



Communication and Culture: Implications for Hispanic Mothers with Deaf Children

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UNIVERSITY OF MIAMI

COMMUNICATION AND CULTURE:
IMPLICATIONS FOR HISPANIC MOTHERS WITH DEAF CHILDREN

By

Alliete Rodriguez Alfano

A DISSERTATION

Submitted to the Faculty
of the University of Miami
in partial fulfillment of the requirements for
the degree of Doctor of Philosophy

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COMMUNICATION AND CULTURE:
IMPLICATIONS FOR HISPANIC MOTHERS WITH DEAF CHILDREN

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Communication and culture: Implications for
Hispanic mothers with Deaf children

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The majority of deaf children are born to hearing parents. The fact that many of these children use sign language as their primary form of communication poses a unique language barrier between them and their hearing families. In addition, for children who are born into Hispanic families, these children have limited access to Hispanic and Deaf cultures unless their families actively pursue involvement with those communities. Data were collected through ethnographic interviews and limited participant observation and analyzed by means of grounded theory methodology. The study investigated how Hispanic mothers communicate with their deaf children who use ASL as their primary language, as well as how these mothers view Deafness as a culture.

DEDICATION

This is dedicated to all the Hispanic families with deaf children that I have come to know and admire. They have provided me with the inspiration to complete this study and will continue to inspire me as I work to improve communication between families and their deaf children.

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INTRODUCTION

The majority of deaf children are born to hearing parents. The Gallaudet Research Institute (2005) reports that 83.4% of deaf children have two hearing parents. The fact that many of these children use sign language to communicate poses a unique language barrier between them and their hearing families. In addition, these children have limited access to Deaf culture unless their families actively pursue involvement with that community. The term “deaf” with a lower case “d” has historically been used for those individuals who do not have the capacity to hear. However, the term “Deaf” with a capital “D” refers to the culture of individuals who share a common signed language. “Hearing Impaired” is a medical term used to denote the audiological condition of a person who cannot hear, and is further qualified by degree of hearing loss (e.g., mild, moderate, severe, profound). For the purposes of this study, the terms “deaf” and “Deaf” will be used as described above.

The concepts of communication and culture are not mutually exclusive. In fact, the two concepts are necessarily intertwined and the process of enculturation is the acquisition of cultural characteristics in a given culture (Gollnick & Chinn, 2002). Through this process, which is typically learned through one’s family and community, the individual becomes competent in the culture’s language and social norms. This socialization process (learning of the social norms of the culture) allows the individual to internalize the rules of the culture and society. For children who do not learn their parents’ language, how does this process of enculturation and socialization evolve? One possibility is that the communication barriers lead to the subsequent disruption of the enculturation process, thus rendering the child ineligible for full membership in the given

culture. Difficulty communicating with hearing people has led many deaf individuals to use signed languages to form their own cultural groups (Gollnick & Chinn, 2002). This allows them to have access to other individuals who use their language and share similar experiences with those who are more accepting.

There is a body of literature that is concerned with families' roles and responses to disability and, although it is broader than the scope of this study, it will be briefly outlined. Turnbull and Turnbull (2001) found that parents have historically been cast in a number of roles that include: parents as the cause of the disability, parents as emotionally disturbed, parents as teachers, and parents as family members. In addition, the impact of disabilities on parents can be far-reaching (Lian & Aloia, 1994). An individual family's expectations surrounding the birth of a child, reactions to different types and degrees of disabling conditions, family structures, and sibling reactions all add stressors, challenges that will determine the overall impact the disability will have on parents.

When a disability occurs in a culturally diverse family, the experience of double minority status can bring additional challenges. This is exacerbated by the communication difficulties inherent in having a deaf child who uses sign language. The child may be caught between two minority cultures within the larger culture of the dominant hearing society.

Although research on Hispanic families in the U. S. with deaf children is lacking, there is a large body of literature on how Hispanic families cope with disabilities in general. Hill's study on parental coping styles (1968) sheds light on the juncture of disability, family, and minority cultural status. The approach he described suggests that an event (A) interacts with a family's resources (B), as well as with the family's

interpretation of said event (C), to produce an outcome (X). As described above, families' interpretations and resources are varied, particularly for minority families.

In a qualitative study addressing the issues urban parents face when they have children who are deaf or hard of hearing, Freeman, Dieterich, and Rak (2002) identified specific challenges. The issue of language is most salient: Parents described how difficult it was for them to communicate with their children who were learning sign language when they themselves did not sign. Parents expressed frustration and felt ill-prepared to communicate with their children. In addition, parents described their struggles with grief and with systemic barriers that included teachers and clinicians who were poorly trained to work with deaf children. Given these difficulties, it is possible that limited English language skills added to childhood deafness represents further restrictions in access to schools and clinicians.

In order to bridge the language gap, families use a variety of strategies to communicate with their deaf children. These strategies can include learning sign language, writing to each other, or using an interpreter. These families may also reach out to other Deaf individuals in order to help their children learn about Deaf culture. In the case of Hispanic families in the U S., however, some of these strategies may be less accessible to them due to the families' lack of English proficiency. How, then, do these families communicate with their deaf children who use sign language and how do they share their own culture and/or allow their children to learn about Deaf culture? The purpose of this investigation was to engage in grounded theory research that focused on how Hispanic mothers communicate with their deaf children who use ASL as their primary language, as well as how these mothers view Deafness as a culture.

The issue of culture is not clear-cut with regard to Deaf culture. There is controversy with respect to minority cultural status for the deaf, including whether cultural identity should apply to the Deaf Community. Proponents of Deaf culture include those who consider themselves to be culturally Deaf, anthropologists, and many professionals who work with the Deaf. In contrast, opponents of Deaf culture believe that it is not a true culture because it developed out of necessity from a disability. Culture, as defined by Hirsch, Kett, and Trefil (2002), in their dictionary entitled *Cultural Literacy*, is “The sum of attitudes, customs, and beliefs that distinguishes one group of people from another. Culture is transmitted, through language, material objects, ritual, institutions, and art, from one generation to the next” (p. 43). Duarte and Smith (2000) suggested that:

Culture refers to aspects of human social life including customs, rituals, habits, attitudes, beliefs, values, and norms. It centers on our symbolic representations of material reality and integrated patterns of knowledge, belief, and behavior that are transmitted from one generation to another. Culture plays a role in creating and maintaining a social order and may be understood as a complex network of symbols. (p. 344)

In discerning whether “culture” applies to the Deaf, Padden (1989) stated that “culture is a set of learned behaviors of a group of people who have their own language, values, rules for behavior, and traditions” (p. 4). Padden distinguished between culture and community, wherein community “is a general social system in which a group of people live together, share common goals, and carry out certain responsibilities to each other.” She also described the basic tenets of Deaf culture, including degree of hearing loss, language use (of American Sign Language or ASL), social relations, and stories and literature of the culture.

Those who contest the legitimacy of Deaf culture consider deafness to be a disability, a sensory impairment that requires medical intervention. In the past, the deaf

were thought of only as disabled people who could not hear and who lacked language skills because of their disability. When ASL was officially recognized as a complete and distinct language in the United States with the help of William Stokoe, an English Professor at Gallaudet University, the Deaf community gained new respect (Padden, 1989). For the Deaf, the official recognition of their language was considered the final step in acknowledging that they had a unique culture. ASL is also listed as an official language in the Linguistic Society of America, which describes the parameters of ASL, including question-asking, hand orientation, and structural differences. Because of this new information, the Deaf community argues that people who are Deaf should be viewed as a linguistic minority (Charrow and Wilbur, 1989).

The culture debate has increased in the past few years with the introduction of cochlear implants. Cochlear implants are surgically implanted devices that bypass the damaged structures in the inner ear, directly stimulating the auditory nerve to facilitate hearing. The implants were approved for children by the Food and Drug Administration (FDA) in 1990. While cochlear implants were hailed by the medical community as a veritable “cure” for deafness, the Deaf community responded negatively to this advance, perceiving that it would lead to the extinction of Deaf culture. As Padden (2002) stated, “Deaf people are described as challenging the ulterior motives of doctors and hearing parents. Hearing parents of deaf children in response accuse Deaf people of unnatural and unnecessary claims to cultural rights” (p. 80).

Another important aspect regarding Hispanic families relates to the traditional Hispanic roles of child-rearing. It is most often the case that the mothers are the primary caregivers for the children, while the fathers work outside of the home in order to provide

for their families. Mothers are therefore, typically more knowledgeable regarding their children. In addition, it is naturally more comfortable for mothers to share information with other women. Harry (1996), in an analysis of the impact of researcher identity in qualitative studies, described the predominance of mothers as opposed to fathers in many family studies and explains how, in her own studies, shared gender allowed greater access, rapport, and trust in working with mothers. Also, as a woman, she was allowed to participate in a greater number of activities with these mothers, which would not have been acceptable otherwise, including traveling together in a car and participating in informal conversations. Due to traditional Hispanic roles, the levels of comfort that were accessible, and the availability of mothers as primary caregivers, the present study focused on mothers and their deaf children.

The process of understanding how Hispanic mothers view deafness and communication with their deaf children who use sign language is complex. While quantitative statistical analyses can describe the numbers of deaf children and Hispanic families in the United States, they cannot explain how a Hispanic mother communicates with her deaf child, how her communicative abilities relate to her perceptions of competence as a mother, or how she deals with the cultural aspects of deafness. In order to answer these multifaceted questions, qualitative analyses were required. This study has increased our understanding of the needs faced by Hispanic families with deaf children, thus allowing for the development of improved services and support.

REVIEW OF THE LITERATURE

There are many challenges related to language and culture faced by hearing parents of deaf children. They include logistical issues, such as methods of amplification, language modalities to be taught, school placement options, and selection of the best speech instruction methods. In addition, concerns regarding the everyday functioning of the deaf child and their family can increase stress within the family environment. Stressors may include reduced literacy skills, difficulties with communication between parents and children, (Freeman et al., 2002), the child's overprotection and limitation of his/her participation in regular life activities (Paul, 1998). These difficulties may lead to more limited support networks, feelings of isolation, and stigmatization which may result in depression, anxiety and anger for hearing parents (Quittner, Glueckauf, & Jackson, 1990). Although these difficulties are also found in the average family in the United States with a deaf child, they are magnified when the hearing parents are limited English-speaking Hispanics whose children use ASL.

The state of Florida generally is reflective of the nation in its distribution and characteristics of deaf and hard of hearing children and youth. Data from the 2004-2005 Annual Survey of Deaf and Hard of Hearing Children and Youth indicate that of Florida's 1750+ deaf students, 82% were born to two hearing parents. Of deaf and hard of hearing students, 45.2% are white (non-Hispanic), 27.7% are Hispanic, 22.1% are Black/African American, and 5.1% are identified as "other" or of multi-ethnic background. Of these Hispanic students, 11.8% of the families use Spanish in the home, 74% use English in the home, and 13.2% use multiple languages in the home. Twenty-three percent of the families regularly sign (although, it does not state what is considered

“regular”), while 61.2% of the families do not regularly sign. In the classroom, however, the numbers are different. The communication mode used for teaching was reported to be 42.1% speech only and 57.3% sign and speech or sign only.

Of Florida’s 1750+ deaf children represented in the survey, 51% were characterized as having a severe to profound hearing loss. Only 11% reported having received a cochlear implant, leaving a large number of children who are unable to use oral language as their primary means of communication. These numbers suggest that there is a considerable mismatch between home language use and classroom language use for many of these students, and this mismatch is further heightened for those children from Spanish-speaking homes.

The purpose of this chapter is to review the literature relevant to the study's aim of identifying ways in which Hispanic mothers with limited English language skills communicate with their deaf children, as well as identify whether these mothers view deafness as a culture or a disability. First, I will review traditional Hispanic roles, perceptions, and issues as they relate to disabilities. Next, I will outline the topic of disability and discrimination, followed by specific concerns related to the Hispanic-Deaf. The second half of the chapter will summarize the complex issues in the debate over the acceptance of Deafness as a culture versus the concept of deafness as a disability.

Hispanic Parents and Disability

Traditionally, Hispanics have held views regarding disability and schooling that have not necessarily been aligned with current American standards and expectations for family participation (Correa & Jones, 2000; Harry, 1992a, 1992b; McHatton & Correa, 2005; Bailey, Skinner, Rodriguez, Gut, & Correa, 1999; Rodriguez & Olswang, 2003;

Zuniga, 1992; Salas-Provance, Erickson, & Reed, 2002). These conflicts are evident in role expectations, child rearing, values, attributions of disability and preferences for treatments.

Parental roles, expectations, and perceptions. Literature on this topic indicates considerable conflict between Hispanic parents and schools in relation to the interpretation of a child's disabilities. In addition also that parents perceive considerable discrimination in their interactions with schools. For example, many Hispanics have felt that it is the schools' job to make sure that their children, including those with special needs, are receiving an adequate education. (Rodriguez & Olswang, 2003).

Lynch and Stein (1987) compared Hispanic, Black, and Anglo families to determine if there were differences in parent participation in their children's special education programs. They determined that the Hispanic families in the study did not participate as often as parents from the other two cultural groups. When asked about the barriers to their participation, these Hispanic families cited work and time conflicts, as well as transportation problems and child care needs. When asked what could be done to increase parent participation, they suggested holding bilingual meetings, selecting convenient times for parents, providing transportation, more advanced notice of meetings, and child care. Finally, when asked what the one major barrier was to their participation, parents cited work, no bilingual communication, and general communication concerns/problems. Many of these parents did not feel that their participation was necessary for their children to receive appropriate services and that the teachers and professionals at the schools could better determine what was needed.

However, this attitude was in direct conflict with the expectations that the school personnel had for active parent participation in developing a home/school partnership.

The acculturation process can also affect parenting styles and beliefs about child development. Gutierrez and Sameroff (1990) studied maternal views of child development in Mexican-American and Anglo-American mothers and found that the Mexican-American mothers who were both highly acculturated and effectively bicultural encompassed more complex views than did the Anglo-American mothers or the Mexican-American mothers with lower acculturation status. The authors concluded from this study that parents with differing levels of acculturation and biculturalism were likely to have differing views of the process of child development.

Rodriguez and Olswang (2003) investigated the beliefs and values about education and language impairment of Mexican-American and Anglo-American mothers with children with language impairments. They concluded that Mexican-American mothers' educational beliefs were typically more traditional and authoritarian; they felt they should not have an active role in their children's education and they often limited their involvement in their children's educational process. However, it was found that there was a great deal of intra-cultural difference, suggesting that stereotypical characterizations would not be appropriate for these families.

Another aspect of traditional Hispanic culture related to disabilities is the perceived cause of childhood disabilities. Zuniga (1992) described some of the traits of medical alternatives such as the use of natural healers and the folk beliefs of mal ojo (evil eye), susto (fright), and mal puesto (evil hex). Salas-Provance, Erickson, and Reed (2002) suggested that Hispanics traditionally believe in a combination of medical and non-

medical causes, including premonitions (dreams during pregnancy), past transgressions, genetic problems, birth trauma, and childhood accidents. A primary aim of their study was to explore the attitudes of Mexican Americans toward the causes and treatment of speech, language, and hearing problems. In order to accomplish this, forty members of one family were interviewed using both open- and closed-ended questions. Their results suggested that the majority of participants believed in medical causes versus folk beliefs, and although the older participants held stronger folk beliefs, some of the younger participants continued to hold similar beliefs. One overall conclusion of this study suggested that the stereotypical views of the Hispanic population and their beliefs regarding health and illness were both supported and rejected. This implies that “both the generational influence as well as recency of immigration must be examined when considering the strength of folk beliefs held by individuals” (p. 158).

Traditional Hispanic attitudes to disability may also result in conflicts regarding definitions of disability. Harry (1992) discussed how the Puerto Rican parents she interviewed in an ethnographic study made sense of their children’s disabilities. One salient feature related to the use of labels. Many of the families agreed that their children may be slower to learn or have weaker command of language in comparison to their peers, but they did not agree with labels of mental retardation or learning disability. They suggested that their children were simply slower learners than other children. Many of the family’s definitions of “normal” were much broader than the schools’ definition. Families suggested that if their children could speak and function in society, then they were normal. They felt that children with disabilities were those children who were unable to care for themselves or had a severe physical limitation. They also defined how the term

“retarded” as “crazy” in their mother tongue; a label that was looked down upon in the community. These parents also suggested that their children’s difficulties in school arose from their confusion in switching from Spanish to English. Some parents felt that teachers’ intolerance of Spanish caused their children’s difficulties and that they would have to choose between English and Spanish for their children.

The traditional framework of Hispanic culture adds another layer to this complex picture. For example, many Hispanics have felt that a child with a disability represents an issue wrapped in religious meaning, such as attributing the child as a blessing or a punishment from God. In a series of studies of Hispanic parents with children with disabilities, the issues of etiology and attribution to treatment preferences and use, Bailey, Skinner, Rodriguez, Gut, and Correa (1999) found that 61% of their Mexican and Puerto Rican parents reported the exclusive use of biomedical, educational, or psychotherapy treatments for their children with mental retardation or developmental disabilities. However, 37.5% of the parents reported the use of the above mentioned treatments in addition to the occasional use of alternative methods. These methods were most often religious rites and practices and folk medicines. These parents suggested that their primary use of alternative treatments was for the purpose of improving symptoms or conditions and not for the cure of an underlying condition or syndrome.

Skinner, Correa, Skinner, and Bailey (2001) found that the majority of the Hispanic families in their study felt that their children’s disabilities were a sign from God. Although a small percentage believed that it was a punishment from God, most felt that their child was a blessing or gift sent from God and many parents reported that their faith increased after the diagnosis of their child’s disability.

Skinner, Bailey, Correa, and Rodriguez (1999) found that most of the mothers (71%) felt that their child was a blessing. Some mothers felt that because they had proven themselves to be exceptional people (or mothers) they were given the charge of raising a child with a disability, while others felt that their sacrifices for the child would be seen as morally virtuous. For the mothers who felt that their child was a punishment from God, they suggested that they deserved it for having committed some wrong in the past or felt that they did not deserve a child with a disability because they had done no wrong.

Disability and discrimination. Conflicting opinions and a lack of cultural understanding between the schools and Hispanic families can lead to decreased communication, and increased isolation and discrimination. For many Hispanics, discrimination is an everyday reality. This can be due to their appearance, language use, or customs, whichever features are considered deviant by the society at large. The same is true for many individuals with disabilities; discrimination is also a part of their daily lives. The creation of social rules by a society also generates a measure by which one can be considered deviant, and in turn, stigmatized (Becker, 1963). Bogdan and Taylor (1994) argued that labels, such as “mentally retarded” can be stigmatizing in our society. They stated that these labels suggest to society how the labeled person should act and how they are to be treated.

As Goffman wrote in *Stigma* (1963), a person would be stigmatized in a society if he or she possessed an attribute that made him different in a negative way from others in that society. He suggested that a stigma could be known as “a failing, a shortcoming, a handicap” (p. 3) and represented a type of relationship between attribute and stereotype. He described three distinct types of stigma: abominations of the body (e.g., physical

deformities), blemishes of individual character (e.g., weakness, rigid beliefs, or mental disorders), and tribal stigmas of race, nation, and religion. Society, then, holds the belief that individuals with a stigma are “not quite human” (p. 5), and discrimination inevitably follows.

In response to Goffman and other similar works that look at deviance and rejection, Bogdan and Taylor (1987) discussed the sociology of acceptance as the opposing view. Their attempt was to move away from how people become outcasts and focus, instead, on how people who are different are integrated or accepted in some communities. They suggested that no matter how different a non-typical person could be, these attributes did not preclude the acceptance of relations. They stated that the tenets of the sociology of acceptance mean that:

An accepting relationship is one between a person with a deviant attribute and another person, which is of long duration and characterized by closeness and affection and in which the deviant attribute does not have a stigmatizing, or morally discrediting, character. Accepting relationships are not based on a denial of difference, but rather on the absence of impugning the different person’s moral character because of the variation. (p. 35)

This type of personal relationship would be representative of one aspect of the sociology of acceptance. A truly developed sociology of acceptance would be realized across societal, institutional, and organizational parameters. Bogdan and Taylor also categorized four major orientations through which accepting relationships are based: family (the family relationship supercedes the differentness), religious (the deviance has special significance and is often the basis of the relationship), humanitarian (concern is with the needs of the atypical person and the alleviation of their suffering), and friendship (the

positive attributes of the person are central and the negatively valued difference is in the background).

The concepts of stigma and acceptance have been directly applied in studies of perceptions of disability with the deaf as well as in Hispanic populations. At the time that Bogdan and Taylor's thoughts on acceptance were published, they reported that the only literature that discussed the acceptance of individuals with differences was Groce's (1985) account of the deaf on Martha's Vineyard. Her study set out to document life on Martha's Vineyard in the end of the 17th century to the mid 20th century, when the incidence of hereditary deafness was so large that the entire population used sign language regardless of hearing ability. Because of the prolific use of sign language, the Deaf were not disadvantaged in the way that the average deaf person is in the larger society. In fact, many deaf individuals were indistinguishable from "hearing;" when residents of Martha's Vineyard were asked to identify those members in the community who were deaf, most simply could not. Groce suggested that profound deafness would be regarded as a true disability in most communities but that since "a handicap is defined by the community in which it appears" (p. 4), the deaf were not handicapped in Martha's Vineyard:

The difficulty in communicating, along with the ignorance and misinformation about deafness that is pervasive in most of the hearing world, combine to cause difficulties in all aspects of life for deaf individuals. On the Vineyard, however, the hearing people were bilingual in English and the Island sign language. This adaptation eliminated the wall that separates most deaf people from the rest of society. (p. 4)

Vazquez (1973) found confirming evidence that greater resilience towards disability existed among ethnic minority families when compared with European

American families. In this study, Mexican American and African American mothers were significantly more accepting of disabilities than were European American mothers.

