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## THE NEEDS AND CHALLENGES EXPERIENCED BY LATINO PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

Lizbeth Quintero

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THE NEEDS AND CHALLENGES EXPERIENCED  
BY LATINO PARENTS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Lizbeth Quintero

June 2018

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## ABSTRACT

With an estimated 1.8 million children born in the US with a developmental disability in the past decade and a 43% increase in the Latino population in the same time period, there are more Latino parents who have children born with a developmental disability than ever before. Due to factors such as language barriers and legal status, Latino parents of children with developmental disabilities tend to experience higher needs. This study explored the challenges and needs Latino parents faced when caring for a child with special needs. The design of the study was qualitative. Participants were a convenience sample of nine Latino women who had a child or children with a developmental disability. Results of the study suggested that there was a large need for more parental education regarding developmental disabilities, support groups, and a larger variety of services and programs available to both parents and children. Increased length and frequency of services were also identified as needs. The most common barriers to the accessibility of programs and services for Latino parents were language barriers and legal status. Other findings discussed focus on the programs and services that parents have found beneficial as well as the role social workers play in the accessibility and attainability of programs, services and resources.

## ACKNOWLEDGEMENTS

The completion of this project could not have been possible without the guidance and advice of my professors, the support and encouragement from the members of my cohort, the participation of the mothers who took part in this study or the continuous inspiration and moral support I have received from my friends and family. I have extreme gratitude for the opportunities I have been given and I am equally grateful to those who have believed in me along the way.

## DEDICATION

Con amor y agradecimiento, le dedico el esfuerzo que llevo acabo este proyecto a mis padres y hermanos quienes han sido mi ejemplo y fuente de inspiración.

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## CHAPTER ONE

### INTRODUCTION

#### Problem Statement

Parenting could easily be one of the most difficult roles of adulthood. A child's dependency on their caregiver requires constant attention, close monitoring and around-the-clock special care. Parents assert responsibility over their children's well-being from birth until adolescence. In addition, many requirements that go into raising a child can make parenting a mentally stressful and physically taxing part of life. The parenting requirements for parents who have children born with Developmental Disabilities (DD), are not only higher, but they also create more stress.

The Centers for Disease Control (CDC) defines developmental disabilities as a "group of severe chronic conditions that are due to mental and/or physical impairments" (cdc.gov, n.d. 2017). Statistics presented by the CDC demonstrate that there has been a 17.1 % increase in DD in the past decade. According to the CDC there are an estimated 1.8 million more children who have been born with DD since 2008 alone (cdc.gov, n.d. 2017). Despite Latino children having a lower probability of being born with a developmental disability than their non-Latino white and non-Latino black counterparts, data suggests that there is an increasing number of children being born with DD cross-culturally; therefore, a

larger number of Latino families are facing more hardships in raising children with DD. Children born with DD require closer attention and more specialized care. As a result, increased parenting requirements are not only associated with higher levels of mental, emotional and physical distress but also, higher levels of parental needs in general. Contrastingly, due to added factors such as language barriers, legal status and lack of education about their child's diagnosis, Latino parents who have children born with DD are at higher risk for mental and physical stress and exhibit a broader range of needs (Al-Kandari, 2014).

According to 2010 statistics, the Latino population in the U.S. increased 43% in the last 10 years (Balcazar, Suarez-Balcazar, Adames, García-Ramírez & Paloma, 2012). Currently, the Latino population comprises 16% of the total U.S. population; accordingly, the disability rate amongst Latinos is 10.4% (Balcazar, Suarez-Balcazar, Adames, García-Ramírez & Paloma, 2012). Data indicates that overall, Latino families living in the U.S. are less likely to access health and other community support services, including the services needed to care for children with disabilities (Bailey, Skinner, & Correa, 1999). Latino parents of children with developmental disabilities have more difficulty meeting their needs and the needs of their children due to factors such as language barriers, inadequate knowledge of systems and services, poor help-seeking behavior, distrust of service providers and perceived discrimination by service providers or the agencies they represent (Bailey, Skinner, & Correa, 1999).

