ___)
   — other (age began: ___)

7. Does child have any conditions other than deafness that may affect her/his development or education?
   — No
   — Yes (check)
     — visual impairment
     — learning disability
     — emotional problem
     — attention deficit
     — mental retardation
     — brain damage
     — epilepsy
     — cerebral palsy
     — other

8. Does child have a hearing aid?  __ No  __ Yes
   If yes, when did he/she get it? ________________________________
   Child wears aid:
   — always
   — sometimes
   — rarely
   — never
   Aid was provided by:
   — parent purchase
   — school
   — private insurance
   — public assistance

9. Has a cochlear implant been considered for child?  __ No  __ Yes
   If yes, has child been evaluated for implant?  __ No  __ Yes
   If yes, was surgery performed?  __ No  __ Yes  When? ________________________________
   Satisfaction:
   — very satisfied
   — somewhat satisfied
   — somewhat dissatisfied
   — very dissatisfied
   What part of cost was covered by insurance?
   — none
   — less than 50%
   — 50–75%
   — more than 75%

Section II: Special Services for Child and Family
1. Is child enrolled in early intervention or other school program?  __ No  __ Yes
   What is the name of the program? ________________________________
What communication mode is used?

- speech alone
- cued speech
- sign + speech
- sign alone
- gestures

Services provided at home? No Yes
Services provided at center? No Yes
Any deaf adults on staff? No Yes

2. Is this program provided by your local school district? No Yes

3. How much time per week do you spend in formal program (at home/school/center)? __ hrs.
   does your child spend in formal program (at home/school/center)? __ hrs
   do you spend at home teaching your child? __ hrs.

4. How do you evaluate program?

   a) Staff listens and responds to my concerns, ideas and questions
      Always Sometimes Rarely Never
      4 3 2 1
   b) Program is flexible enough to respond to my child’s specific needs
      4 3 2 1
   c) I am considered an active member of the team
      4 3 2 1
   d) staff is considerate of time and energy limits of our family
      4 3 2 1
   e) my child seems to like the program
      4 3 2 1
   f) My child’s progress has been:
      _ greater than I expected
      _ about what I expected
      _ somewhat worse than I expected
      _ disappointing

Section III: Decision Making

1. Who is involved in making decisions about your child’s care?

   a) mother
      Very involved Somewhat involved Somewhat uninvolved Uninvolved
      4 3 2 1
   b) father
      4 3 2 1
   c) grandparents
      4 3 2 1
   d) friends
      4 3 2 1
   e) family doctor
      4 3 2 1

2. Who has been most or least supportive?

   a) spouse or partner
      Not applicable Very supportive Somewhat supportive Not very supportive Unsupportive
      NA 4 3 2 1
   b) child’s grandparents
      NA 4 3 2 1
   c) other relatives
      NA 4 3 2 1
   d) friends
      NA 4 3 2 1
   e) other parents of deaf children
      NA 4 3 2 1
   f) clergy
      NA 4 3 2 1
   g) family doctor
      NA 4 3 2 1
   h) specialist (e.g. audiologist)
      NA 4 3 2 1
3. Which of the factors listed below most influenced the decisions you have made?

<table>
<thead>
<tr>
<th>Factor</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Somewhat unimportant</th>
<th>Very unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) recommendation of professional</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>b) recommendation of friend</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>c) services provided by local school district</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>d) cost of services</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>e) availability of services close to home</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

4. What characteristics of the person (or persons) who most influenced your decision were most important to you?

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Very important</th>
<th>Somewhat important</th>
<th>Somewhat unimportant</th>
<th>Very unimportant</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) experience with deafness</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>b) information he/she provided</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>c) provided unbiased information</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>d) listened to my concerns</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>e) took into account family resources</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

5. Since your child’s diagnosis, have you met with any deaf adults? __ Yes __ No __ How many? __

6. Since your child’s diagnosis, have you met any other parents with deaf children? __ Yes __ No __ How many? __

Section IV: Use of Resources

1. Which resources have you used since your child’s diagnosis?

<table>
<thead>
<tr>
<th>Resource</th>
<th>Used, found helpful</th>
<th>Did not use</th>
<th>Used, did not find helpful</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) written information about different approaches</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>b) videotaped information about different approaches</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>c) sign language or cued speech instruction</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>d) parent meetings</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>e) individual counseling</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>f) interpreter</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>g) other</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Section V: Attitude About and Knowledge of Deafness