McHatton and Correa (2005) discussed the types of discrimination perceived by single Puerto Rican and Mexican single mothers of children with disabilities. Their qualitative study of mothers' perceptions suggested that many of these mothers perceived discrimination based on their culture, based on their child's disability, or on the combination of both their culture and their child's disability. Discrimination was felt from many sources, including strangers, professionals, and family members. For many of these mothers, as the primary caretakers of their children with disabilities, the discrimination was felt as an attack on them and they felt compelled to respond on behalf of their children. The main types of discrimination they faced dealt with difficulties in accessing services for their children due to their limited knowledge of English, assumptions that a child's disability was caused by a function of minority lifestyle, constant reminders of their children's inabilities, and rejection of the children by others. In fact, for many of these mothers, the primary reason that they were single mothers was because the fathers of the children could not accept that they had a disability.

The Hispanic-Deaf. The mismatch of language modalities in families with deaf children who use ASL can cause immense problems within the family. Many families simply do not learn to use ASL as fluently as the child does, further distancing themselves communicatively from the child. For these reasons the issues can appear far greater for the Hispanic family with a deaf child versus a child with another type of disability. Maestas y Moores and Moores (1984) stated that in addition to these concerns, there are few Hispanic professionals trained to work in special education.

Erickson (1984) discussed the unique challenges brought on by the impact of a double minority status for Hispanic deaf children. She suggested that both the sensory handicap and the difference in cultural and linguistic characteristics must be considered in planning for these children. She discussed the history of bilingual education, special education, and bilingual special education in the United States and acknowledged that in the case of the Hispanic deaf child, all of the professionals from these branches of education need to work together to ensure the best academic fit for the children. This, however, has not been the common scenario for Hispanic deaf children.

Takala, Kuusela, and Takala (2000) discussed the results of a five-year longitudinal sign language intervention project for 81 hearing families with deaf preschool children. The children learned sign language informally with a deaf mentor in play situations for an average of 2 to 4 hours per week while their families received lessons at Saturday meetings and intensive weekend workshops around 4 times per year. At the conclusion of their study, the children's competence in sign language improved. The parents, however, reported that their sign language skills did not improve significantly. Despite these results, the families agreed that their children greatly benefited, intrafamily communication eased and their network of families in similar situations expanded. When they looked specifically at the parents, mothers participated at a higher level than did fathers and fathers reported that sign language was difficult more than did mothers.

Lane (1999) hypothesized a similar scenario in which two hearing parents with no previous knowledge of deafness had a deaf child. He detailed their probable trials and tribulations in attempting to communicate with their deaf child and discussed how the

professionals had discouraged the use sign language with him in order to force him to learn to read lips and talk like hearing children. In this example, very little was communicated between the parents and the child, and what was communicated was often concrete messages about present objects. While this scenario is fictitious, Lane stated that it was based on common occurrences for deaf children born to hearing parents. He continued this scenario to show how this child, enrolled in an oral school, did not learn either English, due to his hearing loss, or ASL, due to his restriction from it. He had no friends and would likely not become educated. He purported that “he cannot be hearing and his society will not let him be deaf, so he falls between both cultures and both languages, English and ASL” (p. 159). He argued that the biggest mistake parents made was to listen to the “audist” professionals and not learn about Deaf culture and language; they had closed their minds. In conclusion, Lane quoted Victor Hugo: “What matters deafness of the ear when the mind hears. The true deafness, the incurable deafness, is deafness of the mind” (p. 162).

Akamatsu and Cole (2004) argued that for the refugee or immigrant deaf child, second language learning should be at least as difficult as it is for hearing immigrants or refugee children. They suggested that ASL should likely be the language most accessible for the deaf child learning a second language in the United States, but cautioned that if ASL was learned after the critical language period, it could be difficult for the child to acquire native-like fluency. They also posited that parents’ communication with their deaf child could be further impacted by parents’ misconceptions about sign language or

parents' fear that their children would gain a greater command of sign rendering the parents powerless in their inability to communicate with their child.

Gerner de Garcia (2000) discussed the issue regarding Hispanic deaf children who communicate in a signed language that is not ASL. These children may use a home sign or a native country sign; however, they may be seen as having no language in United States schools. She stated that "linguicism," the low status Spanish is given in this country, doubly impacted children from Spanish-speaking countries. She also discussed the importance of the link between language and culture for Hispanics. She suggested that it would be difficult to consider one without the other, a notion that Deaf culture activists would agree with.

With the compounded language issues seen in the Hispanic-Deaf, the question of which language should be taught to these children arises. Secada (1984) presented a framework for language/modality options for Hispanic deaf children. This framework ran along a continuum from oral to manual modalities and from English to native language usage. His framework allowed for 9 different language/modality options, as follows:

Language Options for LEP Students

Modality Options for Hearing- Impaired Students	English and Native Language		
	English	English and Native Language	Native Language
Oral	1. English as a second language (ESOL)	2. Bilingual Education	3. Oral native language
Oral and Manual	4. Rochester Method, total communication, Exact English	5. Projecto Oportunidad	6. Oral/manual native language mixtures
Manual	7. ASL, Pidgin sign	8. ASL & native country sign language	9. Native country sign language

In the center of this framework (number 5) is a specialized program, Proyecto Oportunidad. This program combined features of bilingual education (native-language instruction and ESL) with features of total communication. Secada suggested that future work was needed to systematize the decisions professionals must make when working with diverse populations. It should be noted, however, that even if a perfect option was established for a child, the chance of a professional or classroom that could accommodate this option is not likely.

Deafness: Culture or Disability?

The question of whether deafness is a disability or a culture remains a controversial issue that is not easily resolved. However, there is one central aspect of these two supposedly divergent opinions that unifies them: the salient issue of language. For those arguing that deafness is a disability, they contend that the deaf do not have easy access to the mainstream language. In addition, technological advances (such as cochlear implants) are facilitating the acquisition of deaf children's oral language, thus perpetuating the notion that deafness is a disability that can be cured. Proponents of Deafness as a culture assert that the Deaf have their own language, just as other linguistic minorities in the United States have (akin to Hispanics).

For Deaf people in the United States, the use of ASL is one of the major identifying characteristics of those who are part of Deaf culture (Padden, 1989; Charrow & Wilbur, 1989). In fact, ASL is a more important qualifier of cultural membership than degree of hearing loss (Kannapell, 1989). Humphries (1993) stated that only those who have access to ASL can be a part of Deaf culture. For them, ASL is the basis of the

culture. He also stated that for the Deaf, their cultural identification and use of ASL are the most important factors in their lives.

Wikipedia (2005) estimates that there are 200,000 to 2 million signers in North America. Although ASL is now officially recognized as a complete and distinct language in the United States, the U.S. Census Bureau has yet to list it as an option for languages spoken at home. Therefore, it cannot be determined with much certainty how many individuals in the United States use ASL. This fact highlights the question of the U.S. government's acceptance of ASL as a whole and complete language.

Culture. In the continued controversy over the legitimacy of a Deaf culture, Parasnis (2002) suggested that the shift from the idea of deafness as a disability to a minority group led to the question of whether deafness was a natural variation in hearing ability. She stated that:

The debate centers on whether medical science should seek a cure for deafness on the view that it is a disability, or whether hearing status should be perceived as an innate physical characteristic exhibiting variation, such as race or skin color, and therefore be left alone. (p. 8)

A different perspective was offered by Davis (1997), who stated her rejection of cultural membership based on physical characteristics and the passing of culture by genes as opposed to people. She deepened her argument by saying that culture was to be passed on by family, which is not the case for the 90% of deaf children that are born to hearing families, most with no history of deafness and therefore no knowledge of Deaf culture. She concluded by disagreeing with the need for the Deaf to fault hearing parents of a deaf child for wanting their child to have as many options in his or her life as possible.

Reagan (1995) explored Deaf culture from a sociocultural perspective to illustrate how and why the Deaf community argues against the notion that deafness is not a

disability. He described how the Deaf prefer to be thought of as a linguistic minority and that “the Deaf community should be viewed as comparable to any other dominated cultural and linguistic community in American society” (p. 241). This is obviously a different perspective than that of mainstream America, wherein deafness is considered to be a medical condition or impairment resulting in disability. He also stated that for deaf students to learn to identify with Deaf culture they would need to learn about it in school and suggested that the Deaf view the term “least restrictive environment” in its most common sense to be inapplicable to the Deaf. This is because the Deaf promote residential schools for the Deaf to be the ideal way for a deaf child to learn about Deaf culture, which stands in stark contradiction to the current practices in special education classrooms. Reagan offered the alternative term “most enabling environment,” in which Deaf children would not likely be placed within the hearing mainstream. Instead, the educational program that would be of most benefit to Deaf children would be one that contained a great deal of exposure and experience with Deaf adults, as well as be run by the local Deaf community.

Nance (2003) discussed the genetics of deafness, stating that deafness has various genetic and environmental causes. He classified genetic causes of deafness as syndromic and nonsyndromic and described the molecular basis of hearing and deafness. Specifically, he stated that advances in the knowledge of human genetics have raised many ethical issues, some of which could be considered unique to deafness. For example, Deaf people reject the medical model of deafness and therefore, many Deaf people would prefer a deaf child but would be accepting of a hearing child. Many such parents have negative opinions of genetic testing and the use of prenatal diagnosing of deafness, as

some may use this to identify a fetus that will be aborted because of hearing status. In addition, the opposite is usually true: a deaf child born to a hearing family is often interpreted as a tragedy. Nance traced the negative attitudes of the Deaf towards the medical model of deafness to Alexander Graham Bell's involvement in the Eugenics movement, whose goals were purportedly to create an improved race. Bell promoted sterilization of the Deaf and the outlawing of marriage between Deaf individuals. Due to this, Nance describes the medical profession's ambivalence towards recommendations for selective mating structures among people with genetic hearing losses.

Disability. When Lane (2002) asked a fellow professor if deaf people had a disability, the colleague answered that he believed they did have a disability. He went on to state that it was only common sense to think so because deaf people are limited in their hearing function and any individual limited in some way is disabled. Lane countered by suggesting that common sense be taken out of the equation and asked the question again. Lane didn't believe that the deaf were disabled and based his arguments on historical ideas of disabilities and differences. He suggested that variations in many characteristics are normal, but an extreme difference (e.g., difference in "normal" weight versus gross obesity) could be considered a disability. He stated that what determined whether or not an extreme difference was considered a disability depended on "norms and the technologies of normalization" (p. 359) and was defined "in a particular culture and a particular era" (p. 359). He believed that this type of thinking suggested that "the disability did not lead to the treatment; rather, the treatment led to the disability" (p. 360). To clarify, he gave the example of height and explained how being short was not considered a disorder until doctors began to inject growth hormones to make children

taller; by virtue of having a treatment, shortness had now become a disorder that could be treated. He stated that the only groups that do not benefit from the medicalization of such social differences were the groups being targeted, as this projected the responsibility for change onto the socially rejected rather than the society at large.

Lane continued by discussing the term “audism,” coined by Humphries in 1977, as related to racism and sexism. He stated that “audism insists that inherent biological factors determine individual traits and capacity” (p. 364) and that being deaf resulted in the loss of choices due to the social construction of the meaning of deaf, not because of the actual sensory limitations that come from being deaf. He argued that deafness did not constitute a disability in the regular sense in our society because the deaf are found in all types of professions. It is not a given that academic achievement will be low as there are deaf people with doctoral degrees and these individuals can raise deaf children successfully without the need of professionals. His concluding answer to the original question was that since our society is a hearing society, if it deemed the deaf to be disabled, they were. However, to a Deaf person, the word “deaf” takes on new meaning. For the Deaf, it means “like me,” people who are Deaf, who share in the cultural norms, who use sign language, who feel that being Deaf is a positive attribute, not a disability. He concluded with a call for the “disowning of the disability label” (p. 369) as the honest thing to do in the case of deafness.

An example of deafness viewed as a disability by a doctor but not by his Deaf patient is recounted in Stein, Barnett, and Padden (2001) wherein a pediatrician had difficulty understanding why Deaf parents of a newborn had declined a hearing test for their child. The pediatrician then became informed by experts in the field of Deaf culture

and began to understand why his request for a hearing test was viewed as culturally insensitive by the Deaf parents. The authors also described what “culturally sensitive” vocabulary physicians should use when speaking with their deaf patients. For example, to use “deaf” or “hearing” as opposed to “normal” or “abnormal” and using “speech delay” as opposed to “language delay.”

Cochlear implants. Cochlear implants have been hailed by the medical community as a great advancement in the cure for deafness. Children under the age of 12 months are now receiving cochlear implants and the practice of implanting bilateral cochlear implants is on the rise. Children with cochlear implants have shown great advancements in their speech and language skills. In addition, improved access to auditory information will likely positively effect cognitive, behavioral, and social development in children (Quittner et al., 2004). However, as cochlear implants continue to gain popularity with the hearing world and change the future of children born with profound hearing losses, they continue to lose popularity in the Deaf community.

In discussing the ethical issues of cochlear implantation in young children, Balkany, Hodges, and Goodman (1996) stated that the cochlear implant is “such an emerging technology that has the potential to change fundamentally the way people live” (p. 748) and acknowledged that with change comes conflict. They posited that a major issue is to whom the deaf child belongs and how Deaf culture should be taught to a deaf child. Traditionally, enculturation is achieved through one’s family and community (Gollnick & Chinn, 2002). However, the members of Deaf culture believe it is the responsibility of the Deaf to educate the deaf, a term known as horizontal acculturation, which stands in stark contrast to how Americans teach values to their children by passing

them on generation after generation. The Deaf feel that a child born deaf belongs to the Deaf world and must be raised as such. Balkany et al., citing the legal opinions regarding who should decide whether a deaf child should receive a cochlear implant, reported that the courts state that self-interest groups (like the Deaf community) must be excluded from making this decision and that families have the right to privacy and to make decisions based on what they believe is best for their children. The authors stated that many respected Deaf advocates have purposefully shared misinformation regarding cochlear implants (e.g., they cause brain damage and mental illness, do not work, and cause death) with the Deaf community in order to turn the Deaf community against cochlear implants.

In response to the claims and criticisms from Balkany et al., Lane and Bahan (1998) stated that being deaf was more like a normal human variation as opposed to a disability and stated that “much remains unknown about the language, psychological, and social outcomes of the procedure” (p. 299) in referring to cochlear implants. They reported statistical information on the ambivalent gains of cochlear implants on speech and auditory functioning. They stated that deaf children are healthy children and considered the idea of operating on healthy children to be unethical. In addition, they stated that the issue is a cross-cultural conflict of values and that one side cannot be chosen over the other side morally, “hence there is an ethical dilemma” (p. 303).

Swanson (1997) described how cochlear implants in Canada have caused much strife for the Deaf community while at the same time have been viewed by the medical community as a great advance in the fight against hearing impairment. The Deaf community staged demonstrations at provincial legislatures lobbying the government to

stop funding cochlear implants as they felt that cochlear implants were marginalizing Deaf culture. Swanson presented both sides of the argument: the right to be Deaf, a linguistic minority, and the right of hearing parents to have a deaf child who can hear and speak in the hearing community. The Deaf community raises the point that deaf children's self-esteem is at stake because they are being told they are disabled and need to be cured of their deafness through cochlear implants. Many of the hearing parents that Swanson spoke with stated that the medical community did not discuss the existence of Deaf culture and did not offer the use of sign language as an option for their deaf children. She concluded with suggestions for how hearing parents of deaf children could make informed decisions. Of interest was the suggestion to have families meet other deaf individuals with a variety of linguistic backgrounds: those who are oral, those who use total communication, and those who only use ASL.

Levy (2002) set out to determine the existence of Deaf culture and to what extent it would be justifiable for Deaf culture to die out because of the advancement of cochlear implants. He stated that the issues regarding cochlear implants are "a genuine moral dilemma" (p. 135) because either option would be difficult: "either the destruction of a culture or the sacrifice of the interests of potential implant recipients" (p. 135). He discussed Deaf culture proponent's argument and proposed the following rationale: Deaf culture does indeed fit the traditional concept of culture due to the fact that it is an ongoing culture, it holds special values that are expressed in material forms, and because the members engage in special activities that distinguish it from another culture. However, he described how Deaf culture is unique in that it is not passed on in the family as are most cultures, but through schools and other Deaf individuals, as most deaf

children are born to hearing parents who would likely want their children to be a part of the hearing world. Hearing parents, unlikely to be fluent in sign language, would suggest that the best way to ensure a deaf child's participation in the hearing world is through cochlear implantation. Levy felt that it is a parent's prerogative to want their deaf child to be a part of their hearing culture and that they should have no special obligations to Deaf culture. His final statement reported that due to the disadvantages the deaf face because of their disability, the medical improvements that are currently available outweigh the benefits of Deaf culture: "Though Deaf culture might well be intrinsically valuable, I conclude - with regret - that the kinds of measures that would be required to maintain it are not permissible" (p. 153).

Mowl (2002) described the movement towards cochlear implants as the "extinction of deafness" (p. 233) referring to the movement as "Neo-Bellism" in allusion to A. G. Bell and his role in the eugenics movement. Bell's self-proclaimed mission was to halt intermarriage among the deaf in order to curb the number of genetic cases of deafness in the United States. Those who believe that this extinction is real and imminent are fearful of its possibility, suggesting that it would be unnatural.

Perhaps the clearest and most neutral presentation of the difficult issues in whether or not to implant young children comes from Berg, Herb, and Hurst (2005). They presented both sides of the argument and suggested that parents should only make the decision to implant after careful consideration of all options and allow for the child, during their period of emerging autonomy, to make decisions in the future as to whether or not to continue to use an implant. They suggested that "the benefits and burdens can only be evaluated by the person who bears them" (p. 245); however, the most difficult

aspect of cochlear implantation is that the greatest benefit is gained when children are implanted early and thus, too young to make an informed decision for themselves.

However, the current benefits received from early implantation must be weighed against the harm caused by delaying intervention or the possibility that current technological procedures could preclude future advancements with better outcomes.

Pilot Study

Based on the information gathered from the previous literature review, I completed a pilot study for a course in advanced qualitative research. This study made use of a purposive sampling procedure. This included the use of participants who were available and previously known to the researcher. Two mothers with deaf children were selected. The first mother, a Spanish-speaking woman of Mexican descent, was selected for the initial observation and interview. I was able to test the interview questions and use this interview as a stepping stone to further delineate future interview questions. The second mother, of Puerto Rican descent, was selected for the second interview. This mother was purposely selected because she spoke fluent English. Conducting the interview in English allowed me to follow-through during interview questions in my primary language to help me identify what types of redirections, follow-up, and questioning language I would use in English so that I could study them and transfer these techniques into Spanish.

This study used two types of data collection. The first was an observation of a Hispanic mother with her deaf child. For this observation, I went to the family's home, set up the mother and her daughter with a game that encouraged joint participation and turn-taking, and observed the resulting dialogue. Following the game, I asked some

guiding questions in order to observe the mother's and daughter's communication skills during conversation. I made brief notes during the visit and then utilized a tape recorder upon leaving the home to document my impressions and the finer details that could not be written during the observation. This information was then typed up as a field note.

The second type of data collection involved two semi-structured interviews that utilized ethnographic interview questions. The original questions were developed based on Spradley's (1979) work and the questions were geared toward my interests in how Hispanic mothers were communicating with their deaf children who used sign language to communicate and how these mothers viewed the concept of deafness as a culture. Follow-up questions were asked when appropriate, and new questions were formulated in the field as new topics arose. Through this process, I realized that the question regarding concepts of culture was difficult and vague. One of the mothers had no clear understanding about what Deaf culture was, much less that it existed as a culture separate from American or Hispanic culture. The other mother had a clearer concept in her mind but felt that the division between the hearing and Deaf cultures was large and difficult to navigate. The large variation in responses to this question suggested that further research should delineate questions pertaining to culture in a much more detailed and specific manner.

Each interview was audio-taped with permission of the mothers, then transcribed verbatim. The Spanish transcription and audio taped interview was given to a native Spanish speaker who listened to the audio tape recording and made any spelling, accent, and grammatical corrections needed. Next, I translated the interview into English. These

transcriptions were then analyzed and coded in the same manner as the observation. No documents were reviewed for this study.