Furthermore, poverty, divorce, low education and social isolation are factors that augment Latino parent's difficulty in addressing their needs (Bailey, Skinner, & Correa, 1999). Studying the needs reported by Latino parents who have children with DDs could reveal important information about the challenges and most frequent needs experienced by this population. Moreover, understanding the needs and challenges of this population could help agencies and service providers deliver better and more specific services and resources that could help parents decrease mental and physical stress and as a result, become better care-givers to their children. Becoming better care-givers would make it possible for parents to create a thriving environment for them and their children (Algood, Harris & Hong, 2013). Very limited information is available about experiences faced by Latino parents who have children with DD, this study intends to fill the gaps in this area.

### Purpose of the Study

The purpose of the study is to examine the needs and challenges experienced by Latino parents who have children with a developmental disability. This study also aims to further understand the different attitudes, mental and emotional challenges, and various changes in the type of needs Latino parents experienced at different stages of their children's development. Another interest of the study is to explore the factors that have interfered with Latino parent's

meeting their needs. A deeper understanding of the type of challenges and needs experienced by Latino parents who have children with DD, will assist in identifying more suitable ways to address presenting issues. Furthermore, this study seeks to shine light on this issue so that further studies relating to this topic could be conducted in the future. The importance of meeting the needs of Latino parents who have children with DD is paramount in regard to the quality of life experienced by their families and the amount of successes manifested in their children who have a developmental disability (Algood, Harris & Hong, 2013).

A qualitative research design will be utilized to address the purpose of the study. This type of research design will allow the investigator to use a relatively small sample size and to focus on human subjectivity or -the participant's experiences in relation to the problem area under study (Engel &Schutt, 2014). Conducting the study utilizing a qualitative research design will allow for one-on-one, in-person interviewing. Investigator observations of participant's tone of voice, body language and facial expressions will provide additional information about the effects that caring for a child with DD has on Latino parents.

The variation of narratives that will result from asking open-ended questions will produce a broader range of self-reported needs and challenges faced by Latino Parents who have children with DD. One factor that can affect a parent's self-reported needs is the severity of a child's diagnosis. Furthermore, utilizing qualitative research design for this study will aid the investigator in exploring a topic in which extensive research has not been done (Engel &Schutt,

2014). In addition, qualitative research design will make it possible for the investigator to involve themselves as the primary tool in conducting the study (Engel & Schutt, 2014).

Research methods characteristic of qualitative research design will be implemented in order to execute the study. A sample of 8 to 10 participants will be used. Participants are required to be Latino and they must have at least one child who has a DD. Convenience sampling and snowball effect sampling will be the methods of choice to find and gather participants. The investigator will create an instrument made up of 15 to 25 questions that will be asked to participants during the interviewing process. The majority of the questions asked to participants will be open-ended questions; this will promote free expression and fuller disclosure of the experiences lived by participants as a result of caring for a child with a DD. The responses of participants will be hand-written or digitally recorded through the use of a voice recorder and later transcribed onto a word document.

### Implications for Social Work Practice

Forming a more complete understanding about the varying challenges endured by Latino parents who have children with a developmental disability diagnosis will create awareness in the social work profession about the emotional, mental and physical needs experienced by Latino parents. Likewise,



results from this study could provide a much clearer image about the difficulties Latino parents encounter in accessing services or dealing with the financial implications that come from raising a child with developmental disabilities; through a more concise understanding of these issues, social work practitioners will be better able to navigate these situations and identify the areas of greater need (O'Mullan, Wayne, Krishnagiri, 2005). Learning more about Latino parents and their specific needs in raising a child with DD will help social workers become more culturally competent. In addition, social workers will also be able to empower parents by educating them about the importance of self-care as well as fostering the belief that as parents, they are capable of making their own choices and have much to offer in shaping their life, the life of their children and society overall (Balcazar et al, 2012). The findings of this study could also provide social workers with information that could help them assess the design and delivery of services, reveal the process and nature of service delivery, clarify clients' perceptions of interventions and understand why Latino parents in need of services do not seek help (O'Mullan, Wayne, Krishnagiri, 2005).

