ABSTRACT

LATINO FAMILIES IN TRANSITION: PHENOMENOLOGICAL STUDY OF
LATINO PARENTS OF CHILDREN WITH COMMUNICATIVE DISORDERS
AND THE QUEST FOR SERVICES ACROSS BORDERS

By

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The purpose of this qualitative, phenomenological study was to identify and understand the cultural and linguistic barriers encountered by Latino parents of children with communicative disorders. A second purpose was to identify the common themes that arise across Latino families regarding their transition to life in the United States and the quest for available and affordable services for their children. The general principles of phenomenological in-depth qualitative interviewing will be described. Linguistic themes regarding the parents' perceptions of their own linguistic abilities and the abilities of their children were identified. Cultural themes were also identified and included differences in lifestyle, knowledge and cultural views of disability, as well as educational roles and responsibilities. Information is provided regarding the role of speech-language pathologists, especially those who are Spanish-speaking. Finally, the importance of the development of cultural competence for all speech-language pathologists is discussed.

LATINO FAMILIES IN TRANSITION: PHENOMENOLOGICAL STUDY OF LATINO PARENTS OF CHILDREN WITH COMMUNICATIVE DISORDERS AND THE QUEST FOR SERVICES ACROSS BORDERS

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TABLE OF CONTENTS

	Page
ACKNOWLEDGEMENTS	iii
LIST OF TABLES	vi
CHAPTER	
1. INTRODUCTION.	1
Statement of Problem	1
Purpose of the Study	
2. LITERATURE REVIEW	4
Qualitative Rigor	4
Foundation of Qualitative Research	6
Interviewing	6
Phenomenological Qualitative Interviewing	
Qualitative Research Studies	
Attitudes, Beliefs, and Perceptions	
Experiences with Special Education Services	
Emotional Well-Being and Support Systems	22
Summary	24
3. RESEARCH METHODOLOGY	26
Study Design	26
Participants	
Procedures	
Data Collection and Analysis	
4. RESULTS	. 33
Linguistic Themes	33
Parents' Perceptions of Their Own Linguistic Abilities	
Parents' Perceptions of Their Children's Linguistic Abilities	
Cultural Themes	
Differences in Lifestyle	37

CHAPTER	Page
Knowledge and Cultural Views of Disabilities	40 42
Family Experiences	44
Maldonado Family	45
Martinez Family	46
5. DISCUSSION	48
Linguistic Clinical Implications	48
Parents' Perceptions of Their Own Linguistic Abilities	48
Parents' Perceptions of Their Children's Linguistic Abilities	50
Cultural Clinical Implications	51
Differences in Lifestyle	51
Knowledge and Cultural Views of Disabilities	52 54
Educational Roles and Responsibilities	55 55
Future Research	57
6. CONCLUSION	59
APPENDICES	60
A. IRB APPROVAL LETTER	61
B. CONSENT FORM FOR NON-MEDICAL RESEARCH	63
C. CONSENT FORM FOR NON-MEDICAL RESEARCH (SPANISH)	69
D. PARENT INTERVIEW GUIDE	75
E. PARENT INTERVIEW GUIDE (SPANISH)	78
F. RECRUITMENT FLYER	81
G. RECRUITMENT FLYER (SPANISH)	83
REFERENCES	85

LIST OF TABLES

TABLE	Page
1. Description of Participants	28
2. Description of Children	28

CHAPTER 1

INTRODUCTION

Statement of Problem

Latinos are the largest and fastest growing minority group in the United States and more than half of the total population growth in the United States between 2000 and 2010 was due to the increase in the Latino population (U.S. Census Bureau, 2010). Despite their large presence in the United States, limited research exists on Latino immigrants (Morales, Flores, Ojeda, & Meza, 2011). According to the American Speech-Language-Hearing Association (ASHA) Code of Ethics:

Speech-language pathologists (SLPs) are obligated to provide culturally and linguistic appropriate services to their clients and patients, regardless of the clinician's personal culture, practice setting, or caseload demographics. In providing services to bilingual individuals, SLPs consider how communication disorders or differences might be manifested, identified, or described in the client's/patient's cultural and linguistic community and integrate this knowledge into all areas of practice, including assessment, diagnosis, treatment, and treatment discharge. (2010, para. 4)

Although it is clear that SLPs have an ethical responsibility to understand how various cultural communities describe communicative disorders, the body of research on Latino children identified with special needs and their families is sparse when compared to the number of Latino children identified with disabilities (Hughes, Valle-Riestra, &

Arguelles, 2008). What is known is that Latino newcomers often experience challenges with language barriers, minimal family and social support, and work-related stress (Hovey, 2001). These hardships are exacerbated by the inclusion of a child with communicative disorders within the immigrant family. Parents who are monolingual Spanish speakers or marginally bilingual and unacculturated into the educational and governmental possibilities for service provision are potentially faced with nearly insurmountable barriers.

One way of becoming more knowledgeable of an individual's cultural and linguistic views and beliefs, is through understanding their lived experience and the meaning they make of that experience (Van Manen, 1990), which can be accomplished through conducting in-depth phenomenological interviews. Although some phenomenological studies have been conducted within the field of speech-language pathology, various types of questions are yet to be explored using such qualitative research methods (Dilollo & Wolter, 2004). As such, a need exists for collection of data from Spanish-speaking and bilingual immigrant parents to investigate the influence of the culture, language, and parenting styles in the interactions and management of their children with speech and language disorders.

Purpose of the Study

The purpose of the current study was to identify and understand the cultural and linguistic barriers encountered by Latino parents of children with communicative disorders by identifying the common themes that arise regarding their transition to the Unites States and the quest for affordable services for their children. A second purpose was to describe the general principles of phenomenological qualitative research and

discusses the clinical implications of the findings. Additionally, this thesis will explain how speech-language pathologists, especially those who are Spanish-speaking, can be at the forefront of service provision for Latino families. Further, it will explain how all speech-language pathologists can expand their cultural competence and facilitate services through enhanced knowledge of Latino culture.

CHAPTER 2

LITERATURE REVIEW

Qualitative Rigor

Qualitative rigor refers to the ways in which a researcher can establish trust or confidence in the results or findings of a research study (Thomas & Magilvy, 2011). Rigor, in the context of qualitative research, provides consistency over time and allows for replication of a study. Due to the open-ended nature of qualitative research, qualitative rigor is amongst the most critical aspects that must be considered. Rigor was first addressed by Lincoln and Guba (1985) within their model of trustworthiness relative to qualitative research. In order to understand qualitative rigor, one must first be apprised of the differences between qualitative and quantitative research. As discussed by Thomas and Magilvy (2011), the focus of quantitative research is on breadth since it is comprised of gathering an array of information in order to gain knowledge, which can often be generalized to a larger number of participants. On the other hand, qualitative research focuses on the depth, as it identifies a phenomenon by gaining deep understanding of that phenomenon or experience with a limited number of participants. Thomas and Magilvy further explain that rather than focusing on generalization to other subjects, the purpose of qualitative research is to gain a deeper insight into the experience or phenomenon in a way that will allow for building of knowledge. Also, qualitative research aids in the development of practices that are client-centered and sensitive to the participants involved in the research. This is not to say that quantitative research is not

valuable, as it provides important information, but qualitative research gives an opportunity to obtain a richer understanding of topics within specific contexts that can otherwise be missed in quantitative research.

The four components of trustworthiness as discussed by Lincoln and Guba (1985) included truth-value, applicability, consistency, and neutrality. More recently these four elements have been referred to as credibility, transferability, dependability, and confirmability (Thomas & Magilvy, 2011). Credibility is similar to internal validity in quantitative research, as it allows others to acknowledge the experiences discussed within a study through the interpretation of the participants' accounts of these experiences. Reviewing individual transcripts and identifying similarities within and across research participants can establish credibility. Transferability is similar to external validity, in that it refers to how the findings of a research study are applicable to another group or in other contexts. Providing a detailed description of the participant demographics, recruitment procedures, and study methods can establish transferability. Dependability correlates with reliability and relates to the extent to which the decision making of the research study can be followed by other researchers. The dependability of a qualitative study can be established by providing thorough descriptions of the purpose of a study, reasons for selecting participants, data collection and analysis, methods of interpreting and presenting results, and clearly explaining the techniques implemented to create credibility of the study. Lastly, confirmability, like objectivity, is established when a study has good credibility, transferability, and dependability. The four aforementioned components of qualitative rigor were considered and incorporated during the design of the current study.

Foundation of Qualitative Research

As discussed by Bogdan and Biklen (2007), anthropologists and sociologists have been using qualitative methods for more than a century; however, the term "qualitative research" was not coined and introduced within the social sciences until the 1960s by Glaser and Strauss (1967). Qualitative research is an umbrella term used to describe research strategies with common characteristics. Data collection in qualitative research has been referred to as "soft" in the past because it is rich in its description of people, but not easy to analyze using statistical procedures. The focus of this research is not on answering specific questions or to test hypotheses, but rather on understanding behavior from the standpoint of the participants. Similarly, ethnography, which is a general term that is sometimes used synonymously with qualitative research, concentrates on describing and understanding culture. The two best-known qualitative research approaches are participant observation and in-depth interviewing. Keeping in mind the focus of this type of research, the researchers in this field of study often take an openended approach and spend considerable amounts of time with participants. Thus, researchers are able to glean valuable insights, not otherwise found in quantitative studies.

Interviewing

Insight into the experiences of an individual can be approached through various means, which can include reviewing documents, studying history, observing people in their natural environments, conducting surveys, gathering information through questionnaires, or reviewing literature. However, when a researcher is interested in understanding the meaning people make of their experience, interviewing is the method

that provides optimal opportunity to do so (Seidman, 2013). According to Morgan (1988), an interview is a purposeful conversation that typically involves two people and is often directed by one of the individuals in order to gather information from the other. Van Manen (2014) stated that the purpose of interviewing is to provide an avenue for gathering narrative material in a way that allows for a rich exploration and understanding of human phenomenon. Thus, the interview process can be used as a means of developing a relationship with the participants that allows them to converse about the meaning of those experiences. Relative to the validity of interviewing Latinos, Marin and Marin (1989) specified that interviewing Latino participants on topics that are highly sensitive is appropriate with both males and females across levels of acculturation.

Phenomenological Qualitative Interviewing

Phenomenological in-depth interviewing is a qualitative research method used to describe the naturally occurring meanings of the lived experiences of individuals in particular situations or phenomena, including their nature and meanings (Finlay, 2009). The aim is to find common themes that include all or most of the descriptions of the phenomenon (Bogdan & Biklen, 2007; Seidman, 2013; Van Manen, 2014). This qualitative research method allows for an understanding of how the participants assigned meaning to their own experiences (Seidman, 2013). Husserl first originated the phenomenological movement as a radical new way of carrying out philosophy (Kafle, 2011). In this approach, researchers use primarily open-ended questions, active listening, building on what the participants share to direct the interview forward. As described by Finlay (2009), the focus is on consciousness of phenomena in a way that elaborates on the hermeneutic, or interpretive, aspects. According to Seidman (2013), the

recommended model for phenomenological interviewing involves conducting a series of three separate in-depth interviews with each participant including (1) Focused Life History, (2) The Details of Experience, and (3) Reflection on Meaning.

The first interview, referred to as the Focused Life History, is dedicated to establishing a context for the participants' experience by having them talk as much as possible about themselves in regard to the topic of interest up to the present time. The participants are asked to reconstruct early experiences in their lives that are directly related to the given topic. The focus is on having the participants narrate a range of events in their past that brought them to their current experience. In regard to the current study, this interview was concentrated on the participants' lives growing up in Mexico, their decision to immigrate to the United States and the events leading up to having a child diagnosed with a disability. An additional interview was incorporated in order to gather information regarding the participants' cultural beliefs and practices.

The Details of Experience is the second interview and is intended to provide insight into the concrete details of the experience. Again, the participants are asked to reconstruct these details through narratives. In order to place their experiences into context, the interviewers are interested in relationships with others in regard to the specific topic. Additionally, this interview would allow the participants to reveal, in a narrative, what a typical day is for them. For this study, this information was gathered across two interviews, as the researchers were interested in gathering information about both the current experience of the mother participants and the current experiences of their children.

Lastly, the Reflection on Meaning interview allows the participants to reflect on what their experiences mean to them. This interview gives the participant an opportunity to address the emotional and intellectual connections between themselves and their experiences and allows them to make sense of it all. The previously mentioned interviews require the participants to look at their past and present experiences in detail and lead them to establish an understanding, allowing them to reflect. Within all interviews, the goal is for participants to make sense of what they have experienced; however, this final interview is specifically designed to bring meaning to their attention.

Qualitative Research Studies

Many of the research studies described in this literature review were of interest as they involved Latino participants. Others were considered applicable because they employed qualitative research methods and explored topics that were relevant to the current study.

Attitudes, Beliefs, and Perceptions

Per Westby (2007), development of cultural intelligence is essential when working with families from culturally and linguistically diverse backgrounds.

Professionals who work with diverse populations can begin expanding their cultural competence by becoming knowledgeable about the beliefs, customs, and taboos of various cultures (Earley & Masakowski, 2004). By being well informed about the views and perceptions of a culture, professionals can avoid the use of behaviors, interactions, and language that may be perceived as inappropriate.