Field notes and interview transcripts were coded following the techniques described by Strauss and Corbin (1998). The first step was to conduct theoretical comparisons to highlight the properties in the data. This process resulted in the development of a set of codes that identified concepts, their properties, and dimensions. This stage, known as open coding, involved breaking sections of the data into discrete incidents and labeling them concretely, resulting in 68 open codes. These codes were written in the margins of the transcriptions. The second step was to group the open codes axially, which resulted in 17 subcategories. I developed a coding map to display how the groups of open codes related to their axial codes. The third step was to complete thematic coding which interpreted the story in each group of codes. The main themes that emerged are described below:

Mother's adaptation to child's communication needs. Mothers were able to use several strategies during conversation in order to better communicate with their children. These strategies included using others for interpretations, asking the child for clarification, involving the family, and signing more during spontaneous conversations. For example as recorded in my field notes, one mother used several people to help her understand her daughter:

The mother asked me several questions in Spanish so that I could help her figure out how to sign to her deaf daughter. She also relied a little bit on the middle sister to see if she could help provide the correct sign. The mom was first to go but before she played she asked her deaf daughter several questions on how you sign certain vocabulary for rooms and people in order to review the vocabulary.

Mother's search for empowerment. In an attempt to take control over the consequences of having a child with a disability, these mothers requested services, participated in IEP meetings, and requested information from the researcher. For example:

Mom asked me if I knew of a church down south that had interpreters because she wanted to take D to church so that D could learn about church and about God. She said that D was interested in going to church and that mother wanted her to be able to learn about it and attend with the family. She also mentioned that since D's 15th birthday was coming up, she would want to celebrate it at church and that D should learn more about it in sign language.

Mother's concern due to disabilities. Due to the concerns regarding their children's disabilities, the mothers expressed concerns regarding a variety of issues, including academics, safety, relationships, and disabilities overall. For example, when asked about her daughter, the mother described her abilities, saying: "I don't have her cooking yet because I'm afraid she may burn herself but she helps me do the dishes, clean the table, cooperates a lot."

Mother's difficulty of acceptance. The mothers discussed the struggle to accept their children's deafness. Some issues they described included their feelings toward hearing loss, adaptation to the hearing loss, acceptance of sign language, and acceptance of Deaf culture. One mother described the need to learn sign: "We knew we were going to have to compensate by having to teach her another way to communicate." The same mother described her initial diagnosis:

Well, honestly, to tell you the truth, when it was first told to us, at age 16 months, my husband and I were devastated. We originally thought, it was one of these things where you think it's the end of the world. So it was very, very hard for, you know, brand new, it was a brand new marriage and then having kids kind of early to be told, you know, your first child . . . it's hard enough to come home with a first child who's developmentally

delayed, maybe mild CP, and then ‘Oh, by the way, you’re child is deaf.’ It was very, very hard to take. Now, I have to tell you, I don’t even think of it anymore, I sometimes forget she’s deaf. She hears; in my eyes, she hears. I actually worry about her other disabilities and her other needs versus her hearing.

Changes due to ASL. The fact that sign language was being used in the home caused a variety of changes within the family. For example, one mother explained how sign language became the most important factor for communicative purposes as child frustration was reduced, and the mothers described how their own sign language skills improved. One mother explained how her opinion of sign language changed: “And maybe years down the road, after going through so much with her I finally realized, well, let’s give it a chance. And I now think it’s the best thing in the world.”

As a result of this pilot study and its findings, I found it valuable to design the present study on a larger scale, to fine-tune the interview questions, and to add interviews with the deaf children in order to strengthen the triangulation of the data.

Conclusion

In summary, the literature on communication and deafness raises many controversial issues that range from disability, to discrimination, to language usage. In addition, despite extensive literature regarding the difficulties that Hispanic families face when a child with a disability is born, there is little information on their specific concerns when the child is deaf. From the perspective of the Deaf community, the concepts of Deaf culture and the use of ASL are most important to a deaf child’s identity. For Hispanic families in the United States, the ability to maintain their Hispanic culture and language are most important. When a deaf child is born to a Hispanic family in the United States, a double layer of culture and language issues arise that neither the family

nor the Deaf community can easily navigate. These intersections have not been represented in the literature. Decisions about communication for the deaf child can create conflicts that may alienate them from their families, their peer group, and those in the Deaf community. These implications make this study an important one for the Hispanic-Deaf and the Deaf community as a whole.

The questions regarding Hispanic mothers' communication with their deaf children who use sign language, as well as their views of deafness are multifaceted. The questions could not be answered discretely, as with the use of a survey. They necessitated the use of observations and interviews that are acquired through qualitative methods of research. This study increased the understanding of the needs faced by Hispanic families with deaf children. The research questions for this study were as follows:

- How do Hispanic mothers communicate with their deaf children who use American Sign Language as their primary language?
- What are Hispanic mothers' perceptions of their communication with their deaf children who use sign language?
- To what extent do Hispanic mothers interpret deafness as a culture or as a disability?
- How do Hispanic mothers compare Hispanic culture to Deaf culture?

METHODS

Qualitative research uses a variety of approaches to study naturally-occurring phenomena. Just as the audience and purpose of the research may vary, so do the theoretical traditions that can be used in qualitative inquiry (Patton, 2002). Perspectives can range from ethnography, whose roots lie in anthropology, to phenomenology, whose roots lie in philosophy, to symbolic interaction, whose roots lie in social psychology. While the term ethnography is reserved for studies in which the key strategy is prolonged participant observation and interviewing, it is well established that these methods can be adapted to suit the more pragmatic needs of research in educational settings (Patton, 2002). Analytic methods also vary and can include interpreting data deductively from pre-specified theoretical propositions as proposed by Yin (as cited in Patton, 2002) or inductively from data to theory. The latter process has been most clearly codified in grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998; Charmaz, 2000). In this study I collected data through ethnographic interviews and limited participant observation, and analyzed the data by means of grounded theory methodology.

There are several core characteristics of qualitative inquiry (Patton, 2002; Bogdan & Biklen, 1998). First, qualitative inquiry seeks to study natural events without controlling it. This is done in an attempt to understand the social processes involved in human settings and cultures. Second, the design is flexible in order to adapt to the emerging understanding of the data. This may mean that additional informants will be interviewed if more information is needed or perhaps new questions are developed as theories emerge from the data. Third, the cases to be studied are purposefully selected for

the characteristic under study. Fourthly, it uses the researcher as the instrument for data collection and analysis. The researcher can shift from being a full participant in the setting to that of solely an onlooker, as well as a combination of both, but always has direct contact with what is being studied. Fifth, the researcher seeks to provide thick description from the data in order to discover the insider perspectives as well as to seek out multiple perspectives from which to make comparisons. Finally, since the purpose of most qualitative research is to uncover the naturally occurring social world, inductive analysis is the most common approach. In quantitative research methods, a theory is generated and data are collected and analyzed to determine if the theory is substantiated and can be generalized. In most qualitative research, as data are collected, the goal is to develop theory through analysis of data.

For qualitative studies, the data are generated from three types of data collection strategies (Patton, 2002): 1) in-depth, open-ended interviews from which direct quotations of people's feelings, experiences, and opinions are produced; 2) direct observations that consist of descriptive accounts of people's actions and interactions; and 3) archival data, such as written documents, photographs, or other relevant documents, which are analyzed for content and meaning. With each interview, observation and document analysis, field notes are generated, which become the raw data of the qualitative method. These notes are organized, coded and analyzed. Through this analysis, the inside perspective of the individuals in the study emerge and tell a story.

Strauss and Corbin (1998) refer to qualitative analysis as “a nonmathematical process of interpretation, carried out for the purpose of discovering concepts and relationships in raw data and then organizing these into a theoretical explanatory scheme”

(p. 11). They also suggest that it is through this analysis that the intricate details surrounding phenomena are captured. In short, if the nature of the research is to deepen understanding of social processes, qualitative research methods are the vehicle to use. In the present study, the research questions could only be answered via the use of qualitative methods, as the purpose was to understand Hispanic mothers' views, feelings, perspectives, and actions as they related to communication with their deaf children.

Grounded Theory Approach

Grounded theory, developed originally for sociological researchers by Glaser and Strauss (1967), sets out to determine “how the discovery of theory from data - systematically obtained and analyzed in social research - can be furthered” (p. 1). They suggest that previous books on qualitative methodological research focused on the verification of theory; however, their method of grounded theory allows the researcher to develop the theory from the data.

One major strategy that Glaser and Strauss emphasize is the use of a general method of comparative analysis, whose purpose is joint coding and analysis in order to systematically generate theory and is used in combination with theoretical sampling (described in the next section). In the process of the constant comparative method, the researcher compares incidents that are applicable to each category, integrates the categories and their properties, delimits the theory that is emerging, and finally writes the theory.

Sampling

This study made use of a purposive sampling procedure (Patton, 2002; Bogdan & Biklen, 1998) for the initial sampling. In this type of sampling, participants were selected

because they were representative of the phenomena of interest, were “information rich,” and facilitated the developing theory. The aim then was to learn more about the participants being studied as opposed to selecting large random samples with the hope of generalizing a theory to them. Several different strategies for selecting these cases could have been used, including extreme or deviant case sampling, intensity sampling, and heterogeneity sampling. This study used homogeneous sampling whose purpose was to describe a particular group in great detail.

The group studied was 12 Hispanic mothers, living in the southeastern United States, with little or no English language skills, and their deaf children ages 5 through 13 who used sign language as their primary method of communication. These deaf children had severe or profound hearing losses, no other disabilities, and had not received a cochlear implant. In addition, 3 deaf mentors who work in the homes of Hispanic families with deaf children were also studied. These were added to the design by theoretical sampling (Strauss & Corbin, 1998), by which additional participants are included to more fully develop the emerging theory. In this way, the constant comparative method of analysis was supported. This came about after the interviews with the mothers and children were completed. As many of the families made reference to the mentors that they worked with and limited information was gathered from the children, it became clear that adding the mentors’ perceptions would assist in testing the emerging concepts.

The participants for this study were recruited primarily through recommendations, based on study criteria, from various community agencies including the Deaf Services Bureau and the Alliance for Families with Deaf Children, through referral from other participants in the study and through personal contacts with members of the Deaf

community who were able to refer appropriate participants. Although I am a speech-language pathologist who has a private practice in the local community, no current or former clients were contacted to participate in the study. It was felt that this method of recruitment had some drawbacks that could include a perception of coercion to participate due to our current or previous relationship and the possibility that they may not feel comfortable sharing their opinions with me for fear that I may not agree. In all cases, mothers, children, and mentors were informed that they could withdraw from the study at any time should they change their minds. All participants who were contacted and qualified for the study agreed to be apart of the study. In addition, all participants completed the study.

Participants reflected a range of sign language skills (from none to fluent), a range of mothers' English proficiency (from none to some fluency), ages of children (from 5 to 13 years of age), a range of mentor experience working with deaf children (from 10 years to 25 years), a range of mentors' ethnic background (from American to Hispanic), and a range of mentors' degree of hearing loss (from hard-of-hearing to profoundly deaf). The participants agreed to in-home observational visits and tape-recorded interviews at a time that was convenient for them.

Family demographics

A visual representation of the families in this study is found in Appendix A. The 12 families in the present study represented 8 different Latin-American countries: Nicaragua, Uruguay, Cuba, Santo Domingo, Puerto Rico, El Salvador, Guatemala, and Colombia. All of the mothers spoke Spanish as their primary language and although

several spoke to their children in a mix of English and Spanish, all the mothers requested that the interviews be completed in Spanish.

Ms. Mendoza is the grandmother of Erica, an 11 year-old girl. Ms. Mendoza has lived in this country for over 4 years and has a 6th grade education level from her native country. Erica lives with her grandmother during the school week and usually goes to her mother's home on the weekends. Her mother, Ms. Trujillo, lives with her son, age 3, and has a 10th grade education level from her native country. Erica and her mother emigrated from their native country 3 years ago when Ms. Trujillo was pregnant with her son. Erica was diagnosed at the age of 2 years in her native country and was fitted hearing aids at the age of 5. The cause of deafness is unknown. Both Ms. Mendoza and Ms. Trujillo communicate with Erica through oral Spanish and Erica communicates to them in short oral Spanish phrases and through 1- or 2-ASL sign phrases.

The Jimenez family emigrated from their native country 4 years ago. The family consists of the parents, Lucas (age 11), and three additional siblings. Ms. Jimenez has a 10th grade education level from her country. Lucas was diagnosed at the age of 3 in his native country and fitted with hearing aids shortly thereafter. The cause of deafness is unknown. Lucas communicates through ASL and I needed an interpreter to interview him due to his high level of fluency. His mother communicates with him through oral Spanish, ASL with oral English, a combination of English and Spanish, and through his older sister that often acts as the family interpreter.

The Lopez family is comprised of mother, father, Gilberto (age 9), and a younger brother, who emigrated from their native country 5 years ago. Ms. Lopez has a university degree from her country. Gilberto was diagnosed at the age of one in his native country.

The cause of deafness is thought to be a blood infection that caused his hearing to deteriorate during his first 12 months of life. He uses short ASL phrases to communicate with his family and his mother uses a combination of ASL, oral English, and oral Spanish to communicate with him.

The Alvarez family emigrated from their native country 5 months ago. The family is comprised of mother, father, Luis (age 8) and two older sisters. Ms. Alvarez completed the university in her native country. Luis was diagnosed at the age of 4 in his native country. The cause of deafness is unknown. Luis currently communicates through gestures, a handful of ASL signs and vocalizations. His mother communicates with him through oral Spanish and the few ASL signs that she has recently learned.

The Rodriguez family arrived in the US 11 years ago when Jose (age 11) was an infant. Ms. Rodriguez lives with an older daughter and Jose visits on the weekends, as he attends a state school for the deaf and lives on campus during the week. Ms. Rodriguez completed 1 and ½ years of university in her country. Jose was diagnosed in the US at the age of 3 and fitted with hearing aids at the same time. The cause of deafness is unknown. Ms. Rodriguez communicates with Jose via ASL and oral English, and Luis communicates in the same manner.

The Gomez family emigrated from their native country 3 and ½ years prior. The family is made up of mother, father, Tomas (age 9), and a younger brother. Ms. Gomez completed 3 years of university in her native country. Tomas was diagnosed at the age of 18 months in his native country and he was fitted with hearing aids at the age of 3 years. The cause of deafness is thought to be due to a premature birth that resulted in reduced

oxygen to the brain. Ms. Gomez communicates with Tomas via oral Spanish combined with ASL and he communicates via ASL.

Ms. Vergara arrived to the US in 1993. Her deaf daughter stayed behind in her native country and joined her mother 3 years ago. Ms. Vergara's additional 4 children were born in the US and she is currently separated from the children's father. She completed the 3rd grade in her native country. Gustavo (age 12) is the middle child, was diagnosed in the US at the age of 3 and fitted for hearing aids at the age of 4. The cause of deafness is unknown but likely genetic as he has an older deaf sister. Gustavo communicates via ASL and his mother communicates via oral Spanish and home signs.

Ms. Saez arrived to the US 15 years ago, then married and had 5 children. She completed the 6th grade in her native country. Her oldest child and only son, Victor (age 13), had difficulty talking and she sought a diagnosis at the age of 2 in the US. However, the doctor did not take her concern seriously and he was not diagnosed until the age of 5 at which point he was fitted with hearing aids. Victor communicates via oral English and ASL signs, and his mother communicates with him in the same manner.

The Perez family arrived in the US 2 months ago. The family is comprised of mother, father, and two deaf daughters. Ms. Perez completed technical college in her native country and the family was well integrated in the Deaf community in their native country. The oldest daughter, Christina (age 7) was diagnosed at the age of 8 months and fitted with hearing aids at 2 ½ years. The younger sister was diagnosed at 4 months and fitted by 6 months. Both sisters were diagnosed in their native country. The cause of deafness is thought to be genetic, although genetic testing was unable to confirm this. The family communicates via the use of their native sign language (NSL), although Christina

is beginning to learn ASL at school and is starting to incorporate some ASL into her communication with the family.

The Osorio family emigrated from their native country 1 year ago. The family includes mother, step-father, Lourdes (age 12) and a younger sister. Ms. Osorio completed 2 years of technical college in her native country. Lourdes was diagnosed in her native country at the age of 2 months and fitted with hearing aids by 2 years of age. The cause of deafness was maternal contraction of rubella at 2 months gestation. The Osorio family became fluent in their native country's sign language but now that they are in the US, Lourdes has forgotten much of her NSL and communicates primarily through ASL. Her mother continues to communicate with her primarily through NSL but is beginning to learn ASL from Lourdes.

Ms. Obeso arrived in the US 7 years ago with her husband and daughter. She completed the university in her native country. She had Jesus (age 5) in the US and was concerned about his speech and hearing. He was diagnosed in the US four months ago and he was fitted with hearing aids shortly after that. The cause of deafness is unknown but thought to be a progressive hearing loss. Jesus is learning ASL with his mother at home through DVDs, books, and dictionaries. He communicates primarily through oral Spanish and some oral English combined with ASL, and his mother communicates with him through Spanish and English with ASL signs.

Mentor demographics

Lisa was born in the US hard-of-hearing but her hearing loss was progressive and she became profoundly deaf. She grew up speaking oral English and attending an oral school but chose to attend Gallaudet University where she learned ASL fluently. She has

a Master's degree in Deaf Education and has been working with deaf students for 25 years.

Maria was born in the US to Hispanic parents and is hard-of-hearing. She grew up speaking English, Spanish, and signing in ASL and has been working with deaf children for over 10 years.

Robert was born in a Latin-American country but immigrated to the US at a young age. Although he was born hearing, he became profoundly deaf at 7 months of age due to a fall. He communicates through ASL but can read and write in both English and Spanish. He has been working with deaf children for over 10 years.

Data Collection

This study used ethnographic data collection methods. The purpose of this ethnographic inquiry was to describe the lives of people in their everyday natural settings via observations and interviews. The first step involved observations of mothers communicating with their deaf children in their home and allowed the opportunity for the families to meet me, ask any relevant questions regarding the research process, and begin the process of rapport-building. As I speak English and Spanish and am fluent in sign language, I was able to understand all interactions that took place in those languages. During two sessions, a native sign language (NSL) was used and I had the mothers interpret for me what they and their children were signing so that I could understand all interactions. These sessions generated field notes written by me regarding the interactions observed and tape recorded impressions that I completed upon leaving the home in order to document fine details that could not be written during the observations. The purpose of these observations was to describe the setting, activities, and people in the setting, to

check for what was reported during interviews, and to describe the interactions of those in the setting.

My role was that of participant observer in which the emphasis was on observing while also participating to the extent needed for appropriate rapport and respect. This role falls in the middle of the continuum of observation approaches that vary from being an observer only with no interaction with the family, to becoming a full participant that is immersed fully in the interactions with the family. I also informed the mothers that my role was not that of an evaluator; I was there to document their interactions in order to understand them, not to judge them.

Participant observation is a strategy that has many strengths but also some challenges. The central challenge is the issue of observer effects. First, there is the question of possible effects of the demeanor of the researcher. For example, in home-based observations, one challenge is to conduct a non-intrusive observation while also maintaining a comfortable, participatory presence in the family's home (Patton, 2002). Second, there is the question of whether the researcher's presence changes behavior on the part of the person being observed. Copeland and White (1991) have suggested several steps that can be completed in order to minimize observer effects. First, choosing a topic that is interesting to the family allows the family to be more engaged and hopefully less concerned with the fact that they are being observed. Second, providing the family an honest and believable rationale for the study may help the family understand the importance of the study and thus want to contribute by allowing me to observe their natural interactions. Third, the visit will appear less like a staged event if cameras and audio tapes are not visible to the family. Finally, asking the family to comment on their

perceived naturalness of the observation once it has been completed provides information on how representative they felt their interactions were. Since one of the aims of this study was to observe communication, I believed that the mothers would use all of the techniques they had learned and developed in order to show me how they communicate with their children. I also thought it unlikely that a mother could fabricate English or sign language skills for the sake of my study, and all communication appeared natural.

The next step in the data collection process was to complete interviews with the mothers, their deaf children, and the deaf mentors. I began by contacting the families and mentors for an audio-taped, semi-structured interview conducted in Spanish with the mothers and in American Sign Language (with an interpreter in order to capture the interview on audiotape) or oral English with the children and mentors. The style of the interviews was informal and friendly. Ethnographic interview questions (see Appendix A and B) were developed as described by Spradley (1979). In an ethnographic interview, both the informant and the researcher are aware that the conversation has an explicit purpose, the researcher offers repeated explanations as to the purpose of the questions, and ethnographic questions are utilized. Ethnographic questions include descriptive questions that allow the researcher to sample the informant's language, structural questions that are used to uncover the informant's cultural knowledge, and contrast questions which assist the researcher in understanding the meaning of the terms used in the informant's language. One challenge in ethnographic interviewing is achieving a balance between the researcher's information needs and the parents' need to tell their story. Another drawback to this type of data collection includes the issue of bias if the informants may try to make situations look better than they are (Copeland & White,

1991). However, this drawback is reduced when combined with the data collected via the observations and the use of multiple participants.

I developed the mothers' interview guide for this study based on a literature review and from the results of the pilot study outlined previously. This pilot study consisted of one observation and two interviews with two mothers. This pilot study assisted in the development of interview questions as well as allowed further delineation of my research questions for the present study. The questions used with the mothers were first written in English and then translated into Spanish by a non-affiliated, primary Spanish-speaking professional. The translations were compared to the English version to be sure that the meaning and cultural context of the questions matched and to be certain that the questions remained open-ended. The questions developed for this study were singular and open-ended, allowing the mothers to set the tone and to discuss what was of most importance to them. Guiding questions and prompts following each question assisted in the organization of the interview; however, the interview attempted to follow the mother's lead. The prompts were used when more information was needed, to keep the conversation moving in a particular direction, and to focus the conversation when it began to stray from the intended purpose.