## CHAPTER TWO

### LITERATURE REVIEW

#### Introduction

A number of studies have been conducted to examine what factors affect a parent's ability to provide the best environment for their children with special needs. These studies have looked into the importance of family dynamics, a parent's support system and the accessibility to services and resources and how these affect a parent's ability to cope with their children's DD. The following studies explore each of these areas and emphasize how each of these factors play a role in the life of parents and children alike.

#### Examining Parent-Child Dynamics in Families of Children with Disabilities

A parent's understanding of their child's diagnosis can affect their parenting style. The following study found that positive emotions have more favorable outcomes in children with a Developmental Disability (DD) (Marquis & Baker, 2014). Marquis and Baker (2014) conducted a longitudinal study that compared the parenting practices enforced by Anglo versus Latino parents. Participants were 191 families enrolled in the Collaborative Family Study (CFS). Seventy-five

percent of the participants were from Southern California and 25% were from central Pennsylvania. The Collaborative Family Study included four separate universities. Mothers of children between the ages of 3-5 were given a brochure that entailed the information regarding the study; participants were later interviewed, and their responses recorded.

The study found that Latino mothers of children with DD reported viewing their children as less responsible for their behavioral problems. This suggests that Latino mothers were more accepting of their children's cognitive and practical limitations than were their counterparts. In contrast, Anglo mothers exhibited higher sensitivity or were more reactive to their children's behaviors than Latino mothers. Additionally, Latino mothers reported higher internalizing and externalizing of problems than their Anglo counterparts (2014). Meaning that Latino mothers had a higher tendency to cope negatively with their children's behaviors; mother's either internalized their negative emotions or projected their negative emotions onto others. Limitations of the study were the following: only intact families were recruited, mothers were of high SES and the children surveyed were too small. A strength of the study was that the cultural factor was taken into consideration –how mother's behaviors toward their children varied depending on ethnicity and culture.

Similarly, in a study conducted by Bailey, Skinner and Correa (1999), 100 Latino couples were interviewed in an effort to identify the needs and supports of Latino families of children with disabilities. The interview comprised of scales and

open-ended questions that covered topics regarding the child with a disability, family characteristics, family resources and supports, beliefs about disability, family needs, and perceptions of services (Bailey, Skinner, & Correa, 1999).

Forty-two percent of the children were young females around the age of three. Twenty-five percent of the children in the sample had Down Syndrome or another type of chromosomal disorder. The Study found that the needs of Latino parents, similar to the needs of other parents of children with disabilities, were wide ranging. Their needs varied depending on already existing supports and the characteristics or dynamics of their family. A limitation expressed in the study was that Latino families were perhaps more willing to express needs than families of differing cultures (1999).

Chavira and Lopez (2000), looked at the effect Latino mother's reactions had on the problem behaviors exhibited by their children who had developmental disabilities. In the Study, 129 mothers of children with DD were recruited. Mothers had to meet the following requirements: be of low social economic status, have a child (ranging from 3-19 years of age) who had a mental disability living at home; were the primary care provider of the child; and were of Latin-American descent. Initially, parents were invited to participate in the study through a letter disseminated by the East Los Angeles Regional Center. Parents who participated in the study were given \$100 as an incentive. In turn, mothers were asked about how they reacted when their child exhibited the identified problem behavior (2000).

In this study, a tool to measure a child's level of impairment was used -the Adaptive Behavior Composite Subscale of the Vineland Adaptive Behavior Scales (2000). The study found that parent's reactions to the problem behavior exhibited by their child who had a developmental disability was associated to the level of impairment their child had. A strength of this study was that time was set aside to determine the severity of the children's condition. On the other hand, limitations present in the study were that: the study did not specify the legal status of participants nor the type of DD the children had. Further, the study did not examine behavioral reactions (2000). Implication of the study point towards clinicians working more closely with parents to educate them and help them understand that a child, regardless of disability, is responsible for their behavior. This will ultimately lead to better parenting practices (2000).