In order to better understand the attitudes of Latinos toward disabilities, Salas-Provance, Erickson, and Reed (2002) explored the views of 40 members of one Latino family through one-on-one interviews. The participants included four generations the family who ranged in age between 21 and 96 years. The interviews took place in the homes of the participants and were conducted in either Spanish or English by a bilingual professional who was also a member of the family. The interviews followed a protocol that was developed based on the literature. The protocol included six open-ended questions relative to the causes and treatment of disabilities in general, as well as disabilities related to speech, language, and hearing. Additionally, four close-ended questions regarding the causes of disabilities and treatments were also included, which explored folk and medical beliefs. The data from the close-ended questions were statistically analyzed using chi-square tests at an alpha level of .05.

The results indicated that the two most common beliefs for cause of disabilities were medical and included use of drugs by the mother during pregnancy (97.5%) and lack of oxygen at birth (95%). Other than those two causes, the remaining 18 of the proposed causes were folk beliefs and ranged from the result of an earthquake (75%), mother being punished (25%), to the mother making fun of an individual with a disability (7.5%). In terms of treatment for disability, the most common folk belief response was praying to a specific saint for favors (65%). The top five most common treatments for hearing or ear problems were medical and all of the participants shared that they would see a professional (100%). Similarly, all but one participant indicated that they would see an SLP for help with stuttering. In terms of the open-ended questions, the participants reported being aware of a wide range of disabilities including those that are physical, cognitive, and communicative in nature; however, physical disabilities were most frequently mentioned. The beliefs regarding the causes and treatments of disabilities

during the open-ended portion of the interview included both medical and folk beliefs, but were overall more medical in nature. For the questions relative to the cause and treatment of speech difficulties, the participants mentioned a variety of medical (e.g., stroke or paralysis) and folk beliefs (e.g., not properly taught or unfortunate family situation). For how to treat speech difficulties, a variety of medical beliefs were reported such as seeing a professional. Three folk beliefs were also mentioned, such as saying prayers or seeing a healer.

In general, the findings of this study support the idea that culture plays a role in peoples' beliefs related to health and disabilities. The results of the study both reject and support the common stereotypical views of Latino population regarding their beliefs on health and disability. As such, one should cautiously evaluate common stereotypes to avoid making incorrect assumptions about cultural groups. As professionals, it is important to foster relationships with the families we serve; thus, not respecting their beliefs and views can potentially interfere with clinical relationships. The authors suggest expanding cultural competence and developing appropriate assessment and treatment practices through increasing cultural awareness and knowledge, enhancing cultural skills, and engaging in cross-cultural encounters.

Kummerer, Lopez-Reyna, and Hughes (2007) conducted a qualitative study that investigated Mexican immigrant mothers' beliefs and perceptions regarding their children's communicative disorder, literacy development, and speech-language intervention programs. Fourteen (14) Mexican immigrant mothers were interviewed following a semi-structured interview guide that provided a list of main questions and supplemental follow-up questions. The mothers were interviewed for the first time when

their child began receiving services at an early intervention program, where the study was conducted, and again every 5 to 8 weeks until a year of data collection was completed. Each mother was interviewed an average of four times and interviews were between 20 and 45 minutes in length. Analysis of the data followed the constant comparative method, which generated a grounded theory (Glaser & Strauss, 1967). This involved examining patterns across time, labeling themes, and comparing interview data across mothers.

The results of this study were organized into topics based on the interview guide and the themes that emerged within those topics. The four themes that emerged from analyzing the data included children's receptive and expressive abilities, speech-language delays, emergent literacy abilities, and language intervention with Mexican families. In terms of receptive and expressive language, the majority of mothers perceived that their children presented with a delay in communication, but felt as though their children's comprehension was fine. Relative to speech-language delays, one of the mothers expressed an awareness that her child had both a "delay" and a "disorder," while the other mothers only reported being aware of their children's "delay" in communication. As a whole, the mothers were found to be more concerned with their children's speech intelligibility and expressive language than literacy abilities. When asked about the cause of the delay, responses were diverse and generally medical in nature or thought to be a result of familial factors. Relative to language intervention with Mexican families, mothers recommended that professionals speak to them in Spanish or to provide an interpreter. Additionally, the parents related that they wanted professionals to provide them with information regarding the process of therapy and include the mothers in the

therapy routines, which demonstrated the notion that Mexican immigrant mothers feel a sense of respect for professionals and identify them as more knowledgeable of the process of intervention. Lastly, the mothers expressed that professionals should use strategies that are similar to those used when working with European American families. The authors suggested that future research should focus on continued exploration of parental perceptions and how professionals can adapt and create intervention programs that meet the needs of families from various diverse backgrounds.

More recently, Yu (2013) was interested in exploring immigrant mothers' perspectives on language choice and maintenance because of the common misconceptions on bilingualism. In previous studies conducted with minority-language speaking families, parents had reported a sense of fear that their children would become confused or that speaking to them in the heritage language would exacerbate their language impairments. As described by the author, many of the families who had this fear had previously been advised by a professional to stop speaking their native language with their children. This is unfortunate as it is contradictory to the positions set forth by ASHA, which encourage supporting families' cultural and linguistic preferences. As such, Yu investigated the language practices of bilingual immigrant mothers with their children with autism spectrum disorders through in-depth phenomenological interviews. The study participants included 10 Chinese/English speaking mothers who had immigrated to the United States from Mainland China, Taiwan, and Hong Kong. Each participant attended three 60- to 90-minute interviews. An interview guide was developed and implemented during the interviews in order to provide open-ended preliminary questions. The researchers used both thematic and narrative methods of

analyses. This involved inductively analyzing the data for the purpose of identifying themes and allowing the study to remain exploratory in nature.

Four major themes were identified including language priorities, English as the language of intervention, beliefs about the effects of bilingualism on development and learning, and practical constraints for language use encountered by the mothers. Relative to language priorities, all of the mothers shared that they were willing to help their children learn whatever language(s) would help them meet social demands. All but one mother stated that English was the most important language for their children to learn, as this is the language of the community and school. Within the second theme, the mothers' responses demonstrated an emphasis on wellness as the overall goal for their children rather than the acquisition of a particular language. However, the mothers stated that English was the language they felt would contribute most to their children's success in school and life. Ultimately, all that mattered to the mothers was that their children lived a good life, which was defined by the mothers as "being independent," "being happy," and "being healthy." Their beliefs on the effects of bilingualism on development and learning revealed that the mothers had some level of reservation speaking to their children in Chinese and felt as though a monolingual environment would be better. They shared that these beliefs had been shaped by the recommendations they had received from professionals. Lastly, within the theme of practical constraints, the mothers expressed that their level of comfort speaking English was dependent on who they were talking with, what they were talking about, and which settings they were in. Despite the mothers' strong proficiency and education in English, they described that their English

was much more constrained in comparison to Chinese. Moreover, the parents indicated that their ability to speak English varied depending on the context.

Overall, the findings suggest that these mothers would benefit from supports that encourage maintenance of the heritage language, as well as assurance from professionals that bilingualism does not harm children's development. Furthermore, the findings are indicative of the serious need for professionals to become apprised of and better educated about the issues related to bilingualism, second-language learning, and heritage language maintenance. It is important that professionals provide culturally and linguistically diverse families with the most accurate and research-based information on bilingualism. This will allow the parents to engage with their children in the language practices that align best with their preferences and natural communication patterns, which they may be able to carry out with more ease.

Experiences with Special Education Services

Hwa-Froelich and Westby (2003) conducted interviews with Southeast Asian families and the staff at a Head Start program to understand their experiences and views on early childhood education. The study participants included nine Southeast Asian families and four Head Start staff members. Observations of the parents during conferences, as well as teacher-child and parent-child interactions were also included in the data. Lastly, the researchers reviewed all written documents given to the parents with information about the Head Start such as brochures, registration forms, and individual plan forms. Three series interviews, which followed ethnographic principles, were held with each family and staff member. The researchers used interview guides to ensure that certain topics were addressed. Follow-up questions were asked when necessary based on

the information provided by the participants. The four domains that emerged through analysis of the data included frameworks of education, parent roles, learning problems/disability, and discipline.

The results of the study indicated that in terms of educational goals, the families had different goals than those described by the staff members. The educational goals that were mentioned by the families included obedience to authority, respect for others, being kind to other students, working hard, and obtaining the highest level of education possible. Further the goals set forth by the staff members, such as developing problem solving skills and independence, were viewed as undesirable to the Southeast Asian families. Similarly, differing views were also observed in regard to the domain of parents' roles. Both groups were found to place a high level of importance on nutrition and good health; however, the disagreement was in the methods used by the parents to ensure proper nutrition. For example, the majority of the parents reported hand-feeding their children to warrant proper nutrition. Consequently, when the children were at the Head Start program, many were not apprised of how to self-feed and as a result did not eat much food.

Relative to learning problems and disability, the two groups disagreed on how children learn and how learning problems and disabilities are defined. The families believed that children learn through observation, imitation, and practice. On the other hand, the staff members believed that children learn and develop differently, whether it is through touch or hearing. The families associated learning difficulties with children being lazy and not working hard, while the staff members associated them with behavioral problems. All of the families viewed disabilities as physical conditions,

deafness, or blindness. Additionally, children with disabilities were expected to be totally dependent on the family for all of their lives. Lastly, within the final domain of discipline, the families and the staff members agreed that bad behavior was related to children being bad students. Both groups also placed an emphasis on collaboration and sharing with peers. The parents, however, described enforcing that their children follow the rules and share, while staff members described only encouraging to do so.

Based on the differences in views between the families and staff members, the authors suggest that professionals working with culturally and linguistically diverse families should be aware of these differences. Furthermore, they discuss that professionals should compare and contrast the families' views to their own. Being aware of these subtle differences will help eliminate the chances for conflict and misunderstanding and can lead to the development of culturally appropriate educational services.

As a special education teacher who worked predominately with children from monolingual Spanish-speaking families, Salas (2004) became interested in interviewing Mexican American parents about their experiences with the special education system and Individualized Education Plan (IEP) meetings. The qualitative study involved 10 Mexican mothers of children enrolled in special education services. A series of in-depth interviews was conducted with the mothers over the course of a school term. The families were also observed during authentic experiences by the researchers who took notes of the observations. The main sources of data were the interviews, as they provided insight into how the parents experienced IEP meetings, as well as how they interpreted what was going on. Thematic analysis of the data led to the identification of two themes

that emerged including: language alienation and lack of respect. In terms of language alienation, it was found that the mothers reported feeling a sense of shame as a result of being a monolingual Spanish-speaker. The study found that many mothers felt nervous and anxious about attending IEP meetings due to their limited English abilities. From the narrative accounts of the mothers, it was apparent that they felt as though they were being silenced, by what the author of the study referred to as language dominance on behalf of the school, which resulted in less collaboration with school personnel. Creating this climate for the mothers lead to marginalization and isolation from participating in IEP meetings. This finding is of importance since the Individuals with Disability Education Act (IDEA) mandates partnerships between schools and parents; however, for this culturally and linguistic diverse group of mothers, it was as though this practice was not being implemented.

Lack of respect was the second theme identified in the analysis. The mothers' experiences demonstrated a lack of knowledge about cultural and linguistic diversity that led to many instances in which the school personnel made confusing and misunderstood statements. This lack of cultural competence resulted in the mothers feeling a sense of mistrust and caused them unnecessary stress. Clearly the experiences of these mothers shine light on the need for a shift toward placing priority on parental involvement, as well as in how diverse families are viewed regardless of their ethnicity, language, socioeconomic status, values, or beliefs.

Similarly, Hughes, Valle-Riesta, and Arguelles (2008) conducted a study through semi-structured interviews that looked into the perception of Latino families in regard to their experiences and views on raising a child with special needs. The researchers were

also interested in the families' involvement in their children's schooling. Participants included 16 families who were purposely selected based on the age of their children and range of disabilities. Within all of the families, the mother was identified as the primary caregiver of the child with special needs and thus participated in the interview. The mothers were interviewed using a semi-structured interview approach that included 13 open-ended questions. Interviews were approximately 75 minutes in length and took place within each family's home. Interview data were qualitatively gathered and coded, which involved line-by-line analysis of transcripts in order to identify relevant information, sort information into categories and developing themes, as well as draw conclusions and verify findings.

The findings of this study indicated that most families recognized their child had a disability and needed special services; however, the families suggested that despite this acknowledgment, they treated their child like a "normal child." The majority also discussed that the level of involvement in their child's life and education was different, as it was more difficult and required more time commitment. Many families reported an overall feeling of frustration, worry, sadness, and helplessness when dealing with their children. All families shared the expectations and goals that they had set for their children. Most mothers mentioned that the primary goal for their child was that they reach a level of independence, as well as make improvements in both physical and academic abilities. Families reported being satisfied with the programs offered in the schools; however, many discussed having specific concerns regarding the amount of progress made by their children. Another recurring topic was the fact that the involvement level is different when raising a child with special needs. Overall, the

authors recommend that programs be developed to target the specific needs and values of Latino families. Further, they suggest that future research involving Latino families is needed to identify programs that are meaningful and culturally appropriate.