For the child interviews, I utilized the same strategies as those with the mothers (e.g., open-ended questions, following the child's lead, etc.). I asked these questions in sign language and in oral English for those children who had sufficient speech skills. For those who had limited speech skills, a sign language interpreter signed my questions and voiced the response of the children. This was done for two reasons: 1) in order to have a voice representation on audio tape, and 2) to ensure that I understood the children's

responses fully. When interviewing the children, I began the session by playing a game that was appropriate for their age or by chatting with them about their interests so that they could get comfortable with me and the interpreter's presence. As the child began to communicate freely, the interview began. However, as will be explained in the findings chapter, although the children were able to converse with me informally quite well, most had difficulty answering more formal questions.

For the mentor interviews (see Appendix C), I utilized the same strategies as those with the mothers and children (e.g., open-ended questions, following the mentor's lead, etc.). Interview questions were developed from questions that emerged during my observations and interviews with the families and all mentor interviews were conducted after all mother and child interviews were completed. I asked these questions in sign language and in oral English for the two mentors that could communicate orally and had a sign language interpreter who signed my questions and voiced the responses of the mentor who had limited oral language skills. This was done for two reasons: 1) in order to have a voice representation on audio tape, and 2) to ensure that I understood the mentor's responses fully.

The interview questions include grand tour questions (which allowed the informant to describe a particular location and time period), example questions (which asked for more detailed information regarding something the informant had shared), experience questions (which asked informants to describe their experience in specific settings), and native-language questions (which helped me learn how the informant's language was used). Follow-up questions and prompts were asked where appropriate. All mother interviews were be transcribed verbatim in Spanish and then translated into

English for analysis. Six of the twelve mother interviews were transcribed by me and the remainder were transcribed by a transcriptionist. I reviewed the accuracy of the transcripts completed by the transcriptionist by listening to the audiotape and reading the transcripts simultaneously, filling in any missing information as needed.

After the mother interviews were completed, demographic information was collected via oral reading (see Appendix D) of selected questions. Since these questions were often very personal, I chose to solicit this information following my initial observation and interview when trust and rapport were better established.

The next step was to look at any types of materials that mothers used during their interactions with their deaf children or any materials that mothers identified that they used to learn how to better communicate with their deaf children. However, very little information was obtained, as only 1 book, one calendar, and one DVD was procured from the mothers.

The final step was a member check that was completed via an additional visit to four of the homes. This third contact with the mothers had several purposes including the need to observe some aspect of communication that was identified during the interview but not observed on the first visit. Other purposes were to clarify the mothers' intended meanings during the past interviews, to discuss opinions of emerging themes, and to ask any follow-up questions. The final purpose was to allow the mothers to ask any questions or make any clarifications that they felt was necessary to clearly document the aspects of their lives that were important for them to share with me. These contacts were documented in the form of transcripts for further analysis. All of the homes could not be visited due to time constraints. However, the interviews completed later were much more

comprehensive. As new questions arose from the earlier interviews, they would be incorporated into subsequent interviews, thus decreasing the need for a follow-up visit with the later interviews.

Data analysis

Each observation was written into a detailed field note for analysis and coding. Each interview was audio taped and then transcribed verbatim. The Spanish transcriptions of the mothers' interviews were given to a native Spanish speaker who made any spelling, accent, and grammatical corrections needed. I then translated the interviews into English to be analyzed and coded in the same manner as the observations. This study used grounded theory methodology to analyze the data following the techniques described by Strauss and Corbin (1998). In this method, theoretical comparisons were continually made between the coding of data and the developing concepts in order to assist in bringing out the properties in the data and were used as a tool to look at the data objectively.

First, in a process known as open coding, the specifics within the data were compared in order to identify the properties of the concepts and to discover the relationships among the concepts. This was accomplished by separating sections of the data into discrete incidents and labeling them concretely. The next step was to code the open codes axially, which related the open codes into subcategories. These axial codes were mapped out with each of the open codes that pertained to them. The next step was to complete selective coding by integrating the axial codes that told the story in each category in the attempt to identify theoretical information from the data.

The data were strategically placed in a data analysis map (see Table 2) as described by Harry, Sturges, and Klinger (2005). This process involved coding the data in several steps, similar to Strauss and Corbin, but also displayed the inductive nature of the coding process, from open coding to statements of the theories. Following the coding, the data were organized into levels. These levels included open codes, conceptual categories, and theme developments. This procedure allowed me to identify the themes that emerged from the data.

Criteria for Quality

In traditional quantitative research, trustworthiness of the data is reached if internal validity, external validity, reliability, and objectivity are obtained at a certain level. In qualitative research, the establishment of trustworthiness in a naturalistic paradigm (Lincoln & Guba, 1985) parallels the criteria in quantitative analyses. However, as Lincoln and Guba explain, the differences are that “qualitative research is conducted not to confirm or disconfirm earlier findings, but rather to contribute to a process of continuous revision and enrichment of understanding of the experience or form of action under study” (p. 278). They state that the guidelines they set forth are characterized by the general customs of publishability for qualitative research. For example, internal validity is answered through the establishment of credibility which is supported by detailed descriptions, quotations, and by a logical design. Credibility is qualitative research method’s greatest strength, due to the large volume of data produced. These data can then be reviewed, if necessary, to confirm emerging analyses. External validity is generally thought to allow generalizations through the use of randomized sampling. That is to say, if a similar group was to be studied using the present study’s methodology, it

may be possible to find the same results. However, qualitative research seeks specific participants in order to gain insight. Attempts to achieve generalization are not our purpose in qualitative research. Reliability suggests that the measures are stable such that utilizing them repeated times would yield the same results. In qualitative research, dependability is sought through ascertaining that the findings in the study are supported by the data. Finally, the objective nature of the data is evidenced by a confirmable audit trail. This study used the following techniques in order to establish the trustworthiness of the findings and the specific strengths and weaknesses are detailed:

- Prolonged engagement: which is the investment of time in order to learn about the Hispanic mothers being studied was a limitation of this study. Prolonged engagement is typically achieved when entire cultures are being studied and the researcher becomes a member of the culture. As this would require repeated contact with the families in the form of multiple observations and interviews and the present study involved only three contacts with each mothers, this criterion was not met.
- Persistent observation: is to identify the characteristics that are most relevant to the problem and focus on them. This study identified those aspects that were most important to the research questions at hand in order to observe it in as many settings as possible. This study was able to meet this criterion as persistent observation was achieved via observation during home visits and via mother, child, and mentor report during subsequent interviews.
- Triangulation: The purpose of triangulation is to verify information gathered. This refers both to the use of multiple sources and multiple methods of data collection.

Multiple sources in the present study included mothers', children's, and mentors' statements in interviews and the researcher's observation field notes. The use of these data collection methods allowed me to compare findings from the various sources, while also collecting multiple perspectives from all participants in the study.

- Peer debriefing: is used to explore themes, ideas, and questions with a peer who does not have a stake in the research. This was accomplished by debriefings between my dissertation chair and me and a peer debriefing group with two fellow doctoral students trained in grounded theory methodology. During these meetings, codes were changed, refined, challenged, and constructed as appropriate.
- Member checks: are used in order to check that participants' intentions were captured accurately. This study requested feedback from the participants regarding summaries of their statements as well as on emerging themes from the data both during interviews and during subsequent follow-up visits.
- Thick description: This study generated large volumes of raw data detailing the environments, activities, actions, and interactions that took place during the visits in order to capture thick description.
- Audit trail: includes the raw data, the data reduction and analysis products, memos, and field notes generated from the data collection. This study kept a careful record of all field notes, memos, transcripts, and audio tapes compiled throughout the process.

FINDINGS

Research Questions: Summary

The two main concerns of the study were to understand the nature of the communication between Hispanic mothers and their deaf children who use sign language, and to ascertain the mothers' perceptions of how issues of Hispanic and Deaf cultures related to this communication. To address these concerns, 4 key questions provided the focus for the research.

- How do Hispanic mothers communicate with their deaf children who use American Sign Language as their primary language?
- What are Hispanic mothers' perceptions of their communication with their deaf children who use sign language?
- To what extent do Hispanic mothers interpret deafness as a culture or as a disability?
- How do Hispanic mothers compare Hispanic culture to Deaf culture?

Interviews and observations were used to address these questions. My intent to examine materials used by mothers yielded very little information, as only 1 book, one calendar, and one DVD was procured from the mothers. The answers to these 4 questions can be summarized as follows:

First, most of the mothers communicated with their deaf children in oral Spanish, with or without the use of a signed language or home signs. The use of oral Spanish with a signed language altered the grammatical structure of the signed language into Spanish grammatical structure. Several of the mothers had also learned their native country's sign language. In contrast to their mothers, most of the deaf children used ASL as their

primary method of communication with their families. However, in order to increase understanding in the homes, children often used shorter phrases, slowed their communication, or attempted to vocalize in English or Spanish while signing, thus changing the grammatical structure of the original communication. Although several of the children had learned their native country's sign language, very few of them continued to use it in the US, likely because there was no source to support it and because their schooling was conducted in ASL. Another important aspect is that few mothers were able to communicate with their children until their children had learned sufficient sign language in their schools and the mothers had either learned it from their children or through their children's school. This meant that any communication before the age of 3 or 5 was frequently non-existent or very limited, often leading to isolation and behavioral problems with the children.

Second, mothers were divided in their perceptions of their communication with their deaf children. Several of the mothers felt that their communication was adequate. This was so even at times when the children stated otherwise. Several other mothers were concerned about their current communication or how they would be able to communicate in the future when they needed to discuss deeper, more abstract topics with their children. Finally, there were a few mothers who felt they had little or very poor communication with their children. In contrast, all of the mentors in the study felt that the communication in the homes was very limited.

Third, when asked if their children's deafness was a handicap, an overwhelming majority of the mothers felt that it was. Many discussed the worries that they had for their

children, including their inability to complete a higher education or to be productive in society, their inability to protect themselves from danger due to their hearing loss, or a general feeling that their child could not do much because of their deafness. Only one of the mothers had experience with the Deaf culture in her native country; however, she continued to feel that deafness was a handicap because in her country, there were few opportunities for the deaf to continue academically and to find jobs when they were adults. Many of the mothers used language that suggested they had not fully come to terms with their children's deafness or were still struggling with some aspect of it. This struggle may also perpetuate the feeling that their children's deafness is a handicap which, in a kind of vicious cycle, perpetuates the struggle for acceptance.

Finally, so few mothers had any experience or knowledge of Deaf culture that they had difficulty comparing Deaf culture to their Hispanic culture. At least one mother stated that she felt that Deaf culture could not exist. Once Deaf culture was explained to the mothers, most of them felt that it was probably important for their children to participate in its cultural events, but few knew if their children had ever participated in them before. The mothers who felt it was important suggested that their child's participation would allow them feel a sense of belonging and participate in a shared experience with other deaf individuals.

Thematic Analysis

The paragraphs above summarize the answers to 4 apparently discrete research questions. However, the full findings of the study are much more complex, pointing to several interrelationships among issues facing the mothers. Charmaz (2006) explained

that, in grounded theory methodology, research questions are seen as “points of departure...a place to start, not to end” (p. 17). Because the purpose of the method is to generate theoretical statements that explain patterns in the data, the data are first fragmented into a set of codes which are then constantly compared to each other as the analyst abstracts underlying connections showing the relationships among disparate pieces of information from disparate sources. What begins as a set of discrete questions emerges into a set of patterns that “complicate rather than simplify knowledge production” (Freeman, deMarrais, Preissle, Roulston, and St. Pierre, 2007, p. 28).

To reiterate this process: Using the methodology of grounded theory, I analyzed the data from 36 interviews and observations into 50 codes, which were then grouped into 11 conceptual categories, and then further analyzed to identify 6 themes that underlay these categories. Those themes, found in Appendix F, were: *facing deafness*, *communicating in the family*, *learning language*, *understanding the diagnosis*, *learning at school*, and *accessing resources*.

These 6 themes provide detailed descriptions of the effects of child deafness on family communication and of mothers’ views of the cultural aspects of their children’s deafness. These descriptive themes have led me to three theoretical statements that characterize the nature of communication in these families: Limited Family-Child Interaction, Mother’s Internal Struggle, and Language Confusion.

Limited Family-Child Interaction

In each of the homes, due to the child’s deafness, family communication was altered in ways that often required new language learning for family members. The

difficulties experienced by families imposed various limitations on family communication. The theme of limited family-child interaction was evidenced in three main ways: First, the child's deafness resulted in a range of thought on the meaning of the diagnosis, which affected parents' progress in developing effective communication strategies with their children. Second, these beginnings often resulted in the development of limited language patterns and conversational topics, a mismatch between parents' and children's communication strategies and, in some cases, evident misunderstandings among family members. Third, these communication issues had implications for children's overall relationships with their families as well as for their success in schooling. This section will review these three themes of Facing Deafness, Communicating in the Family, and Learning Language.

Facing Deafness

The first challenge parents had to face was the fact of their children's deafness. The main aspects of this challenge included obtaining and understanding the diagnosis, interpreting what this fact means in terms of the child's identity as a deaf person, and figuring out appropriate roles and relationships among deaf and hearing siblings.

Diagnosis Issues

The challenges surrounding the diagnosis of deafness included the timing and manner in which parents learned of the diagnosis, their response to the diagnosis in terms of initial denial and gradual acceptance, and issues related to cochlear implants.

Diagnosis history. For the majority of the families, the cause of deafness was unknown, which may have had implications for understanding and accepting their child's

diagnosis. Additionally, several families, as described below, had the experience of receiving misinformation from professionals regarding their children's diagnosis, both in their native countries and in the US.

Ms. Jimenez' description of the process was particularly disturbing as she described the health care situation in her native country as sub-par. Additionally, she felt that she did not have all the information she needed to understand the process of having a child with a hearing loss:

Well, I think that I started to notice when he wasn't speaking by age one. Something's going on here, something's wrong. But in our countries, like things are very backward. I told the doctor, "Look doctor, I think that the child has problems because he's not talking to me." I would hit things, and if he was sleeping he wouldn't wake up. Well, they told me that they would do the audiogram, that they were going to put hearing aids on him, and I thought that that was it, that that was going to solve the problem. Then we realized that it didn't work like that. They told me that he would hear something, but that he had to go to a special school. Well, then I asked if they could operate him and they told me that no, this is how things were done. That the loss would neither hold him back or help him move forward. That it would always be like that.

Ms. Alvarez described a similar situation. She did not know the cause of Luis' hearing loss and was originally discouraged from having Luis' hearing tested:

I took him to the doctor, to the pediatrician, and I told him that I wanted a diagnosis from an ear specialist. Then he told me no, because the boy was going to talk and that there are children that talk late. Then I didn't go with him and I took him to a specialist of that and they did the, the . . . audiogram, and then they told me that he did have a hearing loss.

The cause of the deafness was also a source of much confusion. Ms. Rodriguez wasn't sure, and although the doctor told her Jose was likely born deaf, she felt that his recurrent severe ear infections were the cause. Ms. Trujillo did not have a definitive diagnosis from her doctors but recalls being told that, "From the moment when she got

her hearing aids, she would be able to talk perfectly.” Although Ms. Vergara had two deaf children, she did not see the hearing losses as being hereditary. However, she had no explanation for the losses.

Ms. Saez’ doctor told her that her son’s late talking was normal and caused by her family speaking more than one language. However, she felt differently and continued to ask her doctor why her son wasn’t speaking. Her doctor sent her to a psychologist because, “He thought that maybe I was crazy.” Ms. Perez didn’t know the cause of her two daughters’ hearing losses either. After her first daughter was born deaf, she had genetic testing done, and was told they “had no reason why we would have another deaf child.” However, their next daughter was also born deaf.

Ms. Osorio knew why her daughter was born deaf as she had contracted rubella when she was two months pregnant. She explained that she was grateful that the hearing loss was the only thing that had affected her daughter because the doctors told her that she could have also been born blind, mentally retarded, or with a deformed heart. Ms. Obeso did not know the cause of Jesus’ hearing loss but felt that he was born hearing and began to lose his hearing over time. Because of this fact, her son has to have his hearing tested every 6 months to monitor its progression or deterioration.

Diagnosis denial. Due to their child’s deafness, the families had to deal with entirely new issues. Often times in the beginning, some of the mothers said that they could not believe or accept that their child was deaf. Ms. Mendoza, when asked to describe Erica’s hearing loss, said, “I didn’t even believe it that she was born like that. Asking God every day that she can hear, because she can hear a little in one ear. And she

can hear loud sounds in the other.” When Ms. Alvarez explained why Luis wasn’t diagnosed until the age of 4, she said, “I didn’t want to notice. People would tell me, ‘The boy has problems.’ And I didn’t want to . . . that he would learn later, all children are not the same. And I didn’t want that for my child.”

Ms. Trujillo admitted to denying Erica’s hearing loss even after her mother told her that Erica was having problems. She told her mother that Erica’s inattention was due to her being young. After 6 months of her mother’s insistence, Ms. Trujillo took Erica to the doctor, who confirmed her hearing loss. When I asked Ms. Obeso about Jesus’ father, she said that he had not yet accepted his son’s very recent diagnosis and said, “He says that he doesn’t have to learn [ASL] because he’s not deaf.” Ms. Vergara couldn’t believe that her third child was deaf in addition to her first child. She explained that she did not believe he was deaf until he was fitted with hearing aids.

Lisa, the mentor, felt that although some mothers had initially accepted their children’s deafness, the mothers believed that they did not have to learn ASL themselves and then were shocked to find out that their children were not doing very well in school. Lisa explained, “The parents wait until high school before they start seeing, ‘My child *is* deaf, he *does* have a deaf culture.’” Maria felt that many of the families that she worked with were in denial that their children were deaf or regarding the severity of their children’s deafness: “Right, some of the other families, they do use some signs/talking, and many are sort of in denial saying [their child] can hear.” When asked if parents understood how their children’s deafness differed from Maria’s own very mild hearing

loss she responded, “No, they think, they see me, they see “deaf” as if everybody has the same hearing loss and everybody has the same potential.”

Adaptation. There were several types of adaptations the mothers made to accommodate to having a deaf child. For most of the mothers, the first change they mentioned was the need to learn sign language. In addition, most of the mothers who had learned sign language felt that their ability was continually improving through daily practice with their child. A few of the mothers also mentioned that through their learning ASL they were also learning some English. In addition, many of the mothers had at first denied their child’s diagnosis but then adapted to it and learned to accept it. For example, Ms. Saez explained:

What have I done to adapt? Treat him like a normal child. When they told me, I said that it was not possible to have a son like that, because me and my family are not like that. And why, why, why? So then I said that it couldn’t be. I said that I couldn’t believe that I had a son like that. And if it is true, why is he like that? I didn’t want, in reality, I didn’t want to accept it, didn’t believe it.

Cochlear implant issues. Several mothers discussed cochlear implants. Many of them wanted their children to receive implants but were told their children were not candidates, while others couldn’t afford it or felt that their children could decide for themselves when they were older. Ms. Lopez was very interested in having Gilberto receive a cochlear implant but the doctors felt he was not a candidate at this time, as she explained, “I wish that he could hear. I fought for them to do the operation, the implant, and they don’t want to do it for him. The doctor says that he’s too big. I don’t know, I don’t understand that.”

Ms. Rodriguez felt that the doctors should have told her about cochlear implants, but she never received any information from them. However, she felt that it was a decision for Jose to make on his own saying, “When he grows up, if he wants to make that decision, he can make it.” Ms. Gomez said that Tomas was a candidate, but the price of the implants made it impossible as they had no insurance.

Lisa, the mentor, felt that perhaps cochlear implants were not as helpful as the professionals declared. She also explained that many deaf children did not have a Deaf identity, particularly if they had a cochlear implant, specifying, “A lot of them don’t think they’re deaf. They say they’re hearing, since they can talk. They say, ‘I have a cochlear implant, I’m hearing.’ And I say, ‘No, no, no. Take off your cochlear implant and you’re deaf.’”

Maria told me a story about one of the children she worked with many years ago who had received a cochlear implant. She explained that she saw him in a restaurant and began signing with him and was very impressed by his signing skills. However:

He doesn’t use the cochlear. Once in a blue moon. And then when the parents come, the child was signing to us and all of a sudden he tried to talk to the family and he couldn’t talk to the parents at all. And I was trying to figure out what happened here, what happened with this picture? And this is an American family. The mentality that parents are getting is that once they get the cochlear, their kids are normal . . . I try to tell the parents, “Listen, its fine. You can do the cochlear on the kid. But here’s the thing. You’re kid’s not going to hear like you.”

Deaf Cultural Issues

One of the goals of this research was to understand how the mothers viewed deafness: as a disability or a culture. The concept of Deafness as a culture is not widely understood. From the perspective of the Deaf community, parents’ appreciation of this

concept can be an important contributor to the children's sense of identity. Interviews with mothers generally revealed limited or no knowledge of the concept.