#### The Importance of Services/Resource Attainment for Parents of Children with Developmental Disabilities

The following study assesses the need for social support in parents of children with a diagnosis of Down Syndrome. In the study conducted by Siklos and Kerns (2006), participants of the Down Syndrome group were gathered by the Down Syndrome Research Foundation in Vancouver, British Columbia. Questionnaires that were mailed out were disseminated from a parent/teacher workshop (2006). Those parents who had children ranging from ages 2 to 18 years were asked to complete the questionnaires anonymously and later mail

them in – a modified Family Needs Questionnaire was given to address needs for children with developmental disabilities. In total, 32 parents to children with Down Syndrome formed part of the study. Findings of the study suggested that parents of children with Developmental Disabilities felt that the service delivery system was not providing adequate social supports (2006). One limitation of the study was that it gathered data from a small sample size which was not representative of the population (2006).

In their study, O'Mullan and Krishnagiri (2005), investigated the impact of raising a child with Down Syndrome on a parent's leisure. The study was aimed at understanding the factors that intervene with leisure and the importance of leisure in preserving well-being in parents caring for children with a Down Syndrome diagnosis. Participants consisted of four married couples (ages 33-56) who were parents to children with Down Syndrome ranging from ages 7-9. Participants were Anglo, and they sustained a middle-class status. The study utilized Barth Time Construction tool and used qualitative methods to gather responses from participants (2005). Findings demonstrated that the parents of children with Down Syndrome had limited time available for leisure. Parents also reported having changes in varying leisure activities in order to accommodate their children's capabilities (2005). In addition, parents reported benefits to incorporating more leisure time into their schedules. Limitations of the study were: the use of a small sample size which was not representative of the

population and, the study only focusing on one type of developmental disability (2005).

According to the following study conducted by Balcazar et al. (2012), liberation and empowerment are two ways a parent of a child with a developmental disability can get their needs met. This was a longitudinal study that lasted a year. The participants of the study consisted of 10-15 individuals who had a disability or parents who had children with disabilities. During the year, participants attended monthly meetings at a local library that had to do with advocacy training. Participants were later interviewed. Interviews were conducted using a naturalistic approach, participant's narratives were recorded. Findings of the study suggested that parents of children with DD can develop their own capacity to promote social change through the use of empowering community settings (2012). Similarly, one limitation of the study was that it utilized a small sample size.

Furthermore, the understanding a parent has regarding community-based services could facilitate service attainment. Hiebert-Murphy, Trute and Wright (2008), studied the patterns of entry to community-based services for families with children with developmental disabilities. The purpose of the study was to examine important factors for the entry to community-based services in addition to the relationship between patterns of entry as well as needs and service priorities. This study was part of a longitudinal survey of families living within the Province of Manitoba in Canada. Participants consisted of Forty-three mothers

and 29 fathers from 44 families who had a child with a disability. Most families were married or living as married, most families ranged in SES status.

Overall, 56 interviews were conducted: 27 interviews were completed by mothers, 13 interviews were completed by the fathers and 16 interviews were conducted with both parents. Interviews that lasted from 45 minutes to several hours were conducted. Questions asked during the interview focused on: the referral process, current needs, experiences with professionals and support from friends and family. Findings of the study indicated that the perception parents had on developmental issues and their propensity to identify them as problems was an important factor in their seeking for help. Yet, another finding of the study –the study identified three process factors in efficient service-attainment, these were: problem recognition, formal diagnosis and linkage. Limitations found in the study were lack of diversity in participants.

Previously conducted research has demonstrated that parents of children with disabilities are required to provide more individualized and careful care to their children (Morris, 2014). Parents must find a balance between caring for their children, work and other activities. Morris, L. A. (2014) conducted a study to identify the impact of work on the Mental Health of parents who had children with disabilities (2014). The independent variable in the study was employment status, this was gathered by answering “yes or no” to the question “are you currently working?” On the other hand, the dependent variable was parent mental health, this was measured by a 5-item mental health instrument that rated the



severity of anxiety and depression symptoms (2014). The study was conducted by utilizing data gathered by the National Survey of American Families (NSAF) (2014). The sample used for this study consisted of biological and custodial parents, this included 63,075 mothers and 14,599 fathers –their children varied from ages 6-17 (2014). This study confirmed that mothers of older children with disabilities that work, receive mental health benefits from being away from home (2014). Limitations presented in the study were that the NSAF is based on only one question, this study also did not mention or measure the severity of a child's disability. Lastly, this study did not access for the absence or presence of behavioral problems in participant's children.