In a study by Povenmire-Kirk, Lindstrom, and Bullis (2010) involving individual and focus group interviews, the aim was to determine and explain the needs of Latino youth with disabilities transitioning from school to adulthood. Participants included Latino youth with disabilities and their families, as well as school and transition professionals. The purpose was to identify the current available transition services and barriers encountered by this particular population. A qualitative method was used to obtain an in-depth perspective from the Latino youth and their families and promote their participation in the research study. Interview protocols were written for both the individual and focus group interviews. The young people and their families were asked questions relative to their experience with the special education and transitional services within the school district.

The results yielded five main challenges faced by Latino youth and their families including language issues, concerns relative to documentation and citizenship, lack of culturally appropriate practices, barriers in family participation, and limited resources in school and the community. In terms of language issues, it was found that there was a lack of interpretation and translation services within the school district, available to the youth and their families. Another compounding factor was the number of Latino students with issues regarding citizen documentation. Some of the students were undocumented because their parents were not legal residents, while others were not legal citizens themselves, as they were not born in the United States. This was a major problem since it

often led to hesitation on part of the families to share personal information with the school. This reluctance was found to impact transitional service delivery as it interfered with collaboration between school personnel and families. Additionally, during the interviews with the staff members, it was found that many of them were not apprised of cultural differences. For instance, one of the most frequently set goals for transition was for the youth to live independently after graduation; however, within a focus group interview, one of the Latino fathers clarified and shared that this is not an appropriate goal since many Latino families expect their children to live with their family until they get married. Another theme involved that lack of participation on behalf of families, as described by the staff members. When explored deeper, the families stated that they were not adequately informed about the process or their role in transition planning. Lastly, in terms of available resources for the families, it was found that the staff members felt as though the district was not providing sufficient resources in order to provide the Latino students with quality transition services.

The researchers suggest implementing training programs to help increase staff members' cultural competence in order to ensure that they are setting goals that are culturally appropriate for Latino children. Additionally, they recommended increasing family participation by helping families understand the educational possibilities for service provision relative to special education by explaining the processes, where they can go for help, and whom they can go to with their questions. Ultimately, the researchers concluded that there is a need for change in the service delivery for Latino students with disabilities in regard to transition services at the school level as well as the district level.

Emotional Well-Being and Support Systems

A comparative approach was taken by Magaña and Smith (2006) in their study that investigated the psychological and emotional well-being of mothers who were living with a son or daughter with an autism spectrum disorder (ASD). The aim was to understand the differences in attitudes between Latina mothers and Non-Latina White mothers. The study participants included 20 Latina mothers and 88 Non-Latina mothers who had at least one child diagnosed with ASD. There were several sources of data including interviews within the families' homes and self-administered questionnaires that were intended to measure depressive symptoms and psychological well-being. Two open-ended questions were asked during the interviews including, "What are some positive things about having him/her live at home?" and "What are some negative things about having him/her live at home?" The individuals diagnosed with ASD were also assessed using the Inventory for Client and Agency Planning, which gave insight into the frequency and severity of their maladaptive behaviors.

A number of themes emerged which highlighted the mothers' perceptions relative to living with their son or daughter with ASD. Some themes were common to both the Latina and Non-Latina mothers, while others were distinct to a group. In regard to the positive aspects of living with their son or daughter, both groups of mothers reported on the importance of family unity. Similarly, both groups shared that having their children at home gave them peace of mind, as it allowed them to know that they were being cared for appropriately. Non-Latina mothers were found to report more positive characteristics about their child than Latina mothers. One theme that arose mostly with Latina mothers was the idea that their main role in life was essentially dedicated to caring for their son or

daughter. In terms of negative aspect of living with a son or daughter with ASD, the majority (75%) of Latina mothers reported that there was nothing negative about it, while the number of Non-Latina mothers that expressed this was much less (7%). Both groups, however, shared that having a child with ASD in the home was stressful, limiting, and a general strain on the family. It was found that despite the disadvantages faced by the Latina mothers such as lower income and poorer health, they were found to self-report a better emotional well-being when compared to Non-Latina mothers. Similarly, Latina mothers reported more satisfaction with having their son or daughter living in the home.

The authors suggested that professionals should consider the importance of family cohesion and peace of mind, as it was important to all families in the study. Further, they discuss how cultural traditions should be considered during service delivery since the care of an individual with ASD should be based on the family's needs. Lastly, they emphasized the significance of providing parents with support and interventions to manage stress and help parents' well-being in a way that can be adapted to be culturally appropriate for all families.

In their study of Latina mothers of children with disabilities, Correa, Bonilla, and Reyes-MacPherson (2011) interviewed mothers to understand their current support systems. The participants included 25 Puerto Rican single mothers, who included women who had never been married, or who were separated, divorced, or widowed. The length of the interviews varied from mother-to-mother, but typically ranged between two and four hours. The mothers chose the location of the interviews, which in most cases was within their homes. A semi-structured interview format was used to create natural conversations with the mothers. Additionally, two self-report instruments were used to

measure the mothers' descriptions and perceptions of their support networks while raising a child with a disability. The analysis of the interview data involved reviewing transcriptions and coding for relevant narratives related to social supports.

The results of self-report instruments and interview transcripts together indicated six main features of social support systems. The first was that the mothers had a strong extended kinship that was often times just as important as the support from immediate family members. Next, they found that female relatives most often made up the kinship support systems. When applicable, godmothers played an important role in extended kinship support networks. It was also found that support from the child's father appeared to be minimal. Informal support systems were composed of female friends for the most part. Lastly, the mothers reported having a strong network of support from professionals. The authors discuss how the findings of this study suggest the importance of establishing an understanding of families' sources of support, including extended family in intervention processes, and understanding the role of informal and formal support systems when working with all families. The authors conclude that by being aware of family support networks, professionals can implement more effective intervention programs, as well as promote families' abilities to effectively find and use available resources.

Summary

The aforementioned articles were reviewed to explore the current research involving Latino families of children with special needs and evaluate the qualitative methods being used. It is apparent that in order to improve participation, collaboration, and service delivery when working with individuals of diverse cultural backgrounds,

SLPs must first understand and respect their specific cultural beliefs and values (Salas-Provance et al., 2002; Yu, 2013). Thus, cultural values and parental beliefs are of utmost importance when working with children with communicative disorders, as the primary focus is on the child and the critical role of the family members in the service provision process (Kummerer et al., 2007). By learning more about the experiences of Latino families and other culturally diverse groups through qualitative research, professionals can begin to develop and implement programs that target their unique views and needs (Hwa-Froelich & Westby, 2003; Salas, 2004; Hughes et al., 2008; Provenmire-Kirk et al., 2010). Exploring families' well-being and support systems gives professionals insight into how to develop programs that provide families with the support they need in order for them to effectively find and use available resources (Magaña & Smith, 2006; Correa et al., 2011). Through increased cultural awareness and knowledge, professionals can provide culturally diverse families with services that are not only appropriate, but also meaningful and relevant to them (Salas-Provance et al., 2002; Yu, 2013). As such, this research study explores the beliefs and views of Latino parents for the purpose of discussing how to better serve this population.

CHAPTER 3

RESEARCH METHODOLOGY

The methods section will describe the study design, recruitment, participants, procedures, and details of data collection and analysis.

Study Design

The current study involved a qualitative phenomenological in-depth interviewing design. The aim was to understand the lived experiences of Latino mothers of children with communicative disorders through identification of common themes within and across participants. Data was collected from the mothers through interviews. Rather than testing a hypothesis or developing a theory, the nature of this study design allows for the theory to emerge from the data itself.

Participants

The participants included four Latino immigrant mothers of children with communicative disorders who were interested in sharing their experiences relative to their move to the United States and the subsequent seeking of services for their children. The participants were 18 years of age or older, moved to the United States from Mexico, and had at least one child diagnosed with a communicative disorder. All were mothers of children receiving services at the California State University, Long Beach (CSULB) Speech and Language Clinic located in Long Beach, California. All mothers were born in Mexico and had been residing in the United States from 10 to 20 years. One mother was a monolingual Spanish speaker, and three mothers spoke both Spanish and an Oto-

Manguean language (i.e., Chinanteco or Zapoteco). Oto-Manguean languages are a large language group made up of several language families that are indigenous to Mexico. Both Zapoteco and Chinanteco are South Central Mexican languages with the largest number of speakers in the state of Oaxaca. These languages are tonal, contain affixes, and are written in Latin script. Sentences in both Zapoteco and Chinateco are typically arranged in verb-subject-object order. Zapoteco is an Eastern Oto-Manguean language, characterized by long words and includes clitics, while Chinanteco is a Western Oto-Manguean language characterized by short words (Sicoli, 2005). All mothers reported minimal knowledge of the English language. The participants ranged in age from 32 to 46 years, with a mean age of 39. Their level of education ranged between 4 and 18 years with the mean level of education being 10 years. One outlier was identified, as one of the mothers had attended 18 years of schooling. Three mothers had one child diagnosed with a communicative disorder, while one mother had two children diagnosed. Three of the four mothers reported being members of support groups. All of the families reported being of low socioeconomic background and none of the mothers were employed outside of the home. Table 1 provides a description of the participants.

The children ranged in age from 6 to 12 years, with a mean age of 8. Three of the children were male and two were female. All of the children spoke English and Spanish, while three of the four were exposed to either Chinanteco or Zapoteco in the home setting. All children were enrolled in public elementary schools during the time of the study, had an Individualized Education Plan (IEP), and were enrolled in special day classes within special education programs. One child was diagnosed with Intellectual Development Disability (IDD), one was diagnosed with Specific Language Impairment

(SLI), and three were diagnosed with Autism Spectrum Disorders (ASD). All of the children were diagnosed between the ages 0:9 and 4:5, with a mean age of 2:5. Table 2 provides a description of the children including gender, age, diagnoses, ages at which they were diagnosed, and place of diagnosis.

TABLE 1. Description of Participants

Participant	Gender	Age	Time in	Languages	Level of
			U.S.	Spoken	Education
			(years)		(years)
1	Female	37	10	Zapoteco Spanish	18
2	Female	40	20	Chinanteco Spanish	4
3	Female	46	19	Spanish	11
4	Female	32	19	Chinanteco Spanish	6
Means:		39	17		10

TABLE 2. Description of Children

Child	Gender	Current	Age Diagnosed	Diagnosis	Place of Diagnosis
		Age	(years:months)		
1	Female	11	0:9	-Developmental	-Pediatrician
				Delay	(Oaxaca City, Mexico)
			1:8	-Hypotonic	-Los Angeles County USC
				cerebral palsy	Medical Center
			10:0	-IDD	-Pediatrician
					(Los Angeles, CA)
2	Male	10	4:5	ASD	Harbor Regional Center
					(Long Beach, CA)
3	Male	8	2:5	ASD	Harbor Regional Center
					(Long Beach, CA)
4	Female	6	1:5	ASD	Harbor Regional Center
4	Telliale	U	1.3	ASD	(Long Beach, CA)
					(Long Beach, CA)
5	Male	7	2:9	SLI	Harbor Regional Center
					(Long Beach, CA)
Means:		8	2:5		

Procedures

Institutional Review Board (IRB) approval was granted on August 1, 2014 from CSULB (See Appendix A). The subjects of this study were parents who met the following criteria: (a) had at least one child diagnosed with a communicative disorder, (b) moved to the United States from Mexico (c) be a Latino/Latina who speaks Spanish as the primary language. The principle investigators (PIs) distributed and posted information packets in English and Spanish, which included a Consent Form (Appendices B & C) and an informational Recruitment Flyer (Appendices D & E), at the CSULB Speech and Language Clinic. Flyers included contact information. The consent form informed the parents of the possible risks and benefits of participating in the study. Since the parents would be asked to discuss their experiences relative to raising a child with a communicative disorder, one risk was that they might experience emotional distress and become uncomfortable. Another possible risk was breach of confidentiality. As such, specific measures were used to protect against or minimize the risks. For example, confidentiality was maintained by conducting the interviews in a private clinic room and by using pseudonyms for each participant in recorded data. In terms of benefits, the research suggested that participants benefit from having someone to listen to their stories in qualitative interviews (Patton, 1990; Hutchinson, Wilson, & Wilson, 1994; Kavanaugh & Ayres, 1998). According to Murray (2003), giving participants an opportunity to tell their own stories allows them to begin the process of making sense of what has happened to them. Once the parents reviewed the information packets and contacted the PIs, they were informed of their options: (a) participate in the research study or (b) decline participation in the research study. Parents who expressed interest in participating in the

research study and agreed to the time obligations scheduled their first interview. Each parent signed the Consent Form on the day of, but prior to, the first scheduled interview.

In the current study, the interviews were guided by general themes, but did not rely on a strict protocol. However, a Parent-Interview Guide (Appendices F & G) was created in order to provide preliminary open-ended questions. Instead of utilizing the recommended three-interview series, the researchers adapted an interview guide that included a six-interview series. The six-interview series included the three recommended interviews, but integrated an additional three interviews in order to align with the purpose of the study. The six interviews included (1) Focused Life History, (2) Birth Practices and Details of Daily Life, (3) The Details of the Child's Current Experience, (4) Details of Current Experiences with School and Medical Services, (5) Linguistic and Cultural Guidelines, and (6) Reflection on Meaning. Priority was placed on following the participants' lead, asking follow-up questions, and building upon their responses. The interviewer allowed the participants to lead the sessions, while exploring the issues raised. Efforts were made to create an informal and natural conversation between the mothers and the interviewer.