Perception of handicap/Deaf cultural knowledge and participation. Anticipating that the concept of deaf culture might be new to the mothers, I began these aspects of the conversation by talking about culture in general and then making comparisons of Deaf culture to other cultures that the mothers did have experience with. I would then ask them about how they viewed it and their children's participation in it. Their responses varied with the extent of their awareness and their openness to the concept.

Some parents seemed to reject the concept outright. Ms. Mendoza, for example, didn't believe that her granddaughter was deaf enough to be considered part of Deaf culture even though Erica is profoundly deaf. Similarly, Ms. Alvarez initially had difficulty understanding that Deaf culture could exist. When I asked her about it she responded, "No, that can't exist." However, I told her that it did exist, to which she replied, "It's very interesting and it's very important, for their development. For them to feel good about it, well, it's very interesting."

This initial lack of awareness followed by interest was expressed by several parents. Ms. Osorio seemed somewhat surprised that a Deaf culture existed outside of any other culture and had difficulty thinking beyond what the Deaf could not do as opposed to what they could do. She said, "I'm really surprised. I had no idea that something like that existed. That it has a history and heroes and the like. But I guess that makes sense."

Some parents had an awareness of activities among groups of deaf people but had not thought of it in terms of an aspect of identity. For example, Ms. Jimenez, seemed aware of the possibility, stating that she had heard of reunions in which Deaf people took part and felt that “they all know each other. That’s what I see. If not from one place, then from another. They always know each other.” However, Ms. Jimenez explained that the family had not participated in any Deaf cultural events aside from activities that were provided by the school. Similarly, Ms. Rodriguez had heard about Deaf cultural events but didn’t know that it was considered a culture: “Yes, [our deaf mentor] gets together. I ask her what she’s doing on Christmas or Thanksgiving. She always tells me that she’s getting together with her Deaf friends. And many times they all get together and have parties.”

Some parents had actually had their children participate in activities for the Deaf. Although Ms. Gomez did not have prior knowledge of the specific term “Deaf culture” she had found a Deaf club at a church where other Deaf adults gathered. She had Tomas participating in the club: “Yes, then we go to that church-We go there. And there they explain to him about the love of God and all that.” She went on to describe the deaf club at her church by saying, “They get together and do something really nice, all together. They eat pizza, drink soda and all that. Then, it’s good. And they are in their world where they know how to understand each other.” She stated that she felt that the Deaf culture and Hispanic culture had similarities, adding:

[The Deaf] have the same needs as us. And the only thing that changes is the way that they communicate. But that’s the only thing I understand that would be different. They don’t need to have a special bed, a special chair.

They don't need special food that's different or anything. No, it's the same. The only thing is that they need to have another language.

Some parents responded with immediate interest to the concept of Deaf culture.

Ms. Lopez did not have any previous knowledge of Deaf culture but was very intrigued by it and wanted to have her son participate in it because "he likes to be social and here he is bored on the weekends. If there's something for him to do, I would like to put him in, whatever, sports, culture, whatever there is. So he can be entertained." Ms. Vergara had never heard of Deaf culture but felt that it would be acceptable if her children were participating in Deaf cultural events. Ms. Saez explained her feelings this way:

It's fine. I have no problem with that. If he wants to, OK. Well, I do have to see who he's going with, make sure it's people that we can trust. OK, there's no problem. He can go, if there is an opportunity for me, I will go with them, too. And I'll take my other girls.

When I discussed Deaf culture with Ms. Obeso, she felt that it was a very important thing for the Deaf:

I think that it's very nice. Very interesting. Very, very important. To prepare oneself to, one day, be in the middle of that culture and to know how to be involved in it. Not to be left to the side, because, imagine, what would you be doing there? No, it's good to know that your son is like that and you have to prepare to one day be there in the middle of all that and know about it.

Opinion of Deaf culture. Ms. Jimenez expressed her opinion of Deaf culture like this:

I think it's good. It's a way, sometimes when one person can talk with him, that's deaf, he feels like more . . . like this woman who is married with a deaf man and they have hearing children and [my son] goes there and always talks with them. It's like going to another country and no one speaks your language. It's the same like when we go somewhere where his friends and their parents go. He is another kid, like he understands. It's good.

Ms. Rodriguez said, “That’s good, it’s good that they can share with one another.”

Similarly, Ms. Osorio said that she thought it was great because Lourdes “loves to hang out with other people that sign. It makes her feel good and she livens up when she finds people that sign.” She also explained that when new people come to the house that don’t sign, Lourdes was “not really interested in talking to them.”

Only one mother, Ms. Perez, had extensive knowledge and participation with the Deaf community in her native country:

Yes, I integrated many into the association. At the girl’s school, the older one, there was this little boy, that the mother, no, she said that she didn’t want to go and that she wouldn’t go to any association. Then I was telling her, “Look, it’s good because they’ll be with other Deaf people because that is their world. When they grow up, even if you don’t want to take him, when he’s a man, he’s going to go there because that is where they get together and have their parties, do everything.” You understand? And that was it, then later, she would go there more than me! Because later I gave birth to the younger one and I couldn’t go, you understand? And she was the one then telling me about what had happened, what was going on, that thing happened and whatever. That’s good for them, particularly when they are young. When they are older not so much, because they have their own lives, I don’t know, you understand? Because . . . for them to see that they are not the only ones, you understand? That there exists more like them.

I then asked Ms. Perez about the Deaf community’s feelings regarding having a handicap versus being a language minority within the larger, hearing community:

Yes, it could be . . . But you know that it’s not seen like that in [my native country]. Let me explain myself. In [my native country], you didn’t have many opportunities to work, to study. It was too much trouble. There are very few deaf in [my native country] that make it to the university. I think that it was because there weren’t interpreters. Because they didn’t have people, I don’t know, that really were dedicated to interpreting university classes, I imagine. Over there were very few. In fact, over there were two girls, one studied chemical engineering, the other something about sugar industry or something. And the two of them, that was, you know, that was

like a great commemoration. Because there are so few deaf people that make it to the university. Because I couldn't never understand that.

Deaf bond. Although the idea of Deaf culture was new to many of the families, they often talked about similarities among deaf people. Ms. Mendoza explained it this way: "Because I look at her, when I took her to her mother's, she found another girl who had the same problem, and those two starting talking there and they left me behind!"

Ms. Jimenez was surprised that I knew Lucas' teachers and then said she didn't know why she was surprised because it appeared that all the people that were involved with deaf people all seemed to know each other at some point. Ms. Alvarez felt that the extent of Luis' opportunity to engage with other deaf children was through his school with other deaf students. Ms. Saez also echoed the notion that her son only had deaf friends.

The idea of friendships among deaf children was supported by one of the few children who was able to discuss friendships extensively. Lourdes said:

Many, many of my deaf friends live in Homestead. I have many friends that are hearing as well. But, mostly deaf. Many of my friends are really, really smart and they help me with my ASL. You know, they sit there and teach me. We have a lot of fun, I'm really enjoying it here. And you know, for my friend's birthday, it's today. It's Saturday, which is today. Today. And so I'm really happy because my friend, in the 6th grade, it's her birthday today so it's good. I have many, many friends so it's good.

The preference for deaf friends also had implications for family relationships. Robert, one of the mentors, expressed that many Deaf people don't feel a part of their families:

They feel ignored and neglected. What they need, what they want. And so then the children lose it. The Deaf don't like to procrastinate. They like to be up-to-date. They want to be satisfied. The parents don't understand

how they feel and I have to explain to the parents that sometimes I feel the same way. I didn't have the patience when my parents didn't understand me. It's very important to communicate with your child. You have to tell them what's going on. Then they lose trust in their parents. You have to be involved. You have to tell them why you can or can't do something. He has the right to know. When I was young I felt the same thing. I think that the parents should take some class with emotional issues so the parents can understand what the child is going through.

Sibling Consequences

Perhaps one of the biggest impacts felt within a hearing family with a deaf child was the consequences felt by the siblings. Main concerns were issues related to siblings' roles as interpreters as well as parents' perceptions of negative impacts of signing upon the siblings' language development.

Sibling interpreter. In several instances, one sibling within the home was able to learn ASL to a degree that made him or her the interpreter for the child. This new position was not only for the outside world, but oftentimes was the deaf child's main source of communication within the home as well, as the parents would frequently ask the sibling interpreter to tell the deaf child certain things and would call upon the sibling to interpret what the deaf child was saying if the family couldn't understand him or her. Because of this, some siblings felt closer to their deaf sibling, some felt a burden that they thought was unfair, and some families felt that it was causing a delay in the language skills of the sibling interpreter.

Ms. Jimenez explained that her family had recently emigrated from their native country and that they had all learned NSL. Ms. Jimenez explained how she thought that the sign language here in the US would be the same as the NSL she had learned in her native country, but was very disappointed when she found out that it was different.

Because of this, the family was now trying to learn ASL. She said that her eldest daughter went to school with Lucas and was the best signer in the family so she was his main interpreter in the home. When asked if her family was making progress in their ASL communication, she responded, “Yes, because my daughter is the one that knows sign the best, she is the translator. Then she is there, and like that. But I see that we’re progressing. You go understanding a little bit more.” Ms. Jimenez then explained how she communicated with Lucas: “Well, now with a little speech and some signs. And if I don’t understand, his big sister tells him. I say, ‘Please, tell him this and this.’” Lucas confirmed his communication with his sister, saying, “Yeah, my sister knows! She can interpret well. In the future she’s going to go to school and become an interpreter. Definitely.”

Ms. Rodriguez discussed how Jose’s sister had been placed in a school program where deaf and hearing children were in the same classroom and had become so fluent in ASL that she was able to interpret for him. Confirming this, Jose explained how he bridged the gap with his sister when he was having a communication breakdown with his mother: “My sister uses sign language.” Ms. Vergara also explained how she involved the older sister to help interpret for her by having her read what the deaf siblings wrote in English and translating it into Spanish for her mother.

The mentors also described how many of the families communicated. Lisa said, “Like this one family, there’s no communication. It’s like, ‘Tell her to go,’ they tell the sister, she’s the interpreter.” Maria agreed with the notion that siblings often became the family interpreters: “Oh, yes, that happens a lot.” Robert described how one family was

communicating by stating, “The family is very motivated, they are very involved. They want to learn more and they take turns and the sister is the interpreter. She’s the interpreter and the translator and speaks in Spanish for the parents.” When I asked him to describe some other families, he said:

Most of them just sit there and watch TV. There’s no communication. Some have a family member as an interpreter and they tell the member to tell the child whatever it is that they want to tell them. One time, I wasn’t there and the child called his sister to interpret and she said that she wasn’t going to interpret because he had behaved badly. She said, “You don’t respect me, you don’t behave, so fine. I’m not going to interpret.” The sister is mean. She said that she wouldn’t help him and she left. So I told him that he needed to respect his sister. And then the father told them, “Why don’t you two go out and have a good time?” and the sister said, “No, because he bothers me and I have to interpret,” and all of that. And I told him and his sister that when I was growing up, my sister was my best friend because she was my interpreter. And then the sister doesn’t want her brother to be involved.

Sibling delay. In addition to many children becoming interpreters for their deaf siblings, several mothers described a language delay in their hearing children due to the influence of ASL. For example, some of the mothers felt that ASL was affecting their younger children. Ms. Lopez said that her youngest son, a two-year-old, had yet to speak and was mostly signing like his brother and making vocalizations. During the research observation, the child did make many vocalizations without using words, and he even came up to me signing “more” when he wanted to keep playing a game that I was putting away. Ms. Gomez explained the same scenario with Tomas’ younger brother: “He first spoke sign language and then he talked. Since he was very little . . . and he was delayed in speaking. . . . Because he got confused between Spanish, English, and all that.”

In comparison, Ms. Vergara explained her concerns regarding the effects of multiple languages on an older sibling:

My girl [the hearing older sister] has repeated this year because - she has to be talking with the other siblings in signs, so then when she comes from class, it's something that the teacher told me is affecting her. Because she also has to understand her siblings in only signs and then later she goes to school, you know that they teach them English, they teach them Spanish, and when she gets home again, she has to talk to signs with the other kids, and like it's confusing her. And her teacher said that it's because of that that she had to repeat the year. She is repeating the year. Last year she had to repeat.

Ms. Obeso disagreed. Because of her strong feelings that all of her children should learn multiple languages, I asked her opinion regarding sibling delays due to sign language and she responded, "No, I think that's ridiculous. I don't believe that. Because there's one thing, when children are small, they don't stop talking."

Communicating in the Family

The second challenge parents had to face was finding a new manner in which the family could use their language in order to communicate with their deaf child.

Language Usage

The main aspects of this challenge included frequent communication breakdowns, their perceptions of their communication with their deaf children, the depth and breadth of communication topics they could communicate about, and the types of communication strategies that they developed and used.

Three mothers represented extreme examples of language usage and perception. Ms. Perez had become involved with the Deaf community and learned NSL to such an extent that she was considered by Deaf people to be a native NSL user. NSL was used in

their home so naturally with their two deaf daughters that she often signed to her husband instead of speaking without realizing it. In sharp contrast, Ms. Vergara, who also had two deaf children, stated that she knew nothing of signs and had virtually no communication with her children. Finally, Ms. Mendoza stated that her communication with her granddaughter was very good, despite the obvious frequent communication breakdowns and frustration demonstrated by Erica during their conversations.

Communication breakdown. Many of the families found it very difficult to communicate with their deaf children and either had limited communication with them or found other ways to bridge the gap. During a visit to the Mendoza home, I saw that Erica was having difficulty understanding her grandmother. I asked the girl in sign language if she understood her grandmother and she replied that she didn't always know what her grandmother was saying and that her grandmother often didn't know what Erica was trying to sign. Several times during their joint communication, Erica signed, "I don't know," but her grandmother didn't redirect or try another way to show her. Perhaps the most difficult part of the situation was that Erica was having obvious difficulty understanding her grandmother but the grandmother was oblivious to the breakdowns. Quite contrary to what I was witnessing, Ms. Mendoza said that the communication was good between herself and her granddaughter. Based on Erica's statements and on my observation, I felt that it was very limited. It was restricted to the specific, concrete things of the moments, like "let's eat" or "Walgreens."

In contrast, Ms. Jimenez was aware of the difficulties she and her child had and explained that she had had many issues trying to communicate with Lucas before finding

a way that functioned for the family. Ms. Jimenez described his early aggressive acts in the home because he could not be understood. She explained, “When he started school, there he started to be able to communicate, it’s like it liberated him.” In the Alvarez family, although the mother and the siblings had figured out their form of communication with Luis, the father continued to have difficulty: “He doesn’t have as much communication with him, he doesn’t have that much. Sometimes he tells me, ‘Listen, what does the boy want, because I don’t understand him.’”

Similarly, Ms. Rodriguez felt that if Jose learned more oral Spanish, she would have better communication with him because she felt that her signing skills were lacking. However, she felt his ability to learn Spanish was more important for his communication with the rest of the family because no other family members had learned any signs.

In some of the homes, the communication between the deaf child and the mother was minimal. For example, I could not be sure how much of Ms. Trujillo’s conversation Erica understood. It seemed that many times she may have just lipread a word or two in an attempt to follow her mother. Overall, I felt as if there was very little communication between Ms. Trujillo and Erica but that Ms. Trujillo had very nice communication skills with her young son. Erica mostly sat there passively and let things happen to her. However, whenever I signed with Erica, the conversation was much more in-depth and lively. Similarly, in the Vergara home, the oldest deaf sister explained that she and her younger deaf brother signed to each other and that the other three hearing siblings talked in Spanish to each other and with mother. However, the deaf siblings didn’t communicate with anyone else, including their mother. She explained that they did their own thing and

if they needed something they would do it themselves. Ms. Vergara supported these statements. When asked how she communicated with her deaf children, she said that they usually played video games by themselves. When I set up a game for them, Ms. Vergara responded that she did not know any signs and that she didn't understand her son. He attempted to sign a few words to her but she pushed the game away and looked in the other direction. However, when I asked Ms. Vergara specifically how she communicated with him, she gave me examples of home signs that demonstrated to me that she did indeed have her ways to communicate. Regardless of the communication that she reported, she continued to state that they had little or no communication and that there was not much that could be done about it. I could not be sure if her hesitation to acknowledge the communication they had was due to embarrassment regarding Ms. Trujillo's lack of ASL learning or from her poor regard of their home signs.

The mentors described the way Hispanic families were communicating with their deaf children with a pessimistic tone. Lisa stated:

They use a combination of everything to try to communicate. But some don't. There's no communication . . . or they gesture, and move around. It's really sad because they don't get the full story. Like one kid knew that something happened to his mom because she never came home at night. Then the brother had to tell him, "jail" and that was all he knew. So, but he doesn't know, he has no idea what's going on . . . they just get parts of the information. If the grandmother died, they know, they're sad, but they don't know why she died. They really don't know the names, like their pets. They're just getting parts of the information. But I know that that is the major problem with communication. They don't get the full story.

Maria explained that in many families the deaf children "just miss a lot. There's a gap. They're behind." In addition, she felt that one of the biggest issues of limited

communication in the families had to do with the mothers' continuing to deny their children's deafness:

They're going to lose the child. They're going to reject their family because they never learned to understand how they feel and understand their emotions towards the family or understand them. I had a girl who was in 4th grade. The parents speak Spanish. She came to school with a note. She gave it to me, I guess she was feeling comfortable, or I happened to be the only one in the classroom. As I read the letter in Spanish, my jaw just dropped. The mother, asking me to explain [to] the child what is the menstrual cycle. [My student] had no idea what to do. I guess the mother just gave her a pad and then she wrote a note so we can explain [to] the child what is it. So we had no choice but to, of course, help the child out. We cannot just abandon them, you know. So I explained the whole thing, this and that, what do you do. That's a consequence because the child later on in life is going to say, "Listen, you sent me a note to school. I was embarrassed. That's not my mother." You know? "Too bad, why should I care about you if you didn't care about me learning sign language to communicate and explain my feelings."

Robert described the communication within the families' homes where he mentored:

It's very interesting, because that's a problem. Some of the parents don't socialize and don't use sign language and they're frustrated, and they don't understand the child. In one family, the child is trying to explain something to the father and the father doesn't understand and the child gets very angry.

Perception of communication. Many of the mothers had varied opinions about their communication with their deaf children that ranged from feeling satisfied with the communication to feeling that there was much difficulty in the communication. Only a handful of the mothers felt satisfied with their communication. Ms. Saez felt that both she and Victor were able to communicate well with each other. She also said that she was not embarrassed to sign in public with him and that she felt, "happy, like I have the privilege that I know how to do that." Ms. Perez felt very confident in her NSL communication skills with her children because she had been immersed within the Deaf community and

could communicate without hesitation with other deaf individuals in her native country. However, she was wondering how her communication would change now that her oldest daughter was beginning to learn ASL in this country. Ms. Obeso felt that she had good communication with Jesus because she used every form of communication she knew to make him understand her. Similarly, Ms. Osorio felt that she had always had good communication with Lourdes because she had learned NSL, but now that Lourdes was more fluent in ASL, they were starting to have some breakdowns. As mentioned earlier, one mother, Ms. Mendoza, seemed unaware of the communication gap and felt that her communication with Erica was very good. She stated, “We don’t have any problems.” However, Erica did not seem to agree. Erica became very frustrated during their conversations together, did not initiate much, and only responded when spoken to. In contrast, Ms. Mendoza’s daughter, Ms. Trujillo, felt that both her own and her mothers’ communication with Erica needed to improve.

Several of the mothers felt that their current communication was good, but were worried about how they would communicate in the future. For example, although Ms. Jimenez felt that her current communication with Lucas was adequate, she felt that she would need to improve her communication with him as he continued to grow: “That’s what worries me the most. That I’m going to have to learn more to be able to communicate with him.” Ms. Lopez felt that Gilberto was starting to leave the family behind in communication aspects. She described how she had to get a dictionary and books in order to learn the signs that Gilberto used that she didn’t know yet. In addition, Ms. Alvarez declared that “sometimes I feel a little bit strange. Because sometimes he

understands me and other times he doesn't . . . that makes me get a little exasperated.” Similarly, Ms. Rodriguez stated that she often felt “uncomfortable” and felt that her signing skills should have been much better. Ms. Gomez felt that her communication with Tomas had greatly improved since her signing ability had improved, but was still left behind at times when Tomas signed very quickly. In contrast to the majority of the mothers, one stated that there was no communication between her and her deaf children. Ms. Vergara plainly stated, “It’s not happening.” However, I felt that she had much more communication with her children than she readily admitted to.

While most of the mothers felt that they had relatively good communication with their deaf children, the mentors typically felt that the communication in the homes lacked severely. Lisa felt that her students didn’t receive much information at home, were often left in the dark, and didn’t “have that connection at home.” Maria felt that many of the mothers didn’t truly understand or accept their children’s deafness, which kept them from truly learning ASL. She also felt that it would cause the family to “lose the child.” She explained that the deaf children would “reject their family because they never learned how they feel and understand their emotions.” Robert also agreed with this and felt that the families could only talk about limited, concrete topics, causing the deaf children to “feel ignored and neglected.”