1. Do you agree or disagree with the following statements?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Disagree somewhat</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Deaf children should go to ordinary schools</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>b. Children should be taught sign language so they can talk to deaf people</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>c. Although sign language may be useful, it isn’t really a proper language</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>d. As a society, we push out deaf people</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>e. When I am with a deaf person I feel awkward</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>f. All deaf children could learn to speak if enough time and effort were put into teaching them.</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
Section VI: Communication and Peer Relationships

1. Which method of communication do you use with your child at home now?
   - speech alone
   - cued speech
   - speech and sign
   - sign alone
   - gesture

2. Which method of communication does your child use at home now?
   - speech alone
   - cued speech
   - speech and sign
   - sign alone
   - gesture

Section VII: Questions About Your Own Feelings as a Parent (OR Caretaker)

<table>
<thead>
<tr>
<th></th>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Disagree somewhat</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I enjoy being a parent</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I can feel proud of the way I have responded to the special needs of my child</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I can’t make decisions without help</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. My communication skills are quite adequate for my child’s needs</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. I feel that I am successful most times when I try to get my child to do or not do something</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. Since I first brought my child home, I find that I am not able to take care of this child as well as I thought I could. I need help</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>7. My child is often left out of family conversations because of communication problems</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8. As a parent, I can handle anything</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>9. I feel that I am a very good parent</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>10. There are many things I can’t seem to communicate to my child</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Section VIII: Background on Family

1. With whom does child live now?
   - mother only
   - father only
   - both mother and father
   - mother and stepfather
   - father and stepmother
   - adoptive parent(s): (age child adopted ____________________________)
   - other: (who? __________________)

2. Other children in the family (circle the age of any child who has a hearing loss):
   Boys: (ages _____ / _____ / _____ / _____ ) Girls: (ages _____ / _____ / _____ / _____ )

3. Other family members with hearing loss? __ Yes __ No
   How are they related to your child? (e.g., grandmother, uncle) _________________________________
4. Primary language used at home:
   ___ English
   ___ Spanish
   ___ American Sign Language
   ___ Signed English
   ___ other: ________________________________

5. Highest school grade completed by parents:
   mother: ________________________________
   father: ________________________________

6. Occupations of parents:
   mother: ________________________________
   father: ________________________________

7. Racial or ethnic background: ________________________________

Section IX: Satisfaction (answer NA if you don’t have an opinion because child is only recently diagnosed)

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not applicable</th>
<th>Strongly agree</th>
<th>Agree somewhat</th>
<th>Disagree somewhat</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I am satisfied with the range of options available for my child.</td>
<td>NA</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I have been able to obtain all the information I need to make decisions for my child.</td>
<td>NA</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. The first professional I consulted pointed me in the right direction.</td>
<td>NA</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. Knowing what I know now, I would choose the same approach as I chose originally.</td>
<td>NA</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Appendix B: Interview

OPCIONES: Parental Decision-Making Interview

I. Background Information

1. How old is ______? When is his/her birthday?
2. What kind of a hearing loss does ______ have? (profound, severe, moderate/bilateral, unilateral)?
3. Who lives in ______’s home? Any others deaf or hard of hearing?
4. Where do you live? How would you describe the area or community where you live? (city, suburb, country, farm . . .)
5. Do you work outside of the home?
   What types of jobs do the members of your family have?
6. What language(s) does your family use in your home?
   Which language is more comfortable for you to speak?
7. How good is your Spanish? English?
   What about your other family members?
8. Where is your family from originally (United States, Puerto Rico, Mexico, etc.)?
   If originally from another country (not born in U.S.),
   How long have you lived in the United States?
   Why did you (your family) come to the United States?
II. Prediagnosis
9. Before your child, did you know or meet any deaf or hard of hearing people?
10. Did you know any deaf or hard of hearing people when you were growing up?
11. Did you know any famous deaf people? Who?
12. When did you first sense that _______ couldn’t hear well?
   What made you think that?
13. Did you tell anyone that you believed your child did not hear well?
   What was their reaction?