The participants attended six 60-minute individual interviews, following the aforementioned series, in a private room at the CSULB Speech and Language Clinic. Several strategies were employed to help the participants feel comfortable throughout the interview process. Participants chose the interview dates and times, which allowed for flexibility and helped guarantee that they attended all interviews. All mothers chose to be interviewed at times when their children were concurrently receiving speech and

language intervention in a separate clinic room. Mothers received compensation for parking and/or transportation fees in appreciation of their participation.

The interviewer was bicultural, biliterate, and fluent in English and Spanish. The participants were encouraged to speak the language(s) of their preference and to codeswitch and code-mix when they wished. The interviewer matched their language selections as much as possible. Since the interviews were audio recorded and later transcribed verbatim in their entirety, the participants were given the opportunity to stop an interview at any point and omit disclosed information. They were informed that they could ask for sections to be deleted at any point during the interviews; however, once each interview was complete, the participants were not able to review audio recordings or transcripts. At the completion of each interview, the participants were thanked for their time and the next interview was scheduled.

Data Collection and Analysis

The interviews were audio-recorded and later transcribed verbatim in their entirety. The transcriptions were initially written in Spanish and then translated to English for further analysis. Audio recording was warranted as it ensured identical replication of the contents of each interview in order to facilitate analysis. Additionally, it provided detailed insight into the performance of both the participant and the interviewer to help validate the accuracy and completeness of the data (Barriball & White, 1994). Further, it reduced the potential for interviewer error. Seidman (2013) reported that a 90-minute recording normally takes from 4 to 6 hours to transcribe. For this study, it was estimated to take from 3 to 4 hours to transcribe a 60-minute recording.

The text generated from the interviews was inductively, rather than deductively, reduced (Seidman, 2013). This means the researchers studied the text with an openmind, without trying to test a hypothesis or developed theory, allowing the theory to emerge from the data itself (Glaser & Strauss, 1967). Analyzing in order to grasp and formulate a thematic understanding is not a rule-governed process, but rather an open act of "seeing" meaning (Van Manen, 1990). Since the transcripts were up to 45 pages in length, the first step in the analysis was studying and reducing the text by reading it and marking with brackets the sections that were relevant and of most interest. During this process, the sections that were bracketed were labeled and organized into categories. Labels were initially tentative, allowing the themes to emerge on their own. Next, the markings were studied for connections and patterns amongst the excerpts and various categories. This was done within and amongst the transcripts in order to identify themes. This process is typically referred to as "classifying" or "coding" in the literature. There are computer programs available that can help with this process; however, for this study, this was done using the paper copies of the transcripts and subsequently transferring the reductions and markings back to the computer. The last step in the process of analysis is interpreting the data. For the current study this involved identifying clinical implications from the findings relative to the field of speech-language pathology, which will be covered in the discussion section.

CHAPTER 4

RESULTS

Data analysis identified two primary linguistic themes: parents' perceptions of their own linguistic abilities and parents' perceptions of their children's linguistic abilities. Additionally, three primary cultural themes were identified: differences in lifestyle, knowledge and cultural views of disability, and educational roles and responsibilities. Findings are presented below in relation to these issues as they emerged across all (4 out of 4) or most (3 out of 4) of the mothers. All responses were in Spanish and transcribed into English by a native Spanish speaker. To provide a more complete portrait of the families' experiences raising a child with special needs, two family descriptions are provided.

Linguistic Themes

The following section will discuss the two primary linguistic themes including:
(1) parents' perceptions of their own linguistic abilities; and (2) parents' perceptions of their children's linguistic abilities.

Parents' Perceptions of Their Own Linguistic Abilities

All mothers reported they *did not speak English when they arrived to the United States*. One mother said, "I knew nothing. I communicated with signs or I just wouldn't say anything. When I was in situations where people were speaking English to me, I would just be quiet and didn't say anything because I didn't know what to tell them."

When asked how they communicated when they first arrived to the U.S, the mothers

reported that they *did not feel the need to immediately learn English after their move here* because they were able to communicate with others in Spanish. For instance, one mother stated, "Well, all of the people that I was around were relatives of my husband and everyone spoke Spanish. Even at the store and in the community people spoke Spanish." Another mother shared, "Where I had more difficulty was at the regional center, but even then they had interpreters there who helped us communicate." It became apparent that the lack of knowledge of the English language on behalf of these mothers was not due to resistance to learning but, rather, as a result of the large Latino presence in the United States who are knowledgeable of Spanish.

Each mother shared knowing that *English classes for parents were offered at their children's schools; however, none of them have been able to attend these classes.* When asked to elaborate, it was apparent that this was due to various socioeconomic barriers. One mother said, "It is something I am truly interested in because I know I will be able to help my son more, but since I have to take the public bus to drop my son off at one school, drop my older daughter off at another school, and pick them up at different times, its difficult to make it to the classes." Other mothers had similar responses relative to transportation difficulties and minimal support from family members due to commitments such as work. Another mother said, "I try and guess at who does and who doesn't speak Spanish and things like that. I was going to English classes at Long Beach City College, but it was too much of a time commitment with all of the other services I take my son to." All mothers also reported a *low level of comfort speaking English*, even after several years in the United States.

Three of the four mothers stated that they were educated in an Oto-Manguean language indigenous to Mexico (i.e., Chinanteco or Zapoteco), which was their heritage language growing up. Further, they indicated that they learned Spanish in their adolescence without formal instruction. One of the mothers discussed the circumstances that lead her to start learning Spanish when she said, "I was 13 years old when I asked my father to let me go work in Mexico City. I knew I had to help the family since we were very poor. I started working for a lady that had two children. During this time was when I started exploring and I began learning Spanish. I didn't speak Spanish with my mother or father, we spoke Chinanteco." The other mothers had similar stories growing up, in which they were exposed to Spanish in larger cities within Mexico. They stated that they needed to learn Spanish when they were working as live-in nannies and housekeepers in order to communicate with the families they worked for. Additionally, the mothers experienced differences in lifestyle between their hometowns and the larger cities in Mexico during this time. For instance, one of the mothers shared, "Rich people ate with a fork and knife, but in my pueblo we ate using a spoon or a tortilla. The sixyear-old boy I took care of taught me how to cut my food with a knife and use a fork." These mothers' accounts shine light on the differences in language and lifestyle within Mexico, which will be further explored when addressing the differences in lifestyle between Mexico and the United States.

All mothers reported that they *speak Spanish in the community with their children, but speak their Oto-Manguean language in the home* with their significant others and those that understand it. One mother stated, "I still speak Chinanteco with my husband, mother, father, and brother-in-laws." Of the mothers that spoke an Oto-

Manguean language, all of them discussed the importance of maintaining the language since it is the only way they are able to communicate with their families who still reside in Oaxaca, Mexico. These mothers also reported that they felt more comfortable speaking the Oto-Manguean language than they did speaking Spanish, as the Oto-Manguean language was their heritage language growing up. During the interviews, which were conducted in Spanish, these mothers were observed to ask for clarification of the meaning of some words when asked follow-up questions. One mother said, "I sometimes have to ask what words mean in Spanish because I am not familiar with some of them."

Parents' Perceptions of Their Children's Linguistic Abilities

All mothers reported that their *children speak both Spanish and English*. They noted that their children learned English at school and associated it as the language of the community. By contrast, Spanish was learned in the home setting and is primarily spoken within the home.

All indicated that their current overall priority for their children involved functional communication/language and academic growth (i.e., reading and writing).

One of the mothers shared, "My priority is in her academic level. Before I placed priority only on speech because of her difficulty communicating, but now I want her to write and read. I just don't know how to motivate her to be interested in it." Similarly, another mother talked about her goals for her son when she said, "His communication is a priority to us. I also hope he progresses more academically because he is already in 3rd grade. I told his teacher that one of my long-term goals is for him to leave reading and writing.

Obviously he may never get to learn at a college level, but its essential in life to be able to read and write." All mothers had similar goals for their children that involved academics.

Three of the four mothers reported that they exposed their children to the Oto-Manguean language in the home. For instance, one mother shared, "I try to teach my children Chinanteco because I would like them to be able to communicate with their grandmother if they ever get to meet her. She lives in Oaxaca still. My son can count from one to ten in Chinanteco." The other mothers that spoke an Oto-Manguean language shared similar stories about speaking their language to their children. Another mother said, "We also speak to her in Zapoteco. I notice that there are some words that stick and she says sometimes. We'll speak Zapoteco around her and there are some things she seems to understands."

Cultural Themes

The following section will discuss the three primary cultural themes including: differences in lifestyle, knowledge and cultural views of disability, and educational roles and responsibilities.

Differences in Lifestyle

All mothers reported *being from a pueblo* (i.e., small town). One mother described her hometown when she said, "It's a small pueblo, so small that all of the people know each other. There wasn't even a middle school in our pueblo. Kids had to go to the next pueblo over to go to middle school." Three of the four mothers were from a pueblo in the state of Oaxaca, while one mother reported being from a pueblo in Durango, Mexico.

The mothers described that *life in their pueblo was more relaxed than life in the United States and the rapidly paced cities they live in now*, which include the large cities of Long Beach and Los Angeles, California. Relative to this, one mother said, "Life is more rapid here. Everybody is constantly running around and always has many things to do." The other mothers had similar accounts relative to the differences in pace between Mexico and the United States. For instance, another mother shared, "Well, here it's a city we live in and there we lived in a pueblo. Life was different because over there people live more relaxed and enjoy their time more than they do here." Despite these differences, all of the mothers reported that *they were satisfied with their move to the United States*. Most associated their satisfaction with the acceptance of people with disabilities and the services that are available for their children here in the United States.

When discussing services for children with disabilities in their native country, the mothers indicated that *services are only available in big cities such as Mexico City and Oaxaca City*. One mother discussed this in detail as she said, "When we were in Oaxaca with our daughter, we had to go to Mexico City to see a pediatrician. All of the services were in the larger cities." Since this was reported by all of the mothers, the researchers looked further into the distances from the pueblos to these big cities and found that the pueblos were typically between four and ten hours away by car from the larger cities such as Oaxaca City and Mexico City. One mother compared the services provided in the United States to those in Mexico when she said, "It seems as though therapists are more specialized here and they focus more on helping children in therapy and it's very individualized." Another mother stated, "Since the therapy over there is in a group with many children, the therapists only spend 10 minutes with each child and the progress is

much slower. They aren't like the therapists here, who focus on the child and are more specialized to their needs. Over there it wasn't like that and I didn't like it." This was reported by the mother who immigrated to the United States specifically for the purpose of seeking available and affordable services for her daughter.

Additionally, they stated that *services are expensive and limited in Mexico*. One mother shared, "I would have to pay for the services in Mexico. The very first thing they do is investigate your income and calculate how much you will pay. It would have been harder for me because I would have had to leave my daughter with a family member in order to work to pay for the therapy." All of the mothers shared similar views on the cost of services for children with special needs in Mexico. One of the other mothers said, "There aren't a lot of resources and the ones that do exist are extremely expensive. I think that if I were raising my son in Mexico, he would not be where he is today. He has made progress here and he can communicate now."

Three of the four mothers reported that they *had to quit school to work in order to help their families*. One of the mothers shared her experience when she said, "I went to school, but I only got to the fourth grade. I really liked school when I was a little girl, but it was hard. Since I was the oldest, I had to help my parents out because we were poor. They would tell me to hurry and finish my homework so that I could help out. I knew eventually I had to stop going because I would have to start working." The mother who did not have to discontinue her education studied medicine at a university in Oaxaca, Mexico; however, she was unable to complete the last requirements because of her decision to move to the United States to find better care for her daughter.

Knowledge and Cultural Views of Disabilities

All of the mothers reported that they had no awareness of disabilities prior to having a child diagnosed with special needs. For example, one for the mothers stated, "I was not informed until my daughter was diagnosed with autism. From there, I started to see what a disability is. I go to a support group for parents of children with autism and this is where I learned what autism was. When the doctor first told me, I had no clue what it meant. I left that day thinking it would go away, thinking that it was like the flu." The other mothers had similar stories relative to learning about disabilities when their children were diagnosed. Another mother said, "I did not know. I became aware of the world of disabilities when I found out my daughter was special. When she was diagnosed, at 9 months, is when I saw how many children had disabilities."

The mothers described that when they were in Mexico, children with disabilities were stigmatized as they were often isolated, kept in the home, and not sent to school.

For instance, one mother shared, "What made me so sad was that all of those children were coming from places very far from Oaxaca City, mostly from pueblos far away, and many of the children were wrapped in a blanket and just laying there on the floor. You could tell their living conditions weren't good." Another mother said, "In the pueblo, they don't do much for them and they don't send them to school. They just keep them inside.

I remember one girl who used to like running around and chasing others. People used to call her 'Rebecca la loca' and she really didn't talk much." The other mothers shared similar stories regarding the treatment of people with special needs in Mexico and the unfortunate stigmatization.