Conversational topics. Even though many of the mothers felt that they had good communication with their children, the types of topics that they could discuss with their children were limited. Few of the mothers were able to discuss abstract or deep topics with their children that included sexual, religious, and political topics and they expressed

their concern about these issues. When Ms. Gomez spoke about being able to talk to Tomas about more sensitive subjects, she was clear that she wanted to have enough communication to be able to talk to him about those things personally:

Well, that's exactly why I'm more involved in learning his language, because -Yes, it's important that he can come to me and not go first to his teacher, to ask them - how to get a girlfriend, and all that. So then, at least - sometimes they need for their mother or father to orient them about topics of interest for them. And yes, it motivates me to learn more, to see that he has so many questions and he needs to know everything. Sometimes when we're watching the TV and he asks me what is happening and what they said and all that. So then I'm here and there explaining it to him . . . but some situations are . . . you can't have the opportunity to explain it. Like when he was asking me what was happening with the case of the man that they executed, the one, Saddam Hussein. So then, it's very difficult to get into those current topics with him. For him to understand me directly, and that's what's happening . . . That he feels at liberty to communicate and not feel frustrated in the home. It's like all kids that are growing up, needing to be heard. He doesn't hear but he needs for us to understand him, to comprehend. Sometimes even with us, as hearing people it's happened that we talk and we're not heard. They didn't give us the attention that we required, so then I don't want that to happen with him. Even if it's a little, I have to help him.

Although Ms. Gomez was interested in having more in-depth communication with her son and the family was able to sign with some fluency, it didn't always translate into something that Tomas benefited from, as can be seen in her description of dinnertime conversation:

M: In general, the three of us eat together because their dad is working at night. Only on his days off are all four of here and we eat here together. Then, yes, we sit to eat, and sometimes talking there.

A: Talking in signs, in Spanish with your husband, how?

M: Yes, with him we talk in signs.

A: So then the four of you talk in signs during dinner?

M: With him. If he needs it. Let's say, if I'm talking with [my son], I talk to him in signs. If I talk to dad, I don't use signs. Only with him.

A: And if it's a group conversation it's in signs? And if it's only with dad or the little one it's in Spanish?

M: Yes.

In contrast to the other mothers, Ms. Vergara had limited knowledge about how her children were learning about abstract topics and felt that she was not able to discuss them with her children:

It's something that you can't explain to them. Because my daughter, I could explain to her that she's 15 years old, and that she needs to take care of herself, and she shouldn't be paying attention to people that she doesn't know. I can't explain it to her. Because you know, she's my daughter, but since I don't know her signs, I can't explain it to her, to tell her that something is not good, and if someone tells her things in a certain way that she needs to tell me. It's something that I can't explain to them. And she doesn't know how to write in Spanish, can't read in Spanish, and so then, yes, it worries me, about her, you know, I'd like to explain to her and I can't explain to her about what she should and shouldn't do. I think that maybe at school, perhaps they'll explain it to her. But I can't here in my house. I don't know, I've talked with the teachers several times, but I have forgotten to ask them to tell her what is right and what is wrong. Because I would like to explain it to them but I can't. And thank God that I don't work and am watching them at home. I can take care of them. But like I've told you, I could give them, I would like to give them an explanation, to my daughter, tell her what things are not right for her to do and which are the ones that are right for her to do. I can't explain it to her. That's what's missing for me; I can't explain it to her.

For the mentors, the issue of discussing abstract concepts was one that often left them playing the parental role. Lisa explained that many times she had to explain the more abstract topics like puberty and sex:

Yes. We are talking about it. The teachers. We have to explain all that. They have no idea. Teenagers have no idea about all the terminology related to sex, HIV, you know, all those words. They don't know, we have to explain that to them. I don't know why, but it just seems like they've never explained it to them. And I guess maybe they just don't feel comfortable. Because I can't even remember a kid that already knew all of this stuff before coming to me. Then I have to explain to them why they have their periods and all that stuff. Because then it was like, "Ah! What is that, why?" And then, I've had some girls that say, "If I kiss, I can get pregnant." They have a lot of misconceptions. So that's when you really

have to talk to them. Like we've had to explain to them about the internet and about meeting people on the internet. A deaf guy, he's 25 years old, contacted a girl who was 12 years old in my class. Another girl in the class found him on Myspace on the computer, got his name and everything. Then he started calling through the web cam. So then they started talking about exposing themselves, and he showed them his erection and ejaculated while they were watching him do it on the computer. So I had to explain to them, "Why were you watching him in the first place?" One girl said, "I was curious, I didn't know." Then he asked her to pull up her shirt and pull her pants down, and she did. For her, she was very gullible. Yes, that's one thing that I've noticed about these deaf kids, they're very gullible. And I think it's because they don't have a strong background in what they should and shouldn't do and what will happen if they do do it because no one has ever explained it to them.

Maria experienced frustration in the homes as well. She stated that the children were often very excited to see her and said, "I'm the only person who understands them clearly. You know, how they feel and what they are saying. And I notice that there is a little frustration between the child and the family trying to communicate." When describing how the families were communicating about more abstract topics to their deaf children, Maria responded, "I don't see it happening. It just doesn't happen. I expect one of the families, they do explain. But the others, they just say, 'we're going to the doctor, she's sick, and that's it.'" Similarly, Robert described the topics that the families were able to communicate with their deaf children: "They talk about food, simple things. Most of them just sit there and watch TV. There's no communication."

Communication strategies. A wide range of strategies for communicating were developed for family members of deaf children. However, it was notable that there was generally a mismatch between the deaf children's preferred method of communication and their families' methods of communication. It should be noted that signed languages have their own grammatical rules that differ from oral languages' grammatical structures.

Therefore, if a person was using signs and speaking at the same time (which was seen quite often in the study), the grammatical structure would be that of the oral language and not the signed language. Additionally, some families made up their own home sign languages that Lane, Hoffmeister, and Bahan (1996) state “become idiosyncratic to the families and the child” (p.39). They posited that the use of home sign could range from a simple use of gesture, pointing, and charades to a more complex combination of signs specific to the home that could relay much more information.

Children used ASL in nearly all of their communication with their families. However, many of them used shorter sign language phrases as their families did not understand longer and faster sign phrases. Only two children were observed to use NSL with their families, and they used it with a mixture of ASL as well. The children were also observed to use oral Spanish and English almost equally to communicate with their mothers, and often in combination with signs, both in ASL and in NSL. Lipreading was a method of understanding their mothers that was utilized often, as well as gestures, home signs, and an interpreter (for example, a sibling) to make themselves clearer to their mothers.

In contrast to their children, the mothers generally used oral Spanish most often to communicate with their deaf children. Many of the mothers did use some ASL signs, but often in combination with oral Spanish, using the Spanish grammatical order as opposed to the ASL or the English grammatical order. For example, if the sentence “I see the big dog” were signed, it would look like “Dog big I see” in ASL. However, if spoken in Spanish, the adjective and object would change positions, as in “Yo veo el perro grande”

(“I see the dog big.”). Neither the English nor the Spanish grammar would be the same as the ASL grammar. In addition, mothers were observed to use oral English, gestures, a family interpreter (like a sibling) and NSL, but all to a lesser degree. Often times, several strategies were used at the same time. For example, Ms. Obeso would speak to Jesus in oral Spanish and then insert a word in English and sign language. Therefore, a typical sentence produced by Ms. Obeso could be, “Donde esta el cat (while signing cat)” [which translates to “Where is the cat?”]. Only one family was observed to use sign language naturally, the Perez family, and it was NSL. While they communicated, they used NSL grammatical order and did not speak orally. A small handful of mothers were observed using a home sign with their children.

The majority of siblings used ASL signs combined with oral Spanish or oral English to communicate with their deaf siblings. This meant that the signs that were used were in Spanish or English grammatical order and not in ASL grammatical order. Several of them used oral Spanish and oral English only, and a small handful used NSL to communicate with them as well. Although use of ASL or NSL was often used in combination with oral English or Spanish, the siblings’ often had greater knowledge of the signed languages and a more extensive vocabulary than their mothers.

Overall, the family units were observed to use a family interpreter, most often a sibling who used ASL, to communicate with their deaf child. In addition, in the homes where the family members had learned NSL, those families had a tendency to continue to use their NSL in combination with oral Spanish even though their children were mostly responding to them in ASL.

Learning Language

Parents' learning of a new language in order to facilitate communication with their deaf child was exacerbated by the families' lack previous knowledge of deaf issues or signed languages and the absence of support systems to assist the mothers in their language learning.

Language Learning Issues

The mothers were faced with the challenge of learning a new language in order to communicate with their children. The challenges surrounding this task included identifying what languages were important to learn or maintain, understanding that there were differences between their native oral and signed languages and the oral and sign language used in the US, actually learning the new language, using language learning facilitators to ease the process, and overcoming language learning barriers.

The importance of language. For some of the mothers, it was important to them that their children continued to learn Spanish or not lose their current skills. For example, Ms. Jimenez stated, "That he doesn't lose his Spanish. To speak in English and Spanish. It will be very beneficial for him." In addition, Ms. Obeso was very interested in her son learning Spanish, "Because I think that he needs to learn Spanish. It's a very interesting and important language in this country. Many people speak Spanish. For his education, so that it helps him." Similarly, Ms. Rodriguez felt the need for Jose to keep his oral Spanish skills to enable his communication with his extended family and stated:

It's not that it's not important, but since I don't use many signs, I'd like it more because it would help him more, with three languages. But if I knew how to talk in signs, I would talk to him more in signs than in Spanish. Well, it would be good if he could understand, because all the family is

Hispanic, and none of them know signs, and at least the little that he speaks and that he can read lips, he can understand it.

Many mothers felt that it was important for them to learn sign language since their children were using it. What was very striking to me, though, was that even though most of the mothers had come to the realization that they needed to learn signs, most of them did not learn signs until the children were much older. Therefore, they had no real way to communicate with their children during the early years. For example, Ms. Lopez, stated that she knew she needed to learn sign language once her child was diagnosed at the age of one. However, she did not begin to learn until he had started school at the age of three. Similarly, Ms. Alvarez knew that her country had native signs and that she should learn them, but she did not and waited until her family arrived in the US. She explained that when he was diagnosed at age 4, “I realized that my son needed that language. And that I needed to obligatorily learn it so that I could have good communication with him.” He was now 6 years of age.

Another example was Ms. Gomez who explained it this way: “I always knew that if he didn’t hear, then we would need a way to communicate with him and that he would understand what I wanted to tell him.” He was diagnosed at 18 months; however, and she did not begin to learn any signs until he started school at three years of age.

In contrast, Ms. Trujillo explained that she didn’t know that she needed to learn sign language until she moved to the US. Here they told her that her daughter would need to go to a special school that was in sign language. Although they had been in the US for three years, Ms. Trujillo had learned very little, saying she knew “some things. Her name, yes. Because she herself taught me,” and that she wanted to learn more “so that I can

have better communication with her, because it's nice. It's nice because I have seen it when she's with her classmates and she can communicate with them." Similarly, Ms.

Obeso was very interested in her son learning ASL, as she explained:

I want him to learn. In other words, since we're in the process of signs. Since he likes it, I want to take advantage of that so he learns it well. That he learns it well for his future, so that later he can go and become a translator, to help other children that don't know and don't understand, that is what I want.

In addition, Ms. Saez felt that ASL was very important:

I think that [educators] don't want to leave children abandoned, like deaf children should be pushed aside. Because they have that language, and I feel good about that language because those that don't hear can understand and learn better. They understand well what is going on. But if they don't have that language and don't hear, they're lost in the world, it's like, it would be very sad. It would be sad, but since they don't hear but can see it, they're like, "Oh, OK!" Normal life. They even have more. They are happier than those of us that can talk and hear and all that. When they get together with their friends, they laugh and have a good time.

Only one mother, Ms. Perez, was fluent in her native sign language and used it with native-like proficiency with her daughters. Ms. Perez explained that she wanted her children to keep both ASL, now that they were learning it in the US, and NSL, particularly since all of her family in her native country had learned NSL to be able to communicate with the girls.

Language variety: ASL/NSL/Spanish/English? The question of which language to focus on presented a challenge for the families. Several families had the opportunity to learn their native countries' sign language and felt that they had good communication with their children. However, once they moved to the US, many were very frustrated to

find that sign language they had learned was not a universal language and that signed languages differed from country to country.

For example, Ms. Jimenez explained that she thought that the sign language in the US would be the same but was very disappointed when she found out that it was different from her NSL and now was trying to learn ASL. Her entire family had learned NSL, but in their three years in the US, only his sister was able to learn enough to communicate with Lucas. This was confirmed by Lucas who also explained that he didn't remember much of his native sign since it was not used anymore: "In 2003, when I came back over here, the school told me that I was wrong. They told me that the sign language here was different. So they taught me and now I know I learned it. I learned it well."

Another issue was whether ASL instruction would be given in English or Spanish, since most mothers didn't speak or understand English. Ms. Lopez had learned NSL in her native country and was hoping to take an ASL class taught in Spanish. She stated, "It's completely different. Very few signs are alike. I didn't take too many because when, I was getting ready to come here . . . I realized that it wasn't the same." In addition, Ms. Alvarez had learned some sign in her native country but didn't know why they were different than the ones here in the US.

Language learning: From whom and when? Many issues were involved in determining how and when the mothers and children learned sign language. One important phenomenon that occurred was that few children learned sign language from their families. In fact, only two of the children in the study had learned signs from their parents and the remainder of the children learned sign language at school. However, for

those learning it at school, it was very disconcerting to know that these children likely spent their first few years with virtually no communication in the home. In addition, it appeared that those children who had not learned sign language in the home were currently demonstrating lower language skills likely due to their lack of early experience with language. It appeared that the language skills of those children who learned ASL or NSL earlier and whose parents had also learned it early on were much stronger.

As an example of this, Ms. Mendoza stated that Erica learned ASL through school. Ms. Jimenez also said that Lucas also learned ASL “at school. Everything he has learned, he learned over there at school.” In addition, Lucas had also learned NSL in school I in his native country. Lucas confirmed this and stated, “My school, I learned in elementary school, the teachers taught me.” Similarly, Ms. Lopez stated, “Well, he’s now starting to leave us behind . . . since he’s learning at school, right, I get the dictionary and the books and that and, then when I don’t understand a sign, he translates the word, tries to find the word for me or fingerspells it.” Ms. Osorio explained:

Well, it was very hard at first because I didn’t have all the communication. When she was little she made sounds and all that but when she was around 2 years old I realized that she was not keeping up so I put her in a deaf school. There they taught her [NSL].

For the mothers that did learn sign language, they learned through two primary ways: through their children or by taking classes. The overwhelming majority of the mothers had learned sign language from their children or along with them while only two were teaching it to their children. In addition, although most of the mothers said that they knew that they needed to learn ASL once their children were diagnosed, many of them did not learn it until their children went to school and taught it to their families at home.

For example, Ms. Mendoza explained what she had learned of ASL: “Some, few, what she has taught me, you understand? She comes and moves your fingers and everything.” Erica described how she communicated with her grandmother and it was clear that she didn’t feel very competent in any of the languages that grandmother claimed she spoke to her in. Similarly, although Ms. Jimenez had learned her native country’s sign language at her son’s school, she was currently learning ASL through her son since the family’s move to the US. Ms. Lopez also explained that she learned ASL through Gilberto and with books, “He arranges my hands when I talk.” Ms. Saez also learned her sign language through her son saying, “He would teach me.”

While a few of the mothers took formal sign language classes, several of the mothers had a deaf mentor that came to their homes to teach them or used books and videos. For example, Ms. Alvarez had a deaf mentor coming to their home one time per week who used a book that had hand-drawn pictures of American signs and the words written in both English and Spanish below the pictures. In addition, Ms. Rodriguez’s mentor used a trilingual calendar that showed the calendar in English, Spanish, and ASL.

Ms. Vergara was reluctant to admit that she knew any sign language and only gave examples after several requests: “Yes, [the children] have taught me, but, I also have a real hard head . . . they have brought me sign books. I’ve tried, they’ve also tried with me, showing me, with their fingers.”

The mothers who had learned sign language in school typically learned NSL in their native countries at their children’s schools. For example, Ms. Gomez explained:

There in [his] school it was obligatory . . . once a week the parents would get together to learn signs. And at least that we didn’t have to pay for, and

they were there-like-involving the parents so that we would get in the children's world a little, to be able to understand.

Similarly, Ms. Osorio had learned her native country's sign language through Lourdes' school, but now that they were in the US, she was relying on Lourdes to teach her ASL. I observed the girl showing her mother the ASL signs for the pictures they were looking at and when her mother kept making the signs in NSL the girl would correct her again. Lourdes explained how she was now having to teach her mother ASL since they'd moved to the US, "And now once I came here to Miami, it's completely different. My mom doesn't know the ASL. So, you know, I've been trying to teach her."

In contrast, although Ms. Perez learned had learned her country's native signs at her daughter's school, when her second daughter was born deaf, both Ms. Perez and the older deaf daughter were able to teach the child sign language as a first language. In addition to that, since the family was very involved with the deaf community in their country, they often learned in social settings and with other deaf individuals in public. She explained that, "The teachers at the school said that we looked just like the Deaf, and also, that with the Deaf it was everybody there, you couldn't tell who was deaf and who was hearing."

Finally, Ms. Obeso was the only mother in the study who was currently learning ASL alongside her child and was actively teaching him through the use of several books, dictionaries, and DVDs.

Language learning facilitators. Learning a new language was typically a difficult thing for the mothers to do. However, there were some facilitators identified that allowed them to learn more easily. Mothers learned through their children; many of them reported

that their children would manipulate their mother's hands to make the correct signs and would correct them when they made an incorrect sign. In addition, some of the mothers had taken classes or used books and videos to learn ASL or NSL. One common facilitator for mothers to learn ASL was to have the ASL vocabulary they were learning translated into Spanish. In addition, the use of a deaf mentor in the home was cited as a facilitator for learning ASL. Although most of the mothers did not participate in any deaf cultural events, those who did state that signing with others helped them learn ASL. Several of the mothers that had learned NSL in their native countries stated that their learning of NSL was obligatory at their children's school and was offered as a free service. Additionally, they said that the fact that NSL was taught in Spanish made it much easier for them to learn it.

Maria, the mentor, commented that the main quality that helped families communicate with their deaf children was when they had "the support and the family accepted and the family was involved."

Language learning barriers. Many of the mothers reported that learning ASL was very difficult for them. ASL, being a recognized language and based on American English, is generally taught in English. For some of the mothers, the time needed to learn another language was too great, while for others, the fact that ASL was taught in English meant they could not understand. Still others reported that their children signed too fast for them to understand. Another barrier that was listed by the mothers was a lack of ASL classes in their area. In addition, Lisa was asked if she felt that Hispanic families could learn ASL without learning English and she responded, "I guess not. I guess it just

depends on the families. There are just so few who really learn sign.” Several mothers also stated that their work schedules, child care problems, or lack of transportation hindered their participation in an ASL class.

It appeared that most of the mothers had the same barriers to language learning. Nine of the twelve mothers had full-time jobs outside the home and one mother was searching for a job, half of the mothers did not own a car, and seven of the mothers spoke little or no English. However, some of the mothers allowed the barriers to keep them from learning while others found ways around the barriers, not allowing them to be hindered from the process.

Mother’s Internal Struggle

Considerable struggle was noted within both the mothers and their children. Most of the mothers either directly expressed internal struggle or used language that indicated internal struggle related to acceptance of their child’s diagnosis of deafness. In addition, although the children’s interviews could not capture this due to the limited information they provided, the mentors’ interviews suggested that deaf children often had difficulty identifying themselves as deaf or in bonding with their families. These limited indications suggest that further research regarding children’s struggle is needed.

For the mothers, it seemed that many were struggling because they were uneducated regarding the diagnosis of their child. They may have received incorrect information from their health care provider, received no information, or were in denial regarding the diagnosis or their child’s true abilities as many of them were still grappling

to understand what their child's future would hold. This section will review the theme of Understanding the Diagnosis.

Understanding the Diagnosis

Several factors arose from the mothers' limited knowledge regarding their children's diagnoses. These included general concerns regarding deafness, misperceptions and misinformation about deafness, and how mothers interpreted their experiences.

Concerns

The mothers listed a multitude of concerns that they had specifically regarding how they were able to manage and cope with their child's deafness. These included difficulty with childcare, lack of transportation, long work schedules, and the distance of ASL classes that precluded them from being able to attend. There was also a concern regarding immigration status that left the families in constant fear of being deported and losing out on the resources of the US, worrying about their children having to wear hearing aids for the rest of their lives in order to hear better, the use of ASL resulting in their hearing children's language delays, and a worry about how they would be able to communicate with their children as the children matured. In addition, many of the mothers worried about the cost of hearing aids, hearing aids batteries, therapies, and insurance. For examples of hearing aid concerns, Ms. Mendoza commented that she was "worried, you know, because I wish that she was a girl that didn't need to walk around with those hearing aids," and Ms. Gomez explained how their native country didn't provide the public resources they needed to get Tomas his hearing aids: "Over there it is

tremendous how they don't give any importance to the handicapped person, so then, we as parents of a family had to start to inform ourselves of the places that could help."