Similarly, the following study conducted by Norton, Dyches, Harper, Roper and Caldarella, M. (2016) looked at the effect respite care, stress and uplifts –or lack thereof, had on a marriage who were parents of children with a disability. The participants were recruited through local and regional organizations and through Facebook postings. Out of the 337 surveys submitted online, only 224 were useable. Each participant was asked to complete a demographic questionnaire. Some of the tools used in the study were the Revised Dyadic Adjustment Scale and the Revised Experiences in Close Relationships Questionnaire which measured the degree of attachment in a romantic relationship. Although findings of the study indicated that the amount of respite care a couple engaged in was not directly related to marital quality, it also found that respite care managed to reduce stress. Whereby, reduced stress in a

marriage could therefore increase marital quality (2006). A limitation of the study was that the uplift scores or daily positive experiences were initially high within those marriages who participated in the study.

### Theories Guiding Conceptualization

According to Kirst-Ashman and Hull (2012), Systems Theory refers to the interrelation between micro, mezzo and macro systems in the environment. Systems are made up of individuals, families, groups and organizations. The theory focuses on the idea that multiple systems come together to form a functioning whole in which systems have an impact on one another (2012). The conceptual frame of this theoretical approach helps to understand the role of systems in the accessibility and attainment of resources and other services that could impact the population under study. Observations made through a Systems Theory lens could help identify individual systems that create barriers and make it difficult for Latino parents to meet their needs. Furthermore, Systems Theory is relevant to the study because it would help to provide a clearer understanding on the importance of family dynamics –specially, in families that have children with DD (Al-Kandari, 2014).

In addition, a systems theory perspective would make it possible to explore the impact of social systems surrounding a participant as well as looking into a participant's family dynamic. It would also help to identify the roles social

systems have in improving or deterring the mental, emotional and physical health of Latino parents who have children with DDs (Kirst-Ashman & Hull, 2012). As it relates to family and family dynamics, the systems perspective could help create a clearer image of family dynamics within a home environment and the effect that has on a parent-child relationship. Previous studies have shown that families of individuals with disabilities find themselves having to modify or redefine family roles in their day-to-day functioning (Al-Kandari, 2014). Overall, the systems theory approach would serve as a filtering technique that would be used to highlight the systems or problem areas that need to be addressed.

A second theory that would be applicable to the study would be empowerment theory. According to Hutchinson's definition, empowerment theory focuses on promoting awareness and acknowledgement in patterns of inequality amongst individuals and groups (2017). Awareness about inequality is promoted to further motivate individuals and groups to take action and change unfavorable situations for the better. Empowerment is a concept that relates to the degree of power and control individuals hold over their life, as well as the development of power and control in an individual (Balcazar et al, 2012). This particular theory is relevant to the study because it will seek to create awareness about the needs experienced by Latino parents who have children with DD. Moreover, awareness of the issue will mobilize Latino parents to become empowered and take action to improve their well-being and the well-being of their children.

## CHAPTER THREE

### METHODS

#### Introduction

Included in this section is a comprehensive explanation of the procedures and research methods that will be used during the process of the study.

Components of the study such as the design of the study, sampling methods used, data collection and instruments, procedures, protection of human subjects, and methods for data analysis will be described and further discussed in this section.

#### Study Design

Conducting this study will provide an opportunity to further explore the various needs faced by Latino parents who have children with Developmental Disabilities (DD). The primary focus of this study is to understand the needs and challenges encountered exclusively by Latino parents of children who have DD. An attempt will be made to provide useful information in an area in which little research has been done. Moreover, the findings have the potential of providing information that could improve comprehension of the issue at hand. This would in

turn lead to improved efforts to provide the resources and services necessary to successfully address the needs of Latino parents who have children with DD. Therefore, identifying the needs experienced by this specific population could lead to additional research and an increase in favorable outcomes.