III. Diagnosis
14. When were you first told by a professional, that _______ might be deaf? Who told you?
   How did they tell you?
   Do you remember the exact words they used to describe your child’s hearing loss?
15. Who else was with you, or were you alone?
16. Where were you when you received this diagnosis? Why did you go there?
17. What did you think when you first heard this news?
   How did you feel?
18. How do you feel about how you were told?
19. How did your family and friends react?
20. Did the professional who gave you this diagnosis speak in Spanish or English?
   If in English, was an interpreter provided, or did a family member or friend interpret?
   If someone interpreted for you, how did you feel about using an interpreter while you just learned of your
   child’s deafness?
   If no one interpreted for you, how did you feel?
   Do you think you fully understood what you were told?
   If no—why was that (e.g., complexity of information, language barrier)?

IV. Deafness Information
21. What information about deafness or hearing loss were you given at that time (immediately after diagnosis)?
22. Who gave you this information?
23. Were things explained clearly to you? Did you understand what they were telling you?
24. Do you think you were given enough or too much information at that time?
25. Was the information helpful? Why? Why not?

V. Initial Guidance at Diagnosis
26. When you were first told of your child’s deafness, did anyone advise you about what you should do next? Who
   gave this advice? What did they tell you to do?
27. What did you feel about the way you were given this advice (empathetic, supportive, pushy)?
28. What did you think of their advice? Were you comfortable with their recommendations? Why or why not?
29. Were you ready to hear this advice at that time?
30. In general, did it seem that the professionals were giving you advice so you could decide or do you feel that
   they were telling you what to do?

VI. Process (immediately following diagnosis)
31. What did you do next?
   Get a second opinion?
   Who did you call?
   Did you visit school?
32. Did you feel that you needed to make decisions for _______ immediately?
   What made you think this? Did someone say this to you?
33. Did the professionals (e.g., doctor, audiologist) you met ever give you options or choices to pick from for your child (for example, regarding communication, education, medical treatment)?
   Or did they make decisions for you?
34. Who did you discuss your options with?
35. Who or what was most helpful to you in making these choices (decisions) for your child?
   Why?
36. Was there anything or anyone who was not helpful to you in making these decisions?
   Why?
37. Did anyone say or predict anything about your child’s future life?

VII. Family and Friends
38. Did your family or friends give you advice or help upon learning of your child’s deafness (choosing doctors, medical treatment, school, communication, dealing with new or increased stress, reasons this happened, etc.)?
39. Where does your family live (your parents, in-laws, siblings, cousins, etc.)?
   If you are geographically far from family, how did you deal with this news without the help and presence of your family?
40. Did your church, faith, or religious beliefs help or guide you with what to do with ________?
   If so, in what way?
41. Was there someone in particular who helped you a lot? Someone who did not help you?

VIII. Hearing Aids
42. Were hearing aids recommended for ________? How soon after his/her diagnosis?
43. Did the audiologist speak in Spanish or English?
   If in English, was an interpreter provided, or did a family member or friend interpret?
   Was/is communication with the audiologist clear?
44. Were you offered a choice about hearing aids or were you told your child must have them?
45. Did you feel you had the information you needed about ________’s hearing aids?
46. What were you told to expect from them?
47. How did you feel about putting hearing aids on your child?
   How does ________ feel? Does he/she wear the hearing aids now? Where?

IX. Cochlear Implants
48. Did anyone ever talk with you about cochlear implants?
   Who? What did they tell you?
49. What did you think about this? Did you pursue it further?
50. How did you get information about the implant?
51. Do you know anyone with a cochlear implant?
52. Have you decided whether to get a cochlear implant for ________?
   What influenced your decision?

X. Postdiagnosis/Educational Placements
53. How soon after ________, was diagnosed with a hearing loss, did he/she start school?
54. How did you find out which programs were available?
55. Did you explore different educational options?
   (various settings: residential school, day school, mainstreaming, self-contained classroom; various philosophies: oral method, total communication, bi-bi ASL/English, audio-verbal, etc.)
   Did you visit programs? What was that experience like?
   What did you think of the programs?
56. Did you find out what options were offered by your school district?
   What were they?
What did you feel about them?