Some of the mothers were concerned about sign language. For example, Ms. Jimenez had difficulty finding ASL classes in the US that suited her schedule because "they have them, yes, at school. But they are much later. I'm saying that they are more like at night. But the problem is that in this country, one works more than in one's native country, it is very difficult." Additionally, Ms. Rodriguez was concerned with her lack of ASL knowledge and said, "They get to a certain age that one needs to start talking with them, counseling them and that, and now he's getting older and I can't do it well. We talk, but it's more cut off." Although Ms. Perez was fluent in her native country's sign language, now that her family was in the US she wanted to learn ASL but had barriers:

They told me that there was, giving a class at a school, like a course for parents. But it's too far for me. I don't have a car or anything. Then, at the time of the class, my husband is working, and I'd have to take the girls with me. It's very difficult. If it were around here close I would sacrifice myself. But it's too far.

The mentors also discussed the concerns that the families faced. Maria explained how the immigration issue affected what the families could do to advance their ASL knowledge: "Sometimes they work many hours. The families that are illegal immigrants work pretty many hours to be able to survive and feed their child." When she described what facilitators would help families communicate with their deaf children, she also said, "They should take advantage of the free courses they're giving out. But like I said, it depends on the lifestyle. Some of them don't even have a car." Similarly, when Lisa was describing how they informed the parents about the activities her school had, she said,

“Well, we try to send out flyers for different things. But it’s always the same problem: transportation.”

Misperceptions/Misinformation

Several of the mothers were given false information by their health care professionals or had misperceptions regarding the information that they received.

Professional diagnosis. An example of misinformation obtained from professionals was given by Ms. Mendoza, who was told that Erica would possibly hear in 15-20 years, could not hear very loud sirens, and could not take aspirin. Ms. Trujillo was told that once Erica received her hearing aids she would talk normally and not need sign language, but Ms. Trujillo soon found out that this was not so. Several doctors told the mothers that their children had no problems and were late talkers, but it turned out that their children were deaf. In addition, several doctors could not explain to the mothers why their children were deaf or if their children were born deaf or lost their hearing later.

Deafness. Some of the mothers demonstrated a lack of knowledge regarding how their children’s hearing losses were manifested. For example, Ms. Mendoza described Erica’s hearing loss as a mild problem and attributed Erica’s speech problems to the notion of a “tongue-tie.” Ms. Mendoza explained that Erica could not pronounce “s” sounds and would use “t” sounds instead because Erica had a short lingual frenulum. However, Erica’s production would actually be considered typical of a deaf speaker in that she did not produce the “s” sound. Had Erica truly had a short lingual frenulum, she would not have been able to produce a “t” or an “s” sound as the two sounds are produced in the same place in the mouth. I explained this to Ms. Mendoza, but she told

me that was incorrect and that Erica indeed had a tongue-tie. In addition, Ms. Mendoza was unable to discriminate between Erica's ability to read lips and her ability to hear. She said, "She is hearing me. She is very intelligent, because she reads lips and she knows what you are saying." Another example of misperceptions was given by Ms. Jimenez who explained that she thought everything would be solved once Lucas received his hearing aids:

Because I was ignorant, I didn't know anything. I thought that he was going to go to school, he would put on his hearing aids, and that the teacher would explain everything to him. That he would go to hearing school. Then when they sent him to that school, I thought, "How is he going to learn?" When one finds out, understands, then one sees that one is going to have to know how to communicate.

Additionally, Ms. Alvarez explained that she did not fully comprehend that the type of hearing loss that Luis had:

Look, I don't understand that much about it, but they say he had an 85 in the left and an 80 in the right . . . They only told me that he had more loss in the left than in the right.

She went on to say that she didn't know if he would be able to finish his academics, "But I don't know if in the future he can go to the university and study a career, that he would reach the same milestones, with his language." Additionally, she explained that her comfort level for communication had not really changed since she started to learn ASL because they were not communicating any differently. She felt that their communication would improve when he was "using oral language," explaining that he had limited oral language use because, "he will use oral language when he has more interest in it. When he needs it, the reason for it, and is older and says that he needs to speak orally."

Another example of how parents had misperceptions was given by Maria, the mentor. She stated that she had difficulty explaining to parents what their children's hearing losses meant for their overall potential for oral speech and language development: "they see 'deaf' as everybody has the same hearing loss and everybody has the same potential."

Mother Interpretations

The mothers' interpreted their children's deafness through their experiences and beliefs. These included their perceptions of handicaps, their religious beliefs, their expectations for their children, and what they considered "normal."

Perception of handicap. Several mothers expressed a concern regarding what their children were capable of. For example, Ms. Lopez was interested in Gilberto being able to read in both English and Spanish but said, "If he could, but I don't know if he can understand two languages. I don't know how far he can go." In addition, the mentors discussed some of the families they had worked with. Robert described a mother who did not let her deaf daughter do any activities alone:

The mother was 21 and her mother never let her go out. She was afraid that a boy would rape her and all that. So the girl never when to school, she stayed at home and was not allowed to go out because it was dangerous. So when she moved down here, she didn't know anything, not even Spanish or English. She started here in high school and she was academically at the kindergarten level. She started learning her ABCs. She was isolated all her life. Her mom was paranoid because she was deaf and thought that she couldn't do anything. She had no independence.

Similarly, Maria also felt that some parents doubted their children's potential:

This family believes that their daughter can't do anything. [Dad] said that she was going to live with him for the rest of her life. And I asked him if

he thought his daughter could make a difference and he said no, that she was stuck with them for the rest of their lives.

Religious reference. Several mothers said that it was God's plan that their children were born deaf or that only God knew why they had a child born deaf. For example, Ms. Mendoza said, "God wanted that the girl come to me, with a problem." When Ms. Saez began to question why she had a deaf child, she recalled a moment when "I had forgotten that I have a God that is all powerful, so then only to Him can I ask for help." In addition, Ms. Vergara felt that her children's hearing loss would be miraculously cured, thus restoring their ability to talk:

I think that they will improve. I have a lot of faith in God, and I say that God, one day will make them hear and make them talk, because they don't talk because they can't hear. Their loss is in the ears, they don't have a loss of talking. So then since they don't hear, that's the reason they don't talk. And I have faith in God, I say that they will, one day God will make a miracle that they will hear and be able to talk. Because it's difficult that they can't hear and can't talk. For that reason I say that God will do a miracle in them, I have the faith in God. Because before, he talked less and now I see that he can talk more.

Mother expectations. Several of the mothers thought that once their child had received their hearing aids, their speech and language development would continue along as a normally hearing child's would. Then they found out that this was not the case, their child would need extensive therapy and schooling, and that didn't even ensure that their children would speak intelligibly. In addition, several of the mothers expressed a desire for their children to succeed in school in order to ensure them a future.

"*Normal.*" Another indicator of maternal struggle was seen in the constant use of the term "normal." What was not clear in many instances was whether "normal" meant "hearing" or the opposite of "abnormal." For example, Ms. Mendoza described her

granddaughter as “her hearing problem is the only problem that she has. She is a normal girl, loving, she likes children.” When she was describing her school placement in their native country, Ms. Mendoza said, “She was in a normal school.” Looking for clarification, I asked if she was with hearing children and Ms. Mendoza responded, “Yes, a normal school, her Kindergarten and her first grade. But imagine, we had to go do everything with her.” In describing her at her current school she said, “There in school, she is normal. When she was with [her teacher], normal.” Finally, she said, “Of course, I’d like it if she were normal like you and me, but who can go against the will of God? One has to accept things as they come.”

Ms. Trujillo described Erica’s school placement in their native country just as her mother had: “she was in a normal school over there . . . of children like you and me that would go to school.” When I asked her how Erica’s hearing loss was affecting her daily activities, Ms. Trujillo replied, “Well, for me it would be better if she were a normal girl, you know, there would be much better communication with her.” Ms. Saez stated that she was adapting to Victor’s hearing loss by “treat[ing] him like a normal child.” Similarly, Ms. Jimenez described Lucas friendships by saying, “He has many friends and they like him as if he were a normal child.” When asked if she felt his hearing loss was a handicap, she replied, “No. He, the only thing is that he can’t talk and all that, but no. I see him like a normal child.”

Ms. Alvarez described her acceptance of Luis’ deafness: “No, now I take it as normal. Because he is a child that is, he is progressing. In his normal life. And now it’s much better because we can all learn and we are communicating with him. Yes.” In

addition, when comparing the US with her native country she said, “Here they give them more attention . . . they give them the same importance as a normal person.”

A few mothers made some distinction with the terms “hearing” and “normal.” For example, Ms. Rodriguez described Jose as “like if he were normal because he participates in everything, everything, as if her were a hearing child.” However, she felt frustrated to “have a child that cannot hear well or have-his five senses is how you say it, right? But it’s, he is a normal child.” Similarly, Ms. Vergara described Gustavo’s school placement by saying, “No, no, first with normal children and then they changed him to deaf children. Like at five years, they sent him to that [school for] the deaf children.” When I asked them if they participated in social activities, she said that her children liked to dance. I asked her if they were deaf dances and she replied, “No. Normal ones.” Ms. Perez was the first mother to use the word “normal” along with the words “hearing” to differentiate hearing versus deaf children. I ascribed this to her deep involvement with the Deaf community in her native country.

Language Confusion

As discussed above, mothers of deaf children have several challenges related to their children’s diagnoses. These include the need to acknowledge and accept their children’s deafness, identify adaptations that need to be made, and the learning of a new language. In the case of Hispanic families with limited English abilities, learning ASL in English multiplied the challenges. Oftentimes, the language that the mothers used with their children was a mixture of several languages, as when they spoke oral Spanish while using signs from ASL. This mixture of language in the home, combined with the age of

language learning for the children and the language being taught in the schools creates a mismatch that can lead to language confusion in the child. This language confusion can result in lower language skills and poor academic achievement. This section will review the themes of School-wide Consequences and Resources for Disabilities.

Learning at School

As more American-born deaf children are identified in infancy and fitted with appropriate amplification or cochlear implants early in life, it seems likely that the children would reach typical-hearing children's language milestones, thus enabling the children to be mainstreamed for their schooling. However, the fact that deaf immigrant children who are often late identified and with limited language skills are being placed in self-contained deaf education classrooms could likely have an effect on their general level of academics in the classrooms.

Changing Classroom Demographics

Several of the mentors noted that the self-contained deaf education classrooms they worked in had changed over time. This was due in part to an increase in immigrant students who had limited resources in their native countries and American-born children's access to cochlear implants early in life.

Classroom demographics: American-born versus immigrant status. The mentors who taught in self-contained deaf education classrooms where instruction was in ASL and English commented that their classrooms had changed in the last few years from mostly American-born children to a mix of American-born and Hispanic immigrant children and then to mostly Hispanic immigrant children. Lisa she said that she only had

Hispanic immigrant children at this time but didn't know why "they're all coming from other countries. So then they're delayed. And they put them in the deaf classrooms when they get to this country." Similarly, Robert stated that his ASL classes for parents were, "100% [Hispanic]. All of them are Spanish." This fact forced him to teach his class in Spanish to supplement the written English that accompanied all of his materials and texts.

Native country resources. For the children born in their native countries, many of the parents reported a lack of resources. For some parents, any services for deaf children had to be paid by the parents. Some schools had public services but oftentimes these were not available until the child was older or had no transportation for the children thus limiting their ability to participate. For these reasons, many children did not attend school in their native countries or had limited schooling during their early years, thus leading to decreased language skills overall. Yet another level of language consequences would be added for immigrant deaf children: the need to receive English as a Second Language and ASL learning services once they began schooling in the US.

Cochlear implant issues. Most of the children that were born in other countries were not considered cochlear implant candidates due to their age. I discussed the possibility with the mentors that those children who were implanted early on, typically before 2 or 3 years of age, they were often mainstreamed by the time they reached middle school. Lisa described the few children with cochlear implants who were in her classrooms. She commented that one had discontinued the use of implant while the other two had additional concerns that included learning and reading disabilities that precluded them from being mainstreamed. When this information was discussed with Maria, she

was asked what she thought the implications might be for those children and she replied, “LD, LD with cochlear implants. That’s what we’re going to end up with, and it’s sad, because it’s going to ruin the deaf culture.” She added that many children who received cochlear implants were getting them late and not getting enough language:

The cochlear implant should be a mix. I’m against it and I’m not against it, you know? I think cochlear implants can help, but I think that sign language needs to be included. You know, I want to see the next generation, like 10 years from now, and I would like to come back and hope that’s it’s nothing like this. If not, they’ll probably just end up being a custodian. I’m serious. Then people look at the Deaf community and they think, “Oh, poor things, they can’t make it.”

Consequences of Late Language Learning

Several consequences emerged for the children that were learning language at a later age. Many children had difficulty communicating, participated in conversations that had frequent communication breakdowns, and had behavioral issues.

Academic history. Many of the children in the study were currently or had already repeated one or more grades. For example, Lucas was repeating the 5th grade because his mother felt that “he came already grown to this country. And he had to, like, start over, to learn everything, English, everything. In a year and a half, he has had to adapt. It’s two languages, English and sign language.” Erica was also repeating the third grade, but Ms. Trujillo couldn’t explain why. She said, “Sometimes she’s ahead and other times she’s behind in a day.”

Some of the children did not receive formal schooling until the children were older. For example, Ms. Vergara explained:

I had the older one, and she came to this country three years ago. She’s been going to school three years. In those three years she’s learned a lot.

I'm very appreciative to the teachers of the school for what they've taught her, and thank God that she came out a good girl. The teacher told me that she began to learn as if she had been put in school as a young child, but she didn't go to school when she was little. She got here and started school at the age of 11, because in my country she never went to school. So then while she's been in school she has learned a lot. And what she does, she writes in English. In Spanish she barely knows anything. But now in English, yes, when you don't understand her, she writes to you in English and she tells you what it is that she's trying to say. And I am grateful for all the teachers of the schools that have taught her, and that she has learned so much.

Areas affected. The mothers discussed how their children's hearing loss affected their daily activities, their relationships with their friends, or their academics. The perspectives were varied. Many of the children had mostly deaf friends and many of the children were repeating grades or had repeated grades. For example, Ms. Mendoza did not feel that Erica's friendships were affected since most of her friends were deaf: "Well, I don't think it does [affect her] because there in school, she is normal. When she was with [her teacher], normal . . . And where she goes to school, there are only 5 students." In addition, she felt that Erica's daily activities were not affected:

No, nothing affects her. In no way, in nothing. She, you know, the bus, the television, her food. Her shoes, her clothes, she knows that in the morning she needs to put on her uniform, her socks and her shoes. And she'll tell me "ton tutios" [as in "son sucios"- "they're dirty"] and she'll go clean them.

Ms. Jimenez agreed that Lucas' daily activities and relationships were not affected by the hearing loss and said, "No, he's not affected by that. He, for everything, he does what he wants. He has never asked me why he was like that, why he talks with his hands. Never has he asked me that." However, Ms. Jimenez did feel that Lucas' academics were affected and said, "I think if he had all his hearing and all that, I think

that he would be able to advance more because, of course, it affects him.” Ms. Rodriguez also felt that Jose’s relationships were not affected: “Well, he has his hearing problem, but while he’s with other children it’s as if nothing, like if he were normal because he participates in everything, everything, as if he were a hearing child.”

In contrast, Ms. Lopez felt that Gilberto’s deafness created a disadvantage with his friendships, but not academically: “It affects him, imagine it, to play with the kids here, the kids don’t understand him. He goes out but the kids don’t understand him because all the kids here are hearing.” Ms. Gomez agreed and said, “Perhaps the only thing is that he’s not spending time with some hearing children. Because they don’t understand him or he doesn’t understand them, and then, that would be the only thing.” When Tomas was asked if he had any hearing friends he responded, “No, they don’t understand.”

Ms. Alvarez wasn’t sure what to expect from Luis and said, “But I don’t know if in the future he can go to the university and study a career, that he would reach the same milestones, with his language.” One mother, Ms. Trujillo, felt that the main relationship that was strained was the one between herself and her daughter. The mother wanted her communication to be better with Erica, and she was conflicted about her daughter’s lack of participation in group events. Ms. Trujillo could not understand why Erica would choose to not be involved.

Communication breakdown. Some of the children were not able to answer questions during interviewing. They had difficulty understanding the questions posed to them, often commented off-topic, and had difficulty formulating their thoughts. While

interviewing Erica, it was clear to me that the girl didn't understand the majority of my questions. She attempted to answer me but didn't know what to say many times.

Therefore, most of her responses were off-topic. I couldn't help but wonder if her lack conversational skills had to do with her lack of communication at home or because she started school in the US at the age of 8 with no real language from her native country.

Similarly, although Gilberto used ASL to communicate with his parents, he would ask his parents, "What is she saying?" when the interpreter or I would address him. It was unclear if he truly didn't understand what was being said or if perhaps he was not comfortable with new people's signing and automatically was asking his mother to translate for him.

Behavioral issues. Several of the mothers indicated that their children had frustration and behavioral issues related to not being understood. However, many mothers reported that the behavioral issues subsided once they were able to communicate. For example, Ms. Jimenez stated, "When he started school, he had many problems. He would say something and we didn't understand him and he would hit the walls and the refrigerator, because he was upset with his lack of communication."

Ms. Rodriguez was also concerned with Jose's initial behavior when she sent him to a deaf residential school: "Maybe part of the behavior was also because he's an adolescent, and he's sleeping over there alone. Well, not alone, he wasn't isolated, but not with his family." In addition, Ms. Obeso described how Jesus' behavior was before his diagnosis:

Yes, it was affecting him because no one understood him, no one understood him, and sometimes he was very aggressive. Because, at the

same time, no one could understand him, he was very aggressive, because no one could understand him.

Robert, the mentor, also felt that there were behavioral consequences with the deaf children, often due to their families' parenting styles:

They have behavior problems. They don't have established rules. They don't know how to . . . sometimes the parents don't know how to put their children in time out. So they are weak. Sometimes the parents don't even know what their children are saying, so that's their consequence. The parents get upset and the children do whatever they want to do. The consequence for the parents is that they'll get frustrated and they can't do anything. So it's very important, if they learn sign language, it's very important for the parents to have facial expression and everything. That's the consequence, they won't make it.

Mentors' perception of communication. All of the mentors felt that delayed access to a first language impeded the children's ability to succeed in school. For example, Robert described the communication skills of the students that he worked with:

Some are very late, they learn language very late. They don't come with enough education. If they're born and they're found out they're deaf at one, you've got to start sign, teach, and all of that. If you teach them at 8 or 9, it's going to hurt their child's future and education.

Accessing Resources

All of the deaf children in this study had hearing losses severe enough to require special education placement, amplification in the way of hearing aids, and the use of sign language to access communication. However, these resources were not always available or publicly funded in their native countries. In addition, few opportunities existed for people with disabilities in some of the native countries.

US/Native Country Issues

Many families discussed the advantages of the US versus their native countries for their deaf children and for children with disabilities in general. In most cases, their children were late-diagnosed and few public services were available to their children.

Native country opinion of deafness. The mothers' responses to how their native countries viewed deafness were varied. Several stated that their country had little resources and poor opinions of people with disabilities. Several other mothers claimed that deafness was neither viewed negatively or positively. Even for the mothers that described a tolerance to those with disabilities or an array of services available in their native countries stated that the opportunities available for the deaf were very limited in regard to academics and jobs to be had.

US opinion of deafness. Most of the mothers felt that the US had a better opinion of deafness in comparison to their native countries. They felt that disabilities in general were not as stigmatized and the resources available helped to improve the lives of the deaf in the US.

Native country resources. None of the Latin American countries had newborn hearing screenings and very few offered public services for children with hearing losses. However, several mothers explained that NSL classes for parents were mandatory at their children's schools. For example, the lack of newborn hearing screenings meant that Lucas was diagnosed only when Ms. Jimenez thought there was something wrong. Similarly, Ms. Trujillo explained the lack of resources in her native country:

Where I lived, it was very far. The situation that one has in [my native country] isn't enough for each time that you need to leave money. Because

it is understood that those that teach us, the therapies that they give us, one has to pay for them. Because in [my native country], its like that. You pay.

In some countries, the educational system for deaf children was not acceptable.

For example, Ms. Alvarez stated, “Over there in [my native country] there isn’t, how do I explain it, like there isn’t the good education for deaf kids like him.” In addition, some countries had no resources for young deaf children. Tomas’ native country did not provide him hearing aids until he reached school age, even though he had been diagnosed at 18 months. Maria, the mentor, explained the lack of a future for the deaf this way: “Once they finish school, they’re on their own. There’s nothing for the deaf child in South America.”

Only one Latin American country, Cuba, was reported to be as advanced as the US in certain areas. In some areas, they offered more assistance than the US and in other areas they offered less. For example, although they did not have a mandatory newborn hearing screening, children were diagnosed at a relatively early age and a hearing test appointment was given quickly and free of charge. In addition, hearing aids and batteries were given free of charge or at a very low cost.

US resources. In general, the mothers felt that the US had greater opportunities for deaf people and people with disabilities as a whole. They felt that in the US their children could attend school and perhaps have a career and care for themselves. Unfortunately, although the US was thought to have more resources available for deaf children and their families, many families made little use of them. As mentioned before, several families stated that they knew of free ASL classes but could not attend due to difficult work schedules, transportation issues, and far distances to reach the classes.