When discussing the reasons why children are born with a disability, *various* medical and folk beliefs were mentioned such as a punishment or curse, a scare during pregnancy, "mistake" made by parents, or hereditary factors. For instance, one mother said, "My mom and dad didn't say anything to me about it being my fault. They just blamed themselves because of an argument we had when I was pregnant. They think that my daughter was born this way because of the stress they caused me during that argument. I don't think that at all. I feel as though it is just something related to genetics or maybe there was a lack of oxygen during the birth that the doctors in Mexico didn't tell us about." Another mother said, "Other people would say to me 'Maybe its because of your husband's family', but I didn't ever want to touch that subject because I knew it wasn't anyone's fault. Other people think that it's a punishment from God or a curse someone put on you."

All mothers shared that they were reluctant to seek help due to an initial sense of denial and lack of knowledge, rather than stigma. One mother shared, "It wasn't because of stigma. At first I didn't seek help and stayed in my house because I didn't know. When I look back at when I first found out about the diagnosis, I was in shock and in denial. I didn't even care about what people would think. I had bigger worries."

Another mother said, "More than anything, I think that I was in a state of denial because I had felt like something was wrong for some time but I didn't want to accept it. I would tell myself that everything was okay and that my daughter didn't have anything. I didn't want to believe that there was a problem." Although it is evident that there is a stigma toward children with disabilities in Mexico, these mothers reported that they were more reluctant to initially seek services due to denial.

Educational Roles and Responsibilities

All mothers reported being the sole caretakers and the only person responsible for taking their children to all of their services. One of the mothers said, "I take care of the home, cook, and take the children to school. It's like my job. For my son with special needs, I am the one who takes him to speech and swimming classes. My husband works a lot and since it is heavy work, he comes home very tired. I get very tired too because I have to rush to make sure we don't miss the bus." The mothers also expressed that they did not work and that they felt that their main role was to take care of their children. The mothers described that they would probably be responsible for taking care of their children for as long as it was needed. One mother shared, "With her, I know that she will always stay with me." These accounts are consistent with all of the mothers' experiences. Additionally, all of the mothers stated that they did not drive and relied on public transportation, such as the bus, to take their children to school and carryout their everyday responsibilities.

Furthermore, all of the mothers reported that *the level of involvement in their children's education required more time and was more difficult*. One of the mothers specified, "It is very hard. I have to go to IEP meetings, talk to teachers, help my son with his behaviors, and take him to clinics to help him get better. It takes a lot more effort, but it is all worth it when you see the changes and growth." Another mother said, "It is our responsibility to talk to him and help him as much as we can. It requires more work than other children who don't have problems. For parents who have children with disabilities, it's normal. The other parents do not understand." All of the mothers had

other children who did not have special needs and shared that they felt a significant difference in what was required from them as mothers.

Three out of the four mothers reported *litigating their concerns with their children's school districts*. When sharing her experience with this, one of the mothers said, "I just want the best for my son and at the time I felt as though the professionals were just moving through the motions. I felt as though I was leaving every IEP more frustrated than before. All I wanted was to be heard. We should have good communication. They should make the families feel in confidence and treat us as though we are part of the group. Maybe its because I don't speak English and my Spanish is not very good." Another mother who had also gone into litigation said, "When we were at the other school, all I wanted was to be included more and share my goals. At this new school I can tell the difference in the way they treat us because they know that we fought the other school for services."

All mothers shared that the primary long-term goal for their children was that they reached a level of independence, understood safety/self-defense, and knew what they wanted. One of the mothers said, "I would like for my son to be more independent. I want him to communicate more in the community and be able to ask for what he wants. It would be great if he could learn to take the bus and all that." Similarly, another mother stated, "I would like for her to learn how to defend herself, understand safety, and become more independent. Other parents make unrealistic goals, but I would be happy with her just being aware of her security and knowing how to fend for herself such as knowing what she wants." One mother shared specific descriptions of what she hopes for her children's futures when she said, "I want my son to have a job that he likes and that

he is good at. My daughter, I think she will find a trade such as a pastry chef or cook. I want her to be able to defend herself when I am no longer here. For that, she will need to communicate using her language. More than anything I want my children to become independent and live happy lives."

Additionally, all of the mothers suggested that they viewed *professionals as more knowledgeable and better equipped for improving language outcomes.* For example, one of the mothers said, "Children with special needs rely heavily on the therapists because they are specialized and studied to give services." Another mother said, "The professionals play a big role because they are prepared to teach children with disabilities." Additionally, they stated that they *expecting professionals to share their knowledge and provide strategies that can be used within the home.* For instance, one of the mothers stated, "The professionals should try to work with the families. They should share what they know. Therapists and teachers should give advice about what we can do at home to practice what is done in therapy." Similarly, another mother shared, "Since I dedicate myself to my children, I would like the therapists to give me ideas on how I can help them advance in the areas of reading and writing. They are the professionals, but I am with my kids the most of the time and it would be nice to know what more I can do."

Family Experiences

Although the families interviewed for this study shared many similar perceptions and experiences. As expected, however, each family had his/her own unique circumstances that had an impact upon their views of raising a child with a communicative disorder. To provide a richer description of the participants, two families are highlighted in this section, the Maldonados and Martinezes who were fairly typical of

the families included in this study. Pseudonyms are used to protect the participants' privacy.

Maldonado Family

Pilar is an 11-year-old girl who lives with her 2-year-old sister, mother, father, grandmother, and two uncles. Pilar and her parents arrived from Oaxaca, Mexico over 10 years ago when Pilar was 1-year and 4-months-old. The family decided to move to the United States after they became aware of Pilar's disability when a pediatrician in Oaxaca informed the family that there was a delay in her development and suspected the presence muscular dystrophy at the age of 9 months. Pilar was initially diagnosed in the United States with hypotonic cerebral palsy when she was 1-year and 8-months-old. Per Mrs. Maldonado, her daughter's medical history is significant for cerebral atrophy which was detected by brain-imaging tests in Mexico. Last year, Pilar's diagnosis was changed to Intellectual Developmental Disability (IDD) by her pediatrician in the United States.

The family currently lives in a two bedroom, two bathroom apartment in Los Angeles, California. Mr. Maldonado works as a chef, while Mrs. Maldonado is a housewife and does not work outside the home. When living in Oaxaca, Mrs. Maldonado studied medicine at the Benito Juarez Autonomous University of Oaxaca. Despite being close to the completion of her education, she decided to discontinue her studies in order to move to the United States for Pilar. Mrs. Maldonado explained that she does not speak English and that Spanish and Zapoteco are the languages spoken within the home. All of the family members who live in the home contribute to the expenses. The family has one car, which is only driven by Mr. Maldonado. Mrs. Maldonado relies on public transportation to take Pilar to school and to her therapies.

Pilar is currently enrolled in the sixth grade within a special day class at a public elementary school and has an Individualized Education Plan (IEP). She is receives individualized speech-language services once a week for 30 minutes at school and also attends the CSULB Speech and Language Clinic twice a week for 50-minute individual sessions. The families main goals for Pilar include increasing her expressive language development and working on academics such as reading and writing. Ultimately, Pilar's mother is aware that she will always have to care for her daughter but she hopes to someday see her reach a level of independence and become aware of her safety.

Martinez Family

Antonio is a 10-year-old boy who lives with his older sister (12), younger sister (8), and both of his parents. Antonio's parents arrived to the United States prior to having children 20 years ago. They currently live in a two bedroom, one bathroom home that they rent in Long Beach, California. Mr. Martinez works in construction, while Mrs. Martinez is a housewife who does not work outside of the home. She is responsible for taking care of the children, taking them to school via public transportation, and taking Antonio to all of his services. The family has one car, which only Mr. Martinez drives.

Antonio is in the third grade and is currently enrolled in a special day class at a public elementary school. He has an individual education plan and is mainstreamed into a general education mathematics class. Antonio was initially diagnosed at Harbor Regional Center in Long Beach, California when he was four and a half years old. At school, Antonio currently receives individualized speech-language services two times per week and once a week within a group. He also participates in adapted physical education once a week. Antonio attends the CSULB Speech and Language clinic twice a week for 50-

minute sessions of individualized services. Antonio also attends Tichenor Orthopedic Clinic for Children once a week for 20-minute swim lessons.

Mrs. Martinez explained that she communicates frequently with Antonio's teacher about how he is doing and asks that she send more work home to enable the parents to assist their son. Mrs. Martinez would like to learn English in order to better communicate with the professionals that provide services to Antonio. She and her husband spend time working with Antonio to reduce his sensory and maladaptive behaviors in public. They believe that it is their duty to provide him with discipline and structure so that when they are in the community they do not have to be concerned about "what other parents are saying." Mrs. Martinez described her satisfaction with all of her son's progress and wanted to share the following with SLPs and professionals who work with children with disabilities:

If I could, I would ask you as therapists to try and have patience just the way a mother is patient with their child with special needs. I hope that you help them to the best of your abilities. Children with special needs depend greatly on you since you are specialized and studied to provide these services. In helping these children, someday you will be compensated in a distinct manner. It is something truly beautiful to be able to help children with special needs and have that patience. Above all, I would like to thank all of the therapists who work with children with special needs and tell them to keep fighting because their work is highly valued.

CHAPTER 5

DISCUSSION

The purpose of this study was to identify the common themes that might arise from interviews with Latino parents who have children with communicative disorders in order to understand the cultural and linguistic barriers they may encounter. The study employed in-depth phenomenological interviewing to gain insight into the parents' beliefs, views, and their quest for affordable and available services for their children. Linguistic themes regarding the parents' perceptions of their own linguistic abilities and the abilities of their children were identified. Cultural themes were also identified and included differences in lifestyle, knowledge and cultural views of disability, as well as educational roles and responsibilities. This section will discuss the clinical implications relative to the identified themes, limitations, and future research suggestions.

Linguistic Clinical Implications

Parents' Perceptions of Their Own Linguistic Abilities

There are clinical implications that can be taken from the results of this study that should be considered when working with Latino Families. For example, SLPs should refrain from making assumptions about linguistically and culturally diverse groups. As discussed by Salas (2004), many Latino families face language alienation and feel a sense of shame as a result of not speaking English. Based upon their reports, the mothers in this study feel uncomfortable speaking English despite residing in the United States for more than 10 years. This is not because of a lack of interest or refusal to learn. Rather, it

is due to the large Latino presence in the United States that has allowed the mothers to communicate with others in their home and in the community in Spanish. Additionally, all of the mothers mentioned socioeconomic barriers that have compounded their ability to attend available English classes.

As highlighted by Salas-Provance et al. (2002), one should carefully evaluate commonly held stereotypes in an attempt to avoid making inaccurate assumptions. Particularly, one should not assume that all people of Latino descent speak Spanish as their heritage language. As seen in this study, three of the four mothers actually spoke an Oto-Manguean language as their heritage language and did not learn Spanish until they were in adolescence. It should also be noted that these women did not formally learn Spanish, as their education was in the Oto-Manguean language. That is, these mothers may have adequate basic interpersonal communication skills (BICS) to carry on a conversation in Spanish, but may lack the cognitive academic language proficiency (CALP) to easily understand the language of clinical reports presented to them in Spanish (Cummins, 1980). Nevertheless, one should not automatically assume that this is the case with all families; it is possible that many families have strong BICS and CALP.

Generally, SLPs should prepare to be flexible since effective communication with family members throughout the provision of services is key. For example, during the presentation of assessment results, it is essential that the family understand what is being explained relative to their child's current language abilities and areas of need. Since the language of clinical reports is often academic, formal, and full of clinical jargon, it is important for SLPs to adapt their language to match that of the parent. When working with all families, clinicians should avoid the use of highly clinical language, provide

examples, and check for understanding. When the mothers described their language use on a daily basis, they stated that they spoke Spanish in the community but spoke the Oto-Manguean language in the home and with those that understood it. This gives insight into the language they are most comfortable speaking. As such, efforts should be made to find interpreters who speak the language in which the parents are most proficient in and are most comfortable speaking. In the case of the mothers in this study, it may be nearly impossible to find an interpreter who speaks the Oto-Manguean language.

Therefore, clinicians will need to use the second language, Spanish, to communicate with the parents. Consequently, Spanish-speaking interpreters may also be needed and should be trained so they are prepared to modify their language appropriately to meet the needs of the parents and continuously check for understanding. The focus of SLPs should be on identifying how to communicate effectively and establish partnerships with these parents as it is mandated by IDEA (Salas, 2004).

Parents' Perceptions of Their Children's Linguistic Abilities

As discussed by Yu (2013), the literature on bilingualism indicates that many minority-speaking families are reluctant to speak to their children in their native language due to a fear that it will confuse them. This was not the case for the mothers in the current study. They all reported speaking to their children in Spanish, which was there own second language in some cases, within the home. They all considered Spanish the language of the home, while English was viewed as the language of school and the community. All of the mothers who spoke an Oto-Manguean language (N = 3) exposed their children to this language in the home, but did not converse with their children in that language. Speaking their native languages was expected of the mothers in this study

since they reported a low level of comfort speaking English. Despite these findings, it remains important that professionals provide linguistically diverse families with the most accurate information regarding bilingualism and heritage language maintenance. It is unacceptable for professionals to advise families to stop speaking to their children in their native language as this is the popular myth unsupported by research. Moreover, SLPs have an ethical responsibility to support families' cultural and linguistic preferences throughout the provision of services (ASHA, 2004, 2005, 2011).