Qualitative design will be the research design of choice for this study due to the limited time frame of the study, its cost efficiency, and the possibility to use a small sample size. Additionally, qualitative design would permit the investigator to ask open-ended questions and further, allow participants to communicate their needs instead of selecting answers from a list of presumed needs –as it is the case in surveys and questionnaires. In this way, a qualitative method research design will allow for a more rounded understanding of the problem and its possible solutions as identified by the parents.

There are some limitations to using a qualitative research method design for the study. One limitation is that small sample sizes are not representative of all the Latino parents who have children with Developmental Disabilities. Therefore, the findings of the study might not yield diverse answers relating to the types of needs and challenges experienced by this population. Another limitation is constraint of time. Parents might not have the opportunity to address every need and challenge they have experienced in caring for their children in the time allotted for the interview. A third limitation of conducting the study using qualitative method design, would be the presence of language ambiguities – words could have different meanings to each participant (Atieno, 2009).

Therefore, each participant could form their own interpretation or could attribute different meanings to different words included in the interview questions.

What are the needs and challenges experienced by Latino parents of children with Developmental Disabilities? It is theorized that a strong support system inside and outside the home, availability of support groups, accessibility to education pertaining to Developmental Disabilities, and accessibility to services and resources at their child's schools and other sites in the community are more likely to improve a parent's self-confidence as well as their mental, emotional and physical health. Addressing these needs could, in turn, lead to a parent's empowerment and improvement in their overall outlook of their child's diagnosis.

### Sampling

The sample from which the data will be collected is Latino parents who have children with Developmental Disabilities who reside in parts of, Riverside County, Los Angeles County and Orange County. Parents must meet three criteria in order to participate in the study; parents must be of Latino descent; must have a child or children with a developmental disability and they must reside in the counties of Riverside, Orange or Los Angeles. Parents do not have to be of a specific age and there is no preferred gender. Based on the time constraints of the study, a total of 8 to 10 Latino parents will be asked to

participate in the study. Participants for the study will be recruited by using a combination of snowball and convenience sampling. Other sites that might be explored for potential participants are schools, social media such as Facebook and Instagram, and open support groups in the community for parents who have children with developmental disabilities.

### Data Collection and Instrument

Data for the study will be collected through face-to face interviews with participants. Participants will be asked to answer approximately 15 to 25 open-ended questions. Questions will be available in English and Spanish. Interview questions will be divided into three categories: demographics, self-identified needs and self-identified solutions to address unmet needs. The first five questions will cover demographics, severity of child's diagnosis and services/resources that have been obtained previously. The following questions will pertain to self-identified needs of parents and their children; lastly, the remaining couple of questions will focus on parent's solutions to addressing their unmet needs. A semi-structured interview guide will be used to conduct the interview. The investigator will ask pre-designed questions but will also use participant's answers to formulate additional questions. Participant responses will be either recorded with a voice recorder or handwritten.

## Procedures

Participants from either Riverside County, Los Angeles County or Orange County, will be recruited using non-probability sampling such as snowball and convenience sampling. Furthermore, participants will be solicited through the use of flyers, word of mouth, social media or in person. Each participant will be given a 5-dollar Starbucks gift card as an incentive to take part in the study.

Participants who meet criteria for the study will be gathered from school settings, parent's support groups or other public spaces such as malls.

Prospective participants will be given a brief summary of the study and asked if they would be willing to participate. Phone numbers will be collected from those willing to participate in the study so that they could be contacted, and an interview date could be scheduled. Lizbeth Quintero –the investigator, will be in charge of conducting interviews and collecting data. Data collection will take place at the place most convenient to each participant. For personal protection, the investigator will travel to each participant home with a companion. In preparation for interviews, the investigator will purchase and organize the necessary equipment –voice recorders, notepads and Starbucks gift cards.

All participants will be briefed on the study; they will be informed about why the study is being conducted; who it is being conducted by; the participant's role in the study and the implications of the study for Latino parents who have children with developmental disabilities. Additionally, participants will be given measures of confidentiality. Each participant will also be provided with informed



consent which places emphasis on voluntary participation and the right of participants to withdraw from the study at any given time without suffering consequences.