Robert, the mentor, discussed what he felt distinguished Hispanic families from American families: “I noticed that Americans have knowledge of everything. ‘I have to do this, I have do that,’ they take action.” Maria agreed with Robert and explained that Americans knew that they could research information on the internet and had more knowledge in general. Due to this she felt that American families took more initiative. In general, although the mothers reported limited resources in their native countries, it appeared that they had more access to the limited resources in their native countries than the greater resources available in the US.

Conclusion

The findings of this study present a picture of tremendous challenges for Hispanic mothers of deaf children. These challenges often result in limited family-child interaction, mothers’ internal struggle, and language confusion. The final chapter will discuss the implications of these challenges.

DISCUSSION

Twelve families and three mentors participated in this study of the communication of Hispanic mothers with their deaf children. Most of the families shared similar experiences and concerns. However, a few of the families were able to rise above the difficulties before them and learn how to communicate with their deaf children. For example, 9 of the 12 mothers worked outside the home and one was looking for work. However, some of the working mothers were able to find time in their schedules to learn to communicate with their children. The findings of this study assist in exemplifying many aspects of communication in Hispanic homes with deaf children, as well as offering an explanation of why this communication is often inadequate.

As described in the findings, the themes that developed through the data analysis process led to three theoretical statements that characterize the nature of communication in these families: *Limited Family-Child Interactions*- The initial difficulty experienced by families in learning to communicate well with their children led to limited family-child interactions, which has further implications for how these children relate to their families and participate in activities with them; *Mother's Internal Struggle*- The mothers' struggle to accept their children's deafness and understand the potential/ability that lies within their children suggests that mothers' are perpetuating the idea that their children's hearing impairments become both disabilities and handicaps; and *Language Confusion*- The mixture of languages in the home, combined with the age of language learning for the children and the language being taught in the schools creates a mismatch that can lead to language confusion in the child. This language confusion can result in lower language

skills and poor academic achievement. In this discussion, I will reflect on the implications of these three theoretical statements.

Implications of Limited Family-Child Interactions

Many of the mothers stated that they felt it was important for them to learn sign language, however, most did not learn more than a basic level and the resulting difficulty communicating with their children caused limited family-child interaction. This is reminiscent of Takala, Kuusela, and Takala's (2000) report of their longitudinal study wherein sign language intervention was given to deaf preschool children and their families. At the end of the five-year study, the children had improved their sign language skills, but their parents had not significantly improved. The same was observed with the families in this study. Most of the parents were learning ASL through their children, who continued to improve their skills.

While Lane's (1999) hypothesized scenario was based on common occurrences for deaf children born to hearing families, the experiences of the families in the present study echo his sentiments: limited communication based on concrete messages about present objects. In addition, Lane, Hoffmeister, and Bahan (1996) felt that even in the homes where home sign was more developed, there would still be "frustrated attempts to communicate even simple ideas" (p. 40). Many of the mothers in this study expressed their concern regarding being able to communicate with their children about abstract topics. While many of the mothers may have expressed their concern, few, if any, expressed what outcome they thought it would have. In contrast, the mentors expressed the opinion that this language barrier would likely cause a rift between the deaf child and his or her parents. Additionally, I was left wondering if it wasn't already too late because

several of the children were already in adolescence. If the parents hadn't already learned, when would the right time be? In addition, many of the families who did sign did not use it at the dinner table unless they were specifically communicating with their deaf child. By doing this, they were leaving their deaf child out of the family dinner conversations and limiting their ability to participate. This would be one reason why deaf children don't pick up incidental language, because it is inaccessible to them.

When asked what the children enjoyed doing in the home, many of the mothers replied that the children preferred to be alone playing video games or using a computer. It appeared that many of the mothers did not fully grasp the reasons why their deaf children preferred to be alone and did not want to participate when non-signing guests visited their homes. However, it was quite obvious to me that it was due to the children's feelings of unease caused by not being able to communicate with strangers that did not use their language. This point was exemplified in several ways. First, several mothers explained that their children preferred to spend time with other people who knew sign language, as well as how the children reacted to me when I visited their homes. Although I was also a stranger to them, those children that could communicate in ASL easily opened up and carried on long conversations with me about what games they enjoyed and so on. They also asked me to interpret for them at times to their mother about a specific topic they needed their mother to understand.

In addition to the complexities of communicating, it would be difficult for hearing mothers to teach their deaf children about their Hispanic culture without access to the appropriate vocabulary. These mothers also had limited knowledge of deafness as a culture, much less of the controversy around deafness as a culture. An example of the

controversy would be Davis, (1997) who rejected the idea that cultural membership could be based on physical characteristics such as deafness. He argued that culture cannot be transmitted on the basis of genes; it is an inherently social process. In contrast, Regan (1995) argued that deaf people do not constitute a disability group, but rather a linguistic minority.

Implications of Mothers' Internal Struggle

The mothers' internal struggle was closely related to the concept of "normalcy." Their descriptions of their children often included statements using the word "normal." The World Health Organization (WHO, 1980) made distinctions between the terms impairment, disability, and handicap. An impairment is defined as "any loss or abnormality of psychological, physiological or anatomical structure or function." A disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being." A handicap is defined as a "disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual" (p. 14). With these definitions in mind, it could be determined that an impairment would involve a loss or abnormality of an organ or a system's function, as in the case of the deaf. However, a disability would refer to abilities to function and the limitations inherent in an individual with an impairment that would affect the person as a whole. A handicap would relate to a person in a social context and their ability to adapt. Both disability and handicap would define many of the children in this study, but would not necessarily have to be the case. It would be possible for a deaf child to have a hearing impairment without it necessarily

resulting in the experience of a disability or a handicap. For example, in the Perez home, the fact that the family as a whole could use NSL with native-like fluency would suggest that the daughters were not disadvantaged in any way inside the home. Outside the home, however, there could be a difference depending on where the deaf child was and how well she could function within that environment.

A contrasting view would be the experiences felt by Mrs. Trujillo. She stated that she felt her daughter would be more normal if she could have better communication with her. She felt that better communication would make it easier for her and her mother to care for Erica, and because of their reduced communication, Erica often chose to withdraw socially. In addition, Mrs. Trujillo stated that if she had better communication with Erica, their relationship would be better and she would consider Erica to be “normal.” Therefore, Mrs. Trujillo felt that Erica had both a disability and a handicap, both caused by Erica’s inability to hear. However, Mrs. Trujillo conceded that if she herself learned sign language, it would be another way to reduce the negative impacts of Erica’s hearing loss, thus making her “normal” as well. Lane, Hoffmeister, and Bahan (1996) state that “the central issue in raising a Deaf child is language: the human capacity for language, and the roles of that language fulfills in a social existence” (p. 41). Thus, “because the parents are unable to communicate . . . coping mechanisms are blunted, causing both the family and the child to become handicapped” (p. 40). This reminds us of Becker’s words (1963) that society creates the rules by which to measure deviancy. This deviancy, in turn, would lead to stigmatization. This stigmatization in society would likely play a role in mother’s struggle to accept their children’s deafness. Similarly, Quittner (1990) stated that these difficulties could lead to more limited support networks,

feelings of isolation, and stigmatization which could result in depression, anxiety and anger for hearing parents. In addition, Lane (1999) felt that deaf children had difficulty fitting in the hearing or Deaf worlds, supporting the mentors' descriptions of child identity struggles.

Harry's 1992 study reminds us that for the Puerto Rican families that she worked with, the definition of "normal" included children that could speak and function in society. The majority of the children in this study could not speak or could not speak very intelligibly. In addition, the limited resources in their native countries made it more difficult for the deaf to complete schooling and find a suitable occupation. Therefore, their children could not be "normal" according to the parents' definitions. This idea helps to perpetuate the difficulty of accepting their child's diagnosis, thus perpetuating the possibility of diagnosis denial.

We saw that Skinner, Correa, Skinner, and Bailey (1999) found that the majority of the Hispanic families who were in their study felt that their children's disabilities were a sign from God. For a few of the mothers in this study, it was a blessing, while several others could not understand what had happened to make them deserve a deaf child. This idea could also perpetuate the mothers' feelings that their children's deafness were handicaps and not simply differences in language.

Implications for Language Confusion

Akamatsu and Cole (2004) discussed how ASL was important for the immigrant deaf child to learn but explained that the child would be unlikely to learn it with native-like fluency if it were learned after the critical language period. Unfortunately, most of the children in this study learned ASL after the critical language period and very few

learned NSL during that time. For those children that had learned NSL along with their parents, the fact that they were now living in the US with no language support meant that NSL had faded out of the children's repertoire while ASL increased, even while the parents still held onto NSL like a life line. The reality was that many of these children faced a home of mixed languages. For example, one child might lipread his or her father's oral Spanish, then watch his or her mother use ASL signs while speaking in Spanish, thus altering the ASL into Spanish grammatical order. This same child could then have a sibling who used ASL signs while speaking in English, thus altering the ASL in English grammatical order, and all while learning to read in English and use ASL at school. This lack of consistency in language use could easily lead to language confusion and reduced language skill, as was often seen in the children in this study.

Recommendations for Practice

This study helps to point out many of the concerns and issues that need to be targeted in order to improve the communication in the homes of Hispanic families with deaf children. Although the overall picture is poor, addressing the areas of concern can likely improve the outcomes for these children and their families.

Several suggestions for improving the communication between deaf children and their families were presented by the mentors. Robert proposed a workshop for parents to discuss emotional issues, problems at home, and how to improve communication. He felt that sign language training was vital, particularly by having deaf specialists visiting the homes and using books and video tapes. He stated that he knew that transportation was often a problem, so access to a van would be helpful. Maria also felt that a mentor in the homes would be beneficial. She felt that visits twice a week would be ideal, suggesting

that more visitations per week would interfere with a family's daily routine, but added that it was likely that a family's highest involvement with their deaf child might likely be during those mentor visitations.

From first-hand experience identifying the difficulties faced by Hispanic parents, I feel that the following suggestions merit application:

- Parent workshops to highlight general communication tips that include having the child participate in language, involving the whole family, assuring that children don't miss what is happening in their surroundings, and including children in all family activities and conversations.
- Family get-togethers with other families from all areas of the city that would include support group meetings for parents in Spanish, child care for younger siblings, and joint activities for deaf and hearing siblings. The meetings could include people from the community, both American and Hispanic, so that families could see first-hand how deaf adults participate in the community, as well as offer other adults with whom the parents could practice their signs language skills.
- ASL and deaf culture taught in Spanish in the home that would include all members of the household, including parents, siblings, and extended family members and caregivers.
- In addition to the home learning, several class meetings could take place with other families in the same area every few weeks in order to promote social contacts and networks. There could be transportation provided for those in need or there could be incentives for families that have transportation to car pool with those that don't.

- Game playing activities to promote sign language learning and practice, as seen with Ms. Osorio and Lourdes. This type of natural language use could be very powerful, as well as facilitating family-child interactions.

Future Investigations

After completion of this study, several new questions were raised. Future studies should investigate:

- siblings' experiences with deaf brothers or sisters
- experiences of middle/high school deaf students and young adults
- the comparison of experiences of Hispanic families with American families with deaf children
- A longitudinal study measuring language skills of deaf children for identification of language dominance and to determine differences in language performance by age of diagnosis, age of language learning, mode of language used, parental language skills, and parents' education levels.

Methodological Dilemmas

Throughout the data collection and analysis process, every effort was made to ensure that the guidelines and requirements of the Institutional Review Board were met. This was completed through the use of triangulation, peer debriefing, member checks, thick description, and by maintaining an audit trail. However, regardless of these measures taken, a few methodological dilemmas were still evident.

Prolonged Engagement and Persistent Observation. The investment of time needed to gain the most insight into the Hispanic mothers being studied required additional visits to the homes and multiple observation and interviews. Each family

completed one interview and at least one mother interview. Due to the limited amount of time available for the completion of this study, true prolonged engagement and persistent observation were not achieved. Nevertheless, the interview process did achieve considerable saturation of data in that the central themes showed up again and again.

The Role of the Researcher and My Self-awareness. My ability to remain neutral during the interviews was another dilemma that confronted me on a daily basis. My role in the research was as an observer intent on learning about how Hispanic mothers communicated with their deaf children, not one of evaluator, teacher, or judge. I attempted to remain neutral during interviews when I disagreed with answers to questions and kept my personal comments in the “observer comments” of my documents. Due to the personal nature of interviewing and observing in a home, my complete neutrality could not be ensured. For example, on several occasions I was asked to interpret what a child had signed to a mother when the mother did not understand, I was asked how to sign new vocabulary that a mother wanted to use, and I signed instructions to the child from the mother when they requested it. I felt unable to deny these requests as it was obvious in many homes that my intercession often represented times the closest communication the mother and child had. However, when mothers asked me my opinion in certain matters pertaining to their children or to give them feedback, I reminded them of my role in the research and was unable to comment as I would have if they were patients in my clinical practice.

Conclusion

While this limited study has not attempted nor attained all the levels of triangulation hoped for in the ideal qualitative study, I believe that the use of both

interviews and observations, as well as multiple levels of analysis support the emergence of three theoretical statements that can contribute to the field's understanding of the communication challenges faced by Hispanic mothers of deaf children.

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Appendix A - Family Demographics

Countries represented: Colombia, Cuba, El Salvador, Guatemala, Nicaragua, Puerto Rico, Santo Domingo, and Uruguay.								
Mother	Level of education	Child name/ age	Length of time in US	Country of diagnosis	Age Diagnosed/ hearing aids	Cause of Deafness	Mother 's languages	Child's languages
Ms. Mendoza (grandmother)	6 th grade	Erica/11	4 years	Native country	2 years/5 years	Unknown	Oral Spanish	ASL/some short oral Spanish phrases
Ms. Trujillo (mother)	10 th grade		3 years				3 years	
Ms. Jimenez	10 th grade	Lucas/11	4 years	Native country	3 years/3 years	Unknown	Spanish/ASL with English/ Eng + Span/sibling int	ASL
Ms. Lopez	University degree	Gilberto/9	5 years	Native country	1 year/	Blood infection	Mixes ASL, oral English and oral Spanish	ASL
Ms. Alvarez	University degree	Luis/8	5 months	Native country	4 years	Unknown	Oral Spanish/ some ASL signs	Gestures/ signs in ASL/vocaliz
Ms. Rodriguez	1 ½ years university	Jose/11	11 years	US	3 years/3 years	Unknown	ASL with oral English	ASL with oral English
Ms. Gomez	University degree	Tomas/9	3 ½ years	Native country	18 months/3 years	Premature birth	Oral Spanish with ASL	ASL
Ms. Vergara	3 rd grade	Gustavo/12	14 years	US	3 years/4 years	Unknown, likely genetic	Oral Spanish and home signs	ASL
Ms. Saez	6 th grade	Victor/13	15 years	US	5 years/5 years	Unknown	Oral English and ASL	Oral English and ASL
Ms. Perez	Technical college	Christina/7	2 months	Native country	8 months/2 ½ years	Genetic	NSL	NSL
Ms. Osorio	Technical college	Lourdes/12	1 year	Native country	2 months/2 years	Maternal rubella	NSL	ASL
Ms. Obeso	University degree	Jesus/5	7 years	US	5 years/5 years	Unknown	Mix of Spanish, English, and ASL	Oral Spanish/A SL and English

Appendix B – Guiding Questions with Mothers

1. Tell me about your child.
 - a. What sorts of things does your child like to do?
 - b. What languages does your child communicate in?
2. How would you describe your child's hearing loss?
 - a. When was your child diagnosed?
 - b. What did the professionals tell you about the diagnosis?
 - c. Do you know what caused your child's deafness?
3. How do you feel about your child's deafness?
 - a. How have you adapted to it?
 - b. How does your child's hearing loss affect their:
 - i. Daily tasks?
 - ii. Academics?
 - iii. Peer relations?
 - c. How is your child participate in:
 - i. Home activities
 - ii. Family activities
 - iii. School activities
 - iv. Neighborhood activities
 - d. Do you see your child's deafness as a disability?
4. How do you and your child communicate?
 - a. What languages does your child use with you?
 - b. How has your child learned these languages?
 - c. What languages do you speak?
 - d. What methods of communication do you use with your child?
 - e. Do you want your child to communicate in Spanish?
5. How do you feel about your communication with your child?
 - a. How do you tell your child things?
6. Describe for me a typical afternoon when your child comes home from school.
 - a. Who does your child talk to?
 - b. How does your child spend the afternoon?
7. Describe for me a typical dinner time.
 - a. Who is at the dinner table?
 - b. With whom does your child communicate?
8. What is your opinion of ASL?
 - a. How is it viewed in your community/friends? Do you think that these views are related to Hispanic culture generally?
9. How have you learned ASL?
 - a. In what circumstances?
 - b. When did you decide you needed to learn ASL?
 - c. When did you begin to learn ASL?
10. When you are signing, what language are you thinking in?
11. How has your ability to sign changed since you began to learn it?
 - a. How has your comfort level in signing changed?

12. How do you participate in your child's IEP meetings?
 - a. In what language are the meetings conducted?
 - b. Does your child attend these meetings?
 - c. Who in your family is at these meetings?
13. Are you familiar with the term "Hispanic culture"?
 - a. How do you describe Hispanic culture?
 - b. What does the term culture mean to you?
14. Are you familiar with the term "Deaf culture"?
 - a. Some people say that Deaf people share a common way of being or a culture, just as, say there is a Hispanic culture. What do you think about that?
 - b. Hispanics have their own culture and much of the distinguishing factors of it are in the language that is used. The same can be said for the Deaf culture.
 - c. What are the similarities and differences of Hispanic and Deaf culture?
 - d. Do you participate in Deaf cultural events? Can you give me some examples?

Appendix C – Guiding Questions with Children

1. What languages do you use?
2. How did you learn these languages?
3. How do you and your mother communicate? Your father?
4. How do you and your siblings communicate?
5. How do you and your friends communicate?
6. How do you tell your parents what you need/want?
7. What do you do when you don't understand them?
8. What do you do when they don't understand you?
9. Do you have any deaf friends? Do they use sign language?
10. Have you played with kids who use sign language?
11. Have you ever gone to parties/activities that are only for deaf kids that sign?

Appendix D – Guiding Questions with Mentors

How long have you been working with hearing families with deaf children?

What types of communication have you seen within the families?

The main aspects of usage I've noted so far are using native sign language, using American Sign Language, using a home sign language system, using oral language with lipreading, and using family members as interpreters. How does your observation of communication usage differ from what I've seen?

How do families that communicate well go about the issue of communication?

What do families talk about with their deaf children?

How do families talk about concrete versus abstract topics?

How do families talk about deeper, more sensitive issues (e.g., sexuality, religion ...) with their children? Examples?

For families that are having more difficulty communicating with their children, what are the main barriers to better communication?

What is the difference in communication skills between American families and Hispanic families?

Can Hispanic families learn ASL without learning English? How?

How can Hispanic families improve their communication?

What are the consequences of the current communication abilities of Hispanic families with their deaf children? Compared to American families?

Appendix E – Demographic Information

Where are you from?
Where is your husband from?
Where was your child born?
How long have you been in this country?
What schooling have you completed?
Are you employed outside of the home?
What work does your husband do?
Who are your family members?
Who lives in your home?
Who are the primary caregivers in your household?
What is your child's age?
What is your child's grade level?
What school does your child attend?
What languages do they use at school?

Appendix F – Data Analysis Map

THEORY/ IMPLICATIONS	<p style="text-align: center;">LIMITED FAMILY-CHILD INTERACTIONS: The initial difficulty experienced by families in learning to communicate well with their children leads to limited family-child interactions, which has further implications for how these children relate to their families and participate in activities with them.</p>				<p style="text-align: center;">MOTHER’S INTERNAL STRUGGLE: The mothers’ struggle to accept their children’s deafness and understand their potential/ability suggests that mothers are perpetuating the idea that their children’s impairments become both disabilities and handicaps.</p>			<p style="text-align: center;">LANGUAGE CONFUSION: The mixture of language used in the home combined with the children’s age of language learning and the language being taught in the schools creates a mismatch that may lead to language confusion in the child. This could result in lower language skills and poor academic achievement.</p>			
THEMATIC ANALYSIS: (selective coding)	Facing Deafness			Communicating in the Family	Learning Language	Understanding the Diagnosis			Learning at School		Accessing Resources
CONCEPTUAL CATEGORIES: (axial coding)	Diagnosis Issues	Deaf Cultural issues	Sibling Consequences	Language Usage	Language Learning Issues	Concerns	Misperceptions/ Misinformation	Mother Interpretations	Changing Classroom Demographics	Consequences of Late Language Learning	US/NC Issues
OPEN CODING: (based on initial interviews)	-diagnosis history -diagnosis denial -adaptation -cochlear implant issues	-perception of handicap -Deaf cultural know-ledge and Participation -deaf bond	-sibling interpreter -sibling delay	-communication breakdown -perception of communication -conversational topics -communication strategies	-language importance -language variety - language learning -language learning facilitators/ barriers	-childcare -potential/ability -living situation -immigration status -abuse -danger -hearing aid usage -sibling delay -behavioral issues -money concerns -consequences of work -distance -future communication -transportation	-professional diagnoses -deafness	-perception of handicap -religious references -mother expectations -“normal”	-classroom demographics -native country resources -cochlear implant issues	-academic history -areas affected -communication breakdown -behavioral issues -mentor perception of communication	-native country opinion of deafness -US opinion of deafness -native country resources -US resources