Cultural Clinical Implications

Differences in Lifestyle

Based upon the apparent differences in lifestyle between Mexico and the United States, there are practical implications to consider. Since the mothers in this study shared that the services for children with disabilities are limited, expensive, and only available in larger cities in Mexico, it may be the case that recent immigrants are not apprised of the governmental and educational possibilities for service provision in the United States. It is evident that the mothers in this study have become acculturated in this regard, as exhibited by their awareness of various opportunities for services. For example, all of the mothers take their children to the CSULB Speech and Language Clinic which is a private community clinic. Similarly, three of the four mothers take their children to Tichenor Orthopedic Clinic, a private nonprofit community clinic. This may be a result of the mothers having lived in the United States for 10 or more years, and becoming socially interconnected with other mothers of children with communicative disorders.

Nonetheless, other families may be unaware of the possibilities and may need to be informed of available services and resources.

Professionals, such as SLPs, can be at the forefront of providing families with this information, which can be done through activities that involve community outreach and parent education. For instance, having contact with local public organizations can be one way of raising awareness of existing services to populations that may not otherwise have access to them. These approaches will allow professionals to provide families with information about available resources explicitly, such as the regional center, and offer services and supports as appropriate. As discussed by ASHA (2010), the roles and responsibilities of SLPs are expanded by legal mandates that place a focus on providing appropriate educational opportunities to students from culturally and linguistically diverse groups.

Knowledge and Cultural Views of Disabilities

Since the mothers in this study reported having no awareness or knowledge of disabilities prior to having a child diagnosed with special needs, it is important that professionals provide parents with this information through parent education. SLPs should not assume that families have general knowledge of disabilities and must be ready to explain basic and specific information regarding disabilities and diagnoses in a way that is easily understood and meaningful to them. Additionally, SLPs should be accessible to the families in the future in order to answer questions or provide clarifications when needed. Creating pamphlets and handouts that explain the specific diagnosis, prognosis, and provide available resources for the families can be one way of making this information readily available. The SLP should consider families' native languages and proficiency when providing these supplemental resources. The mothers also discussed that when they were in Mexico, children with disabilities were often

isolated, kept in the home, and not sent to school. This finding also presents implications relative to the SLP's role to counsel families and provide information regarding expected language outcomes.

Moreover, it is recommended that SLPs encourage parents to form and join groups that may include support groups, parent-training and English classes. All of the mothers in the current study reported being involved in parent groups and discussed how beneficial it was to meet other families in similar situations. Since the mothers mentioned not being able to attend English classes due to various socioeconomic barriers (e.g., transportation limitations and lack of childcare), professionals should also begin making efforts toward breaking down these barriers. For instance, providing childcare can be one way of increasing the likelihood of parents attending informational classes or groups. As mentioned by the mothers in this study, all of them relied on public transportation since they did not drive. By promoting networking amongst the parents, they too can begin to work together and coordinate with one another to break these barriers down themselves. Some of the mothers at the CSULB Speech and Language Clinic have begun networking and supporting each other, as many of them attend support groups and have recently started carpooling to the clinic. As discussed in previous studies, understanding support networks of culturally diverse families could lead to better promotion of their aptitude to effectively locate and utilize existing resources (Magaña & Smith, 2006; Correa et al., 2011).

Similar to Salas-Provance et al. (2002), various medical and folk beliefs were mentioned by the mothers in the current study in response to the reasons that children are born with a disability. Professionals should therefore approach each culture on its own

terms and understand the beliefs of others within a cultural context. Furthermore, SLPs and other professionals should consider the practices and beliefs of culturally and linguistically diverse populations carefully in an effort to provide appropriate diagnostic and treatment services. Developing clinical competence with relation to linguistic and cultural diversity includes exploring attitudes toward disability (Kummerer et al., 2007). Cultural competence is an ongoing learning process for students in the field of communicative disorders, as well as practicing SLPs (Westby, 2007).

Educational Roles and Responsibilities

Concurrent with other findings, the mothers in this study reported that their main role in life was to be the sole caregivers of their children (Magaña & Smith, 2006).

Moreover, the mothers shared the idea that the level of involvement in their children's education was different when compared to typically developing children as it is more difficult and intense, and it requires more time, effort, and work overall. These findings were similar to the findings of the study conducted with Latino families by Hughes et al. (2008). That is, the families shared similar experiences relative to involvement in their children's schooling. SLPs can provide families with support by making themselves available to answer questions and promote involvement. Since three of the four mothers shared that they had initiated litigation with their children's school districts, an emphasis should be placed on building positive relationships with families. Thus, fostering collaboration with families should be of priority. This can be done by respecting the families and their views, listening actively to their input, and facilitating family involvement throughout the treatment process. Developing such practices was found to

increase the likelihood of families' engagement in their children's education and sustaining their involvement over time (Hughes et al., 2008).

When describing the future of their children, the mothers expressed goals relative to their children reaching a level of independence and understanding safety/self-defense, which aligns with the findings of other studies involving parents of children with special needs (Hughes et al., 2008; Yu, 2013). SLPs may consider these goals when developing treatment and transitional service plans for Latino children and youth. As discussed by Povenmire-Kirk et al. (2010), it is important that SLPs work collaboratively with parents when developing therapy goals since the aim is to implement goals that are culturally appropriate for Latino children/youth and their families.

Since the mothers viewed professionals as more knowledgeable and better equipped for improving language outcomes, parent education and training may be needed in order to explicate how parents themselves can be effective language facilitators. In this respect, all of the mothers reported that they expect professionals to share their knowledge and provide strategies that can be used within the home. This is indicative of the mothers' willingness to collaborate with SLPs to target therapy goals in the home environment. Through parent-training programs, SLPs can provide families with the strategies and techniques needed to interact effectively with their children to foster positive language outcomes.

Limitations

The limitations of the current study are important considerations when interpreting the results. One consideration is that the current study consists of a small number of participants (N = 4), which limits the generalizability of the results. As

discussed earlier, the aim was not to generalize the findings as much as it was to gather a deep and rich understanding of the participants' lived experiences. Because the participants were recruited from the CSULB Speech and Language Clinic and not from the community as a whole, the findings are not necessarily representative of all Latinos. As such, the findings may be an artifact of the group. It is difficult to say whether or not families who did not participant in the study are facing similar experiences as the participants of this study.

Additionally, the sample of Latino participants in this study is not representative of all Latino groups. Although the mothers are of Mexican descent, the largest Latino group in the Unites States, the majority emigrated from Oaxaca, Mexico and are not representative of all Mexican Latinos. Another limitation is the length of time that is required to carry out a study involving in-depth phenomenological interviewing methods, particularly in regard to the laborious transcription of data. In addition, the information gathered from the study was obtained solely from the mothers' reports and did not include other members of the family or observation of the participants in their natural environments.

Since the data were self-reported, there is a potential for biases maintained by the participants. They may have been selective in what they shared and reluctant to provide information related to all of their experiences within the interviews. Further, the participants could have considered some experiences more or less important than what was actually implied by the data and themes identified. Overall, qualitative research and analysis may be considered subjective; it requires the researcher to be skilled in determining patterns and significance of data. Despite the limitations, the clinical

implications that can be taken from this type of study are rewarding and are important considerations since they can broadly be applied to other culturally and linguistically diverse groups.

Future Research

Additional research is needed to further explore the experiences of Latino families of children with communicative disorders. It is recommended that future studies focus on cultural beliefs and views, linguistic and cultural barriers, families' knowledge of available services, and all other areas of suspected need. Largely, there continues to be a variety of questions that are yet to be explored using qualitative phenomenological research methods within the field of speech-language pathology.

When conducting phenomenological in-depth interviews, researchers should consider adhering to the recommended three-interview series proposed by Seidman (2013). This will not only save time during data collection and analysis, but following the recommended series may also allow the interviewers and participants to maintain a sense of focus during each interview. Nonetheless, a balance should be sustained between upholding the open-ended nature of the interview and maintaining enough focus to follow the structure of the series. Further, following the three-interview series may also allow for the inclusion of more participants. For instance, two additional mothers from the CSULB Speech and Language Clinic expressed interest in participating in the study but, unfortunately, they were not included due to time constraints.

In order to control for the potential subjectivity of qualitative research, researchers may consider incorporating quantitative measures such as surveys and rating scales. This would result in a mixed method that integrates both qualitative and quantitative measures

in a single study. Additionally, it is suggested that an observational measure be incorporated in order to understand the families in their natural environments. With observational analysis, SLPs can then develop programs and strategies that are culturally appropriate and meaningful.

With the Latino community growing rapidly in the United States, additional research should be conducted to better understand the needs of this population with regard to raising a child with a communicative disorder. Researchers should conduct studies that further investigate the influence of culture, language, and parenting styles on the clinical management of children with speech and language disorders. Furthermore, since SLPs are responsible for servicing a wide range of individuals from culturally and linguistically diverse backgrounds, future studies should be conducted that shine light on the intricacies of each individual cultural and language group.

CHAPTER 6

CONCLUSION

The results of the present study provided valuable insight into the experiences of four Latino mothers of children with communicative disorders in regard to the linguistic and cultural barriers they encounter, their views and beliefs, and their quest for available services. Although the results cannot necessarily be generalized due to the aforementioned limitations, the clinical implications are important considerations since they can generally be applied to other culturally and linguistically diverse populations. Further, the results of this study demonstrate the need for all SLPs, regardless of their personal cultural identity, to develop and expand their cultural competence. This can be done through continued education in cultural and linguistic topics, staying up-to-date on current research concerning diverse populations, and conducting qualitative research studies. This study demonstrates the importance of cultural competence, as enhanced knowledge of the relationship between culture and management of communicative disorders will allow SLPs to accurately identify the individual needs of families, as well as to promote development of practices that are respectful of linguistic and cultural diversity.

APPENDICES

APPENDIX A IRB APPROVAL LETTER

IRB APPROVAL LETTER



CALIFORNIA STATE UNIVERSITY, LONG BEACH

OFFICE OF RESEARCH & SPONSORED PROGRAMS

DATE: August 1, 2014

TO: Sinead Campbell, B.A.

FROM: California State University, Long Beach (IRB)

PROJECT TITLE: [589599-2] Latino Families in Transition: Phenomenological Study of Latino

Parents of Children with Communicative Disorders and the Quests for

Services Across Borders

REFERENCE #: 15-013s SUBMISSION TYPE: Revision

ACTION: APPROVED
APPROVAL DATE: August 1, 2014
EXPIRATION DATE: July 31, 2015
REVIEW TYPE: Administrative

This is to advise you that the Institutional Review Board for the Protection of Human Subjects (IRB) of California State University, Long Beach, has reviewed your protocol application.

Your application is approved. The requested modifications have been received, reviewed, and accepted.

Approval is for a period of one year from the date of this letter and conditional upon your willingness to carry out your continuing responsibilities under University policy. If you would like to continue this research after this one year period, please submit a renewal application and an annual report to the Office of Research & Sponsored Programs two months prior to your expiration date of July 31, 2015.

- You must clearly indicate in the header or footer of each page of your approved Informed Consent Form the approval and expiration dates of the protocol as follows: "Approved from August 1, 2014 to July 31, 2015 by the CSULB IRB".
- 2. You are required to inform the Director or Senior Associate Director, Office of Research & Sponsored Programs, in writing (email is acceptable) or through IRBNet within twenty-four hours of any adverse event in the conduct of research involving human subjects. The report shall include the nature of the adverse event, the names of the persons affected, the extent of the injury or breach of security, if any, and any other information material to the situation.
- 3. You may not change any aspect of your research procedure involving human subjects without written permission from the Director, Office of Research & Sponsored Programs or the Chair of the IRB. Please use the Protocol Modification Form on IRBNet to request any changes.

- 1 -

Generated on IRBNet

APPENDIX B CONSENT FORM FOR NON-MEDICAL RESEARCH

CONSENT FORM FOR NON-MEDICAL RESEARCH

CONSENT TO PARTICIPATE IN RESEARCH

Title of study: Latino Families in Transition: Phenomenological Study of Latino Parents of Children with Communicative Disorders and the Quest for Services Across Borders

You are asked to participate in a research study conducted by Sinead Campbell, B.A. and Carolyn Conway Madding, Ph.D., CCC-SLP, from the Department of Speech-Language Pathology at California State University, Long Beach. The results of this study will be contributed to a graduate level thesis and an on-going research project. You were selected as a possible participant in this study because you are a Latino parent who is interested in sharing your experiences regarding your immigration to the United States to seek services for your child with communicative disorders.

PURPOSE OF THE STUDY

To identify the common themes that arise across Latino families regarding their transition to life in the United States, and the quest for available and affordable services for their children.

To describe the general principles of phenomenological research, discuss cultural and linguistic barriers encountered by Latino parents of children with communicative disorders, and explain how speech-language pathologists can facilitate service-seeking through enhanced knowledge of Latino Culture.

The results of this study will be presented at California Speech-Language-Hearing Association (CSHA) and American Speech-Language-Hearing Association (ASHA) conventions, and developed for publication in professional journals.

PROCEDURES

If you volunteer to participate in this study, you will do the following things:

- 1) After informed consent has been obtained from each parent, the PIs will coordinate an individualized interview schedule with each participant. Each participant will choose the interview dates and times to allow for flexibility and guarantee that he/she attends all interviews. The interviews will be scheduled between August 4, 2014 and December 14, 2014.
- 2) Each participant will attend six to ten 60-minute individual interviews in a private room at the CSULB Speech and Language Clinic. Parking expenses and/or travel

will be paid for by the PIs. The number of total interviews conducted will vary dependent upon how long it takes each participant to discuss all of the points included on the Parent Interview Guide (Appendices C & D). The participants will be encouraged to speak whatever language(s) they prefer and to code-switch when they wish. The interviewers will match the participant's language selections, as they are fluent in both English and Spanish.