57. Did _______ participate in an early intervention program (for children ages 0–3 years)?
   If you were offered a choice of programs, what kind of program did he/she start?

58. What made you choose the first special program or school _______ attended?

59. Do you know what the communication and educational philosophies are of this program?
   What was your reaction to their recommendation?
   What did you do then?

60. Did the school/program advise you about how you should communicate with _______?

61. How would you describe this program?

62. How involved were you with _______’s first school/early intervention program?

63. Could the staff and teachers speak with you in Spanish?
   Was the written information or papers they sent you in Spanish?
   How did you feel about this?
   If in English:
     Was an interpreter provided, or did a family member or friend interpret?
     Do you think you fully understood the teachers?
   If not, why not?
   If no one interpreted for you,
     How did you feel?

64. How do you think cultural or language differences between you and the school staff have affected you or your child’s education?

65. Were/Are there any deaf people on staff?
   Were/Are there any staff who were Hispanic themselves?

66. Did _______ like the school/program?
   What about you?

67. What other schools did _______ attend (ask for education placement to present)?

68. Why did you choose those schools?
   Were you offered any options for _______’s communication and/or education since his/her first time in school?
   If you were periodically given options,
     did you feel free to make your own choice, or did you feel pressured or told what to do for your child?
     did you feel you had enough information to make decisions for _______?

69. Who communicates with you to report about your child’s progress?
   Does this person have direct contact with your child?
   Do you feel as though you participate actively in your child’s education now?

70. Have you spoken with other parents of deaf children? Was this helpful?

71. Have you ever met or do you know any deaf adults now?
   How was this experience for you? Did it help you?

XI. Communication

72. How do you communicate with _______? (sign, gesture, oral)
   How does the rest of your family communicate with him/her?

73. Do you speak/sign to him/her in English? Spanish?
   Do you feel it’s important for _______ to know Spanish? English?

74. Is it more important for you that your child be able to communicate with those who speak English, with Spanish-speaking people, or with those who use sign language?
75. If you were going out at night, can you tell this to ________, so that he/she would understand? How would you communicate this to him/her?
76. What do you do at home to help ________ with his communication?
77. How does ________’s school want you to communicate with him/her at home?
   What do you think about this?
   *If you speak to your child in Spanish, do you think it has had any effect on your child’s progress in school?*
78. Do you feel satisfied with your ability to communicate with ________?
   With your family’s ability to communicate with ________?

XII. Decision-Making (the decision making process, and the decisions you made)
79. Overall, do you feel you’ve been able to get enough information to make decisions for ________?
80. In general, do you feel professionals who provided you information encouraged you to make decisions for your child, or did you feel they told you what you should do?
81. Did you feel professionals supported your decisions for your child?
   No matter what you decided?
82. Did you ever change your mind or re-evaluate your decisions for ________?
83. What, in your opinion, are the most important things to consider when you make decisions related to your child’s deafness?
84. Do you think that there are key times when decisions should be made for a deaf child?
85. Have you ever felt pressured to make decisions before you were ready?
86. What are your thoughts about your next step with ________?

XIII. Future
87. How has your daily life changed since you found out about your child’s hearing loss?
88. Imagine your child 10 years from now. What do you think he/she will be doing?
   How do you hope he/she will be communicating?
   Do you expect this to happen?
89. In 10 years, how do you hope ________ will be doing academically?
   Do you expect this?
90. In 10 years, what kind of social life do you hope ________ will have?
   Will he/she have friends who are deaf? Hearing?
91. What are your major concerns for ________ now? and for the future?

XIV. Wrap Up
93. We’re compiling this information for other Hispanic parents with deaf children. Is there anything else you’d like to share with other parents?

References
Rumbaut, R. (2000). Desaparecida el español? The Orange County Registrar for the New Mexican. January, Santa Fe, NM.
Schlesinger H. S. (1972). Diagnostic crisis and its participants. Deafness Annual, Volume II. Silver Spring, MD: Professional Rehabilitation Workers with the Adult Deaf.
U.S. Census Bureau. Census 2000 Summary File 1 (United States), prepared by the U.S. Census Bureau.

Received May 2, 2001; revisions received July 7, 2002; accepted September 16, 2002