- 3) The interviews will be audio recorded and later transcribed verbatim in their entirety. If at any moment within an interview the participant wishes to omit disclosed information, they reserve the right to stop the interview and request that the PIs delete that section of the audio recording. Once each interview is completed, the participant will not be able to review audio recordings or transcripts.
- 4) At the completion of each interview, the participant will be thanked for his/her time and the next interview will be scheduled.

POTENTIAL RISKS AND DISCOMFORTS

- 1) Breach of Confidentiality
- 2) Emotional/Psychological distress: Participants will be asked to provide information about their lived experiences involving the parenting of children with communicative disorders. Discussing these experiences may cause the parent to become emotional and/or uncomfortable. The participant may feel regret after disclosing specific information.

PROTECTION AGAINST OR MINIMIZING RISKS

- 1) Although confidentiality during the interview process will automatically be broken due to the nature of the interaction, confidentiality outside of the interview room will be maintained by using pseudonyms for each parent in recorded data. The interviews will be held in a private location within the Department of Speech-Language Pathology. All personal and/or shared information provided by the parents will not be disclosed to anyone aside from the PIs who will analyze the data together. Audio recordings with this information will be stored under lock and key and will not contain any identifying information.
- 2) Prior to beginning each interview, the participant will be informed of his/her right to bypass any questions he/she does not feel comfortable answering. If at any point the participant wishes to omit disclosed information, they reserve the right to stop the interview and request that the PIs delete that portion of the audio recording. If a participant appears to be experiencing emotional or psychological distress, the

interviewer will:

- -Stop the interview
- -Allow the participant to take a break for as much time as necessary
- -Allow the participant to decide whether to continue with the interview. If the participant decides to discontinue the interview, the interview will pick up where it left off at the next scheduled interview.
- -The participant will be provided with information about available resources that could address emotional challenges at their expense.

POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Although there are not many benefits to the participants, there is some evidence to indicate that most interview participants benefit from having someone to listen to their stories in qualitative interviews. According to Murray (2003), giving participants an opportunity to tell their own stories allows them to begin the process of making sense of what has happened to them.

Students and professionals in the field of speech-language pathology will be given an overview of the general principles of phenomenological qualitative research. They will also gain insight into the cultural and linguistic barriers encountered by Latino parents of children with communicative disorders. Lastly, they will be given information on how they can facilitate service-seeking through enhanced knowledge of the Latino Culture. This will be done by presenting the results of this study at the California Speech-Language-Hearing Association (CSHA) and American Speech-Language-Hearing Association (ASHA) conventions, and publishing in a professional journal.

PAYMENT FOR PARTICIPATION

The participants will not receive payment; however travel and/or parking expenses will be paid for by the PIs. The PIs will make individualized payment plans with each participant during the first scheduled interview.

CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

The interviews will be audio-recorded. If at any point the participant wishes to omit disclosed information, they reserve the right to stop the interview and request that the PIs

delete that portion of the audio recording. Once each interview is completed, the participant will not be able to review audio recordings or transcripts. Dr. Carolyn Conway Madding and Sinead Campbell will be the only individuals who will have access to the recordings. Audio recordings will be stored under lock and key and will not contain any identifying information.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. Participation or non-participation will not affect your chances of receiving services at the California State University, Long Beach Speech and Language Clinic or any other personal consideration or right you usually expect. You may also refuse to answer any questions you do not want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which in the opinion of the researcher warrant doing so. The principal investigators will pay for parking and/or travel expenses as compensation for participating in the study.

IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Sinead Campbell (Principal Investigator) and Carolyn Conway Madding (Principal Investigators, Faculty Sponsor).

Contact Information:

Sinead Campbell: (909) 367-4203 or Srcamp@hotmail.com

Carolyn Conway Madding (562) 985-5283 or Carolyn.Madding@csulb.edu

RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact the Office of University Research, CSU Long Beach, 1250 Bellflower Blvd., Long Beach, CA 90840; Telephone: (562) 985-5314 or email to ORSP-Compliance@csulb.edu

SIGNATURE OF RESEARCH SUBJECT

I understand the procedures and conditions of my participation described above. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.		
Division CO 1:		
Printed Name of Subject		
Signature of Subject or Legal Representative	Date	
STATEMENT and SIGNATURE OF INVESTIGATOR	S	
In my judgment the subject is voluntarily and knowingly possesses the legal capacity to give informed consent to		
Signatura of Investigator	Data	
Signature of Investigator	Date	
Signature of Investigator	 Date	

APPENDIX C

CONSENT FORM FOR NON-MEDICAL RESEARCH (SPANISH)

FORMULARIO DE CONSENTIMIENTO PARA LA INVESTIGACIÓN NO MÉDICA CONSENTIMIENTO PARA PARTICIPAR EN LA INVESTIGACIÓN

Título de estudio: Familias Latinas en Transición: Estudio Fenomenológico de los Padres Latinos de Niños con Trastornos de la Comunicación y la Búsqueda de Servicios Transfronterizos

Se le pide que participe en un estudio de investigación llevada a cabo por Sinead Campbell, B.A. y Carolyn Conway Madding, Ph.D., CCC-SLP, del Departamento de Patología del Habla y el Lenguaje de la Universidad Estatal de California en Long Beach. Los resultados de este estudio serán aportados a una tesis de postgrado y un proyecto de investigación en curso. Usted ha sido seleccionado como posible participante en este estudio porque usted es un padre Latino que está interesado en compartir sus experiencias acerca de su traslado a los Estados Unidos en busca de servicios para su niño con trastornos de comunicación

PROPÓSITO DEL ESTUDIO

Para identificar los temas comunes que surgen a través de las familias Latinas acerca de su transición a la vida en los Estados Unidos, y la búsqueda de servicios disponibles y asequibles para sus hijos.

Describir los principios generales de la investigación fenomenológica, investigar las barreras culturales y lingüísticas que encuentran los padres Latinos de niños con trastornos de comunicación, y explicar cómo los patólogos del habla y lenguaje pueden facilitar servicio de búsqueda a través de un mayor conocimiento de la Cultura Latina.

Resultados de este estudio se presentarán en las convenciones de la Asociación del Habla el Lenguaje y la Audición de California y de la Asociación Americana del Habla, el Lenguaje y la Audición. Los resultados serán desarrollados para publicación en revistas profesionales.

PROCEDIMIENTOS

Si usted se ofrece voluntariamente para participar en este estudio, usted hará las siguientes cosas:

1) Después de obtener el consentimiento informado de cada uno de los padres, los investigadores principales (IP) coordinarán un horario de entrevistas individualizado con cada participante. Cada participante tendrá la oportunidad de elegir las fechas y horas de las entrevistas para permitir la flexibilidad y la garantía de que él / ella está presente en todas las entrevistas. Las entrevistas serán conducidas entre el 04 de agosto 2014 y el 14 de diciembre de 2014.

- 2) Cada participante atenderá entre seis y diez entrevistas individuales de 60 minutos en una habitación privada en la Clinica del Habla y el Lenguaje en CSULB. Gastos de estacionamiento y / o viajes serán pagados por el IP. El número de entrevistas realizadas en total variará depende de cuánto tiempo le toma a cada participante a discutir todos los puntos incluidos en la Guía de Entrevista (Apéndice D). Los participantes pueden hablar cualquier idioma que prefieren. Los entrevistadores coinciden con selecciones de idioma de los participantes, ya que hablan Inglés y Español.
- 3) Las entrevistas serán grabadas a través de audio y transcritas en su totalidad. Si en cualquier momento dentro de una entrevista el participante desea retirar la información divulgada, se reservan el derecho de parar la entrevista y pedir que los investigadores principales borren esa sección de la grabación de audio. Cuando se termine cada entrevista, el participante no se le dará la oportunidad de revisar las grabaciones de audio o transcripciones.
- 4) Al final de cada entrevista, los investigadores principales expresarán gratitud hacia cada participante por su tiempo y la próxima entrevista será planeada.

POSIBLES RIESGOS E INCOMODIDADES

- 1) El incumplimiento de la confidencialidad
- 2) Angustia Emocional / Psicológica: Se les pedirá a los participantes divulgar información sobre sus experiencias que implican la crianza de los niños con trastornos de comunicación. Hablar de estas experiencias puede hacer que el padre se convierta emocional y / o incómodo. El participante puede sentir arrepentimiento después de revelar esta información.

PROTECCIÓN CONTRA O PARA MINIMIZAR LOS RIESGOS

- 1) Aunque la confidencialidad durante el proceso de la entrevista de forma automática se romperá debido a la naturaleza de la interacción, la confidencialidad fuera del cuarto de entrevistas se mantendrá mediante el uso de seudónimos para cada padre en los datos grabados. Las entrevistas se llevarán a cabo en una habitación privada en el Departamento de Patología del Habla y el Lenguaje. Toda la información personal divulgada por los padres no será compartida con nadie aparte de los investigadores principales quienes analizarán los datos. Las grabaciones de audio con esta información se guardarán bajo llave y no contendrán información de identificación.
- 2) Antes de comenzar cada entrevista, el participante será informado de su derecho a

pasar por alto cualquier pregunta que él / ella no se siente cómodo respondiendo. Si en cualquier momento el participante desea omitir la información divulgada, se reserva el derecho de parar la entrevista y pedir que los investigadores principales eliminen esa porción de la grabación de audio. Si un participante parece estar angustiado, el entrevistador hará lo siguiente:

- -Detener la entrevista
- -Permitir que el participante tome un descanso para tanto tiempo como sea necesario
- -Permitir que el participante decida si desea continuar con la entrevista. Si el participante decide suspender la entrevista, la entrevista será continuar donde lo dejó en la próxima entrevista programada.
- -El participante se le proporcionará información acerca de los recursos disponibles que podrían abordar los desafíos emocionales a sus expensas.

LOS BENEFICIOS POTENCIALES PARA LOS SUJECTOS Y/OA LA SOCIEDAD

Aunque no hay muchos beneficios para los participantes, hay cierta evidencia que indica que la mayoría de los participantes en las entrevistas se benefician de tener a alguien que escuche sus historias en entrevistas cualitativas. Según Murray (2003), dando a los participantes la oportunidad de contar sus propias historias les permite iniciar el proceso de dar sentido a lo que les ha sucedido.

Los estudiantes y profesionales en el área de patología del habla y lenguaje se les darán una descripción de los principios generales de la investigación cualitativa fenomenológica. También obtendrán información sobre las barreras culturales y lingüísticas que enfrentan los padres Latinos de niños con trastornos de comunicación. Por último, se les dará información sobre cómo se puede facilitar búsqueda de servicios a través de mejor conocimiento de la cultura latina. Esto se realizara a través de la presentación de los resultados de este estudio en las convenciones de la Asociación de Habla-Lenguaje-Audición de California y de la Asociación Americana del Habla, Lenguaje y Audición, y publicaciones en revistas profesionales.

PAGO DE PARTICIPACIÓN

Los participantes no recibirán pago; sin embargo los viajes y / o gastos de estacionamiento serán pagados por el IP. Los investigadores principales harán planes de pago individualizados con cada participante durante la primera entrevista.

CONFIDENCIALIDAD

Cualquier información que se obtenga en este estudio y que puede ser identificada con

usted se mantendrá confidencial y será compartida solamente con su permiso o de lo requerido por la ley.

Las entrevistas serán grabadas a través de audio y transcritas en su totalidad. Si en cualquier momento el participante desea omitir la información divulgada, se reservan el derecho de parar la entrevista y pedir que los investigadores principales borren esa porción de la grabación de audio. Cuando se termine cada entrevista, el participante no se le dará la oportunidad de revisar las grabaciones de audio o transcripciones. La Dra. Carolyn Conway Madding y Sinead Campbell serán las únicas personas que tendrán acceso a las grabaciones. Las grabaciones de audio se guardarán bajo llave y no contendrán información de identificación.

PARTICIPACIÓN Y RETIRO

Usted puede elegir si desea participar en este estudio o no. Si usted se ofrece voluntariamente para participar en este estudio, puede retirarse en cualquier momento sin ningún tipo de consecuencias. La participación o no participación no afectará sus posibilidades de recibir servicios en la Clínica de Habla y Lenguaje en la Universidad Estatal de California, Long Beach o cualquier otra consideración personal o derecho que usted normalmente espera. Usted también puede negarse a contestar cualquier pregunta que no quiera contestar y todavía permanecer en el estudio. Los investigadores pueden retirar a cualquier participante de esta investigación si surgen circunstancias que, en opinión de investigador hacerlo. Estacionamiento y / o gastos de viaje serán pagados por los investigadores principales.

IDENTIFICACIÓN DE LOS INVESTIGADORES

Si usted tiene cualquier pregunta o preocupación acerca de la investigación, por favor comuníquese con Sinead Campbell (Investigadora Principal) y Carolyn Conway Madding (Investigadora Principal, Facultad Patrocinador).

Información del contacto:

Sinead Campbell: (909) 367-4203 o Srcamp@hotmail.com

Carolyn Conway Madding (562) 985-5283 o Carolyn.Madding@csulb.edu

DERECHOS DE LOS SUJETOS DE INVESTIGACIÓN

Usted puede retirar su consentimiento en cualquier momento y dejar de participar sin penalización. Usted no renuncia a cualquier reclamación legal, derechos o recursos a causa de su participación en este estudio de investigación. Si usted tiene preguntas sobre

sus derechos como sujeto de investigación, comuníquese con la Oficina de Investigación de la Universidad, CSU Long Beach, 1250 Bellflower Blvd. Long Beach, CA 90840.; Teléfono: (562) 985-5314 o por correo electrónico a ORSP-Compliance@csulb.edu.

FIRMA DEL SUJETO DE INVESTIGACIÓN

Entiendo los procedimientos y condiciones de mi participa anteriormente. Mis preguntas han sido contestadas a mi sa en participar en este estudio. Me han dado una copia de es	tisfacción, y estoy de acuerdo
Nombre del sujeto	
Firma del Participante o Representante Legal	Fecha
DECLARACIÓN Y FIRMA DE LOS INVESTIGADORE A mi juicio, el tema está dando voluntariamente y con con- informado y posee la capacidad legal para dar su consentir participar en este estudio de investigación.	ocimiento de consentimiento
Firma del Investigador	Fecha
Firma del Investigador	Fecha

APPENDIX D PARENT INTERVIEW GUIDE

PARENT INTERVIEW GUIDE

Guide for Interview 1: Focused Life History

- Describe your native country and region.
- Why did you decide to immigrate to the United States?
- Do you miss your native country? If so, in what ways?
- Did you know any English when you arrived?
- How were you able to communicate with others when you first arrived to the United States?
- Are there significant differences between your life in your native country and in the United States?
- Are you pleased that you came to the United States?
- When you were in your native country, did you realize that your child needed special services?
- What did you notice in your child's development that caused concern?
- Was your child diagnosed in your native country?

Guide for Interview 2: Birth Practices and Details of Daily Life *Birth Practices*

- Describe the day your child was born.
- Was your child born in a hospital, at home, or elsewhere? Please describe the setting in detail.
- Was there a doctor or midwife who assisted with the delivery?
- Were both parents present at the time of birth?
- Were other people present at the time of birth? If so, who?
- Were there any complications at the time of the delivery or afterward?
- Describe your child when you first saw him/her.
- What was the child's father's/mother's reaction to the child at the time of birth?

The Details of Daily Life

- How many people live in your home?
- What are their relationships to you?
- Describe your home.
- Which persons, who live in your home, contribute to the expenses of the household?
- Who is responsible for childcare on a regular basis?
- Does someone take the children to and from school each day (Car, bus, walk, or other)?
- Does your family eat meals together?
- What type of food do you usually eat?

Guide for Interview 3: The Details of Your Child's Current Experience

- What is a typical day for your child?
- What services is your child currently receiving?
- Are your child's current services what you wish for them to be?
- How do you feel about your relationship with your child's school and school team?
- How do you feel about your child's current development in communication?
- What languages do you use in a typical day?

- What languages does your child use in a typical day?
- What roles do you and other family members play in your child's language learning?
- What roles do teachers and professionals play?
- Does your child's school have programs for parents of ELL students?
- Do you feel your child's school offers supports to foreign-born parents?
- How do you feel about communicating in English now?
- What is a priority for you right now regarding your child?

Guide for Interview 4: Details of Your Current Experience with School and Medical Services

- In what services is your child currently enrolled?
- Who referred you to the CSULB Speech and Language Clinic?
- How did you find the other programs your for child?
- Do you and your family have medial insurance?
- Does your child have an IEP?
- What services is your child currently receiving in the school?
- Do you believe there are other medical or educational services that your child needs but is not now receiving?

Guide for Interview 5: Linguistic and Cultural Guidelines

- How did you meet your child's father/mother?
- What is your current status with the child's father/mother?
- Can you describe his/her background?
- What language(s) do you speak? How are they different form each other?
- Describe your childhood and upbringing.
- What did you know about disabilities before having a child with special needs?
- What cultural beliefs do the people from your native area have in regard to disabilities or differences?
- Did others notice anything about your child that caused concern?
- Were you reluctant to seek help due to any stigma?
- What is the education system like in your native country?
- Are there available programs for children with communicative disorders in your native country?

Guide for Interview 6: Reflection

- What advice do you have for your child's teachers or therapists for how to work with your child to promote his or her communication?
- Do you have any advice for teachers and therapists for how to work with immigrant families?
- Do you have any advice for other parents in your situation?
- What do you think would be the ideal education program for your child?
- What do you think would be the ideal educational outcome for your child?
- What are your hopes for your child's future? What do you imagine and what would you like to see?

APPENDIX E

PARENT INTERVIEW GUIDE (SPANISH)

GUIA DE ENTREVISTA

Guía para la Entrevista 1: Historia de Vida

- Describa su país y región de origen.
- ¿Por qué decidió emigrar a los Estados Unidos?
- ¿Extraña a su país de origen? Si es así, ¿de qué manera?
- ¿Sabía usted Inglés cuando llego?
- ¿Cómo se comunicaba con los demás, cuando llegó a los Estado Unidos por primera vez?
- ¿Existen diferencias significativas entre su vida en su país de origen y su vida en los Estados Unidos?
- ¿Está usted satisfecha/o con su decisión de venir a los Estados Unidos?
- ¿Cuándo usted estaba en su país de origen, se dio cuenta de que su hijo/a necesita servicios especiales?
- ¿Qué notó en el desarrollo de su hijo/a que causó preocupación?
- ¿Fue su hijo/a diagnosticado en su país de origen?

Guía para la Entrevista 2: Prácticas de nacimiento y Los detalles de la vida diaria *Prácticas de nacimiento*

- Describa el día que nació su hijo/a.
- Su niño/a nació en un hospital, en casa, o en otro lugar? Por favor, describa el lugar en detalle.
- ¿Hubo un médico o partera que asistió con el nacimiento?
- ¿Fueron los dos padres presentes en el momento del nacimiento?
- ¿Había otras personas presente en el momento del nacimiento? Si es así, ¿quién?
- ¿Hubo alguna complicación en el momento del nacimiento o después?
- Describa a su hijo cuando lo/la vio por primera vez.
- ¿Cuál fue la reacción de el padre/la madre del niño, sobre el niño en el momento del nacimiento?

Los detalles de la vida diaria

- ¿Cuántas personas viven en su hogar?
- ¿Cuáles son sus relaciones con usted?
- Describa su casa.
- ¿Qué personas, que viven en su hogar, contribuyen a los gastos del hogar?
- ¿Quién es responsable por el cuidado de los niños regularmente?
- ¿Alguien lleva a los niños a la escuela todos los días (en coche, autobús, a pie, o de otro tipo de transporte)?
- ¿Come su familia comidas juntos?
- ¿Qué tipo de comida comen usualmente?

Guía para la Entrevista 3: Los detalles de la experiencia actual de su hijo

- ¿Qué es un día típico para su hijo/a?
- ¿Qué servicios está recibiendo su hijo/a actualmente?
- ¿Son los servicios actuales de su hijo/a lo que deseas que sean?
- ¿Cómo se siente acerca de su relación con la escuela de su hijo/a y los profesionales de la escuela?
- ¿Cómo se sientes acerca del desarrollo actual de su hijo en la comunicación?
- ¿Qué idiomas se utilizan en un día típico?
- ¿En qué idiomas habla su hijo en un día típico?
- ¿Qué papel juega usted y otros miembros de la familia en el aprendizaje del lenguaje de su hijo/a?
- ¿Qué papel juegan los profesores y los profesionales?

- ¿Tiene la escuela de su hijo/a programas para padres de estudiantes que están aprendiendo inglés?
- ¿Siente usted que la escuela de su hijo/a ofrece apoyo a los padres nacidos en el extranjero?
- ¿Cómo se siente acerca de comunicarse en Inglés ahora?
- ¿Qué es una prioridad para usted en este momento con respecto a su hijo?

Guía para la Entrevista 4: Detalles de su experiencia actual con la Escuela y los Servicios Médicos

- ¿En qué servicios está su hijo/a matriculado actualmente?
- ¿Quién lo refirió a la Clínica del Habla y el Lenguaje Clínica en CSULB?
- ¿Cómo se enteró de los otros programas para su hijo/a?
- ¿Usted y su familia tiene seguro médico?
- ¿Su hijo/a tiene un IEP?
- ¿Qué servicios está recibiendo su hijo/a actualmente en la escuela?
- ¿Cree usted que hay otros servicios médicos o educativos que necesita su hijo/a, pero no está recibiendo?

Guía para la Entrevista 5: Directrices Lingüísticos y Culturales

- ¿Cómo conoció a el padre/la madre de su hijo/a?
- Cual es su estado actual con el padre/la madre del niño/a?
- ¿Puede describir a los antecedentes de él/ella?
- ¿Qué idioma(s) habla usted? ¿En qué son diferentes unos a otros?
- Describa su infancia y crianza.
- ¿Qué sabia usted de discapacidad antes de tener un niño con necesidades especiales?
- ¿Qué creencias culturales tienen las personas de su área nativa con respecto a las discapacidades o las diferencias?
- ¿Otros notaron algo sobre su hijo/a que causó preocupación?
- ¿Decidió no buscar ayuda debido a la estigmatización?
- ¿Cómo es el sistema educativo en su país de origen?
- ¿Existen programas disponibles para los niños con trastornos de comunicación en su país de origen?

Guía para la Entrevista 6: Reflexión

- ¿Qué consejo le daría a los profesores o terapistas de su hijo/a sobre cómo trabajar con su niño/a para promover su comunicación?
- ¿Tiene algún consejo para los maestros y terapistas para saber cómo trabajar con las familias inmigrantes?
- ¿Tiene algún consejo para otros padres en situaciones similares a la suya?
- ¿Qué cree que sería el programa de educación ideal para su hijo/a?
- ¿Qué cree que sería el resultado ideal de educación para su hijo/a?
- ¿Cuáles son sus esperanzas para el futuro de su hijo/a? ¿Qué se imagina y qué es lo que le gustaría ver?

APPENDIX F RECRUITMENT FLYER

RESEARCH VOLUNTEERS NEEDED

- o Are you a Latino parent of a child with communicative disorders?
- o Did you move to the United States to seek services for your child?
- O Do you speak Spanish as your primary language?

If you answered YES to these questions, you may be eligible to participate in a research study.

The purpose of the study is to identify the common themes that arise across Latino families regarding their transition to life in the United States, and the quest for available and affordable services for their children. The Principal Investigators will pay for travel and/or parking expenses as compensation for participating in the study.

Commitment: Each volunteer will attend six-to-ten 60-minute individual interviews. The interviewers will ask questions about your experiences related to your move to the United States to seek services for your child.

When: August 4th –December 15th

Where: The interviews will be held in a private clinic room within the CSULB Speech and Language Clinic.

Who: The participants of this study must be 18 years of age or older and meet the following criteria:

- a) have at least one child diagnosed with a communicative disorder
- b) moved to the United States to seek services for his/her child
- c) be a Latino/Latina and speak Spanish as the primary language

If you are interested, please contact

Sinead Campbell or Dr. Carolyn Conway Madding

Cell phone: (909) 367-4203 Office phone: (562) 985-5283

Email: <u>Srcamp@hotmail.com</u> Email: <u>Carolyn.Madding@csulb.edu</u>

Thank you!

APPENDIX G RECRUITMENT FLYER (SPANISH)

SE NECESITAN VOLUNTARIOS PARA UN ESTUDIO DE INVESTIGACIÓN

- ¿Es usted un padre Latino de un niño con trastornos de comunicación?
- ¿Ha venido usted a los Estados Unidos en busca de servicios para su hijo?
- ¿Habla usted español como su idioma materno?

Si usted contestó SI a estas preguntas, usted puede ser elegible para participar en un estudio de investigación.

El objetivo del estudio es identificar los temas comunes que surgen a través de las familias latinas con respecto a su transición a la vida en los Estados Unidos, y la búsqueda de servicios disponibles y asequibles para sus hijos. Los gastos de viaje y/o de estacionamiento serán pagados por los investigadores principales.

Compromiso: Cada voluntario asistirá seis a diez entrevistas individuales de 60 minutos. Los entrevistadores harán preguntas acerca de sus experiencias en relación con su traslado a los Estados Unidos en busca de servicios para su hijo.

Cuándo: 4 de Agosto a 15 de Diciembre

Dónde: Las entrevistas se llevarán a cabo en una habitación privada en la Clínica del Habla y el Lenguaje en CSULB.

Quién: Los participantes de este estudio deben tener 18 años de edad o más y cumplir con los siguientes criterios:

- a) tiene al menos un niño diagnosticado con un desorden comunicativo
- b) se trasladó a Estados Unidos en busca de servicios para su hijo/a
- c) ser Latino/Latina y habla español como idioma materno

Si usted está interesado, por favor comunicase con:

Sinead Campbell o Dra. Carolyn Conway Madding

Celular: (909) 367-4203 Oficina: (562) 985-5283

Email: <u>Srcamp@hotmail.com</u> Email: <u>Carolyn.Madding@csulb.edu</u>

Gracias!

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