Furthermore, data collection will take place during the month of February; during the initial process, participants will be contacted, and interview appointments will be scheduled. Once interviews are scheduled, the investigator will meet with participants at their preferred location and the interview will be conducted. Participants will be given informed consent and they will be asked to authorize the use of a voice recorder to record the interview. All recorded interviews will then be transcribed by the beginning of April and the data will be analyzed. Common themes will be identified, and findings will be published by June.

### Protection of Human Subjects

In order to ensure the protection of human subjects involved in the study, all participants will be informed about the study and the process of informed consent. Debriefing statements will be given to each participant, and all efforts will be made to guarantee that all participants understand their role in the study. To protect against HIPPA violations, names and signatures of participants will not be required. Before data collection begins, investigators will be cautious to include the necessary safeguards to protect participants. During the process of

data collection participant confidentiality will be secured in a number of ways. The names of participants will not be used in hand-written interview notes or voice recordings –instead an identifying number will be assigned to each participant. Transcribed notes will be stored in a computer with password-only access. Only the main investigator will have access to the computer in which the data will be saved. After the completion of the study, written records will be shredded, voice recordings will be erased, and the data saved on the computer will be deleted.

### Data Analysis

Data for this study will be gathered by using a qualitative research design. The data will be collected through face-to-face interviews. Interviews that were hand-written or recorded using voice recording devices will be transcribed and typed into a word document. Spanish interviews will be translated into English and then transcribed. Typed answers will be reviewed, organized into categories and coded to find common themes. Once all answers have been typed into a word document and organized, commonalities between the answers given by participants will be noted and contrasted. Specific needs and challenges will be identified, and similar needs and challenges will be totaled. Relationships between the severity of a child's developmental disabilities and the type of needs experienced by parents will be made.

The findings of the study might indicate that strong support systems, availability of support groups, accessibility to education pertaining to developmental disabilities, and accessibility to services and resources at their child's schools and other sites in the community are more likely to improve a parent's self-confidence as well as their mental, emotional and physical health. Which would, in turn, lead to a parent's empowerment and improvement in the overall outlook of their child's diagnosis. Yet another construct would be that Latino parents of children with DD might have more pronounced difficulties than parents of other ethnic backgrounds; mostly due to factors such as –language barriers, lack of education, lack of understanding of their child's DDs, low Social Economic Status (SES) and, citizenship status.

### Summary

The study conducted will focus on the needs of Latino parents to children with developmental disabilities. The study will seek to gain a more concrete understanding of the types of needs experienced by this specific population. An effort will be made to find a correlation between the severity of the child's DD and the parents self-identified needs. Additionally, the study will utilize qualitative design to gather data from approximately 8 to 10 participants. Participants will be selected through snowball or convenience sampling. All participants will be educated about the study and briefed about their role in the study. The primary

mode of data collection will be through in-person interviewing. Data will be documented either by the use of a voice recorder or hand-written material. Data will be analyzed through careful organization and in-depth examination of participant-given answers. Data will help to identify parent's needs and to better understand the reason behind identified needs.

## CHAPTER FOUR

### RESULTS

#### Introduction

The following section reviews the results yielded by the study. Covered in this section are participant demographics and major findings related to: types of challenges faced by Latino parents who have children with developmental disabilities, identified unmet needs, social workers role in accessibility to services as well as beneficial agencies and services identified by participants.

All participants in the study were found using snowball and convenience sampling. There were nine participants in total, all of which were Latino women who had a child or children with a developmental disability. Participants were given the freedom to choose the time and place for the interview to be conducted; several participants opted to have the investigator interview them at their home, others chose to complete the interview at the investigator's home. Every participant completed the interview by answering all questions that were asked during the interview. The majority of participants resided in Riverside County, however, two participants were residents of Los Angeles County and one other was a resident of Orange County.

The duration of each interview differed. Interviews lasted anywhere from fifteen minutes to sixty minutes. Each participant was asked the same twenty-

three questions in the interview guide. Questions participants were asked during the interview related to demographics, education, work history, marital status and nationality. Other questions focused on their child's developmental disability diagnosis, parent's ability to cope with their children's diagnosis, accessibility to services and resources, previous experiences with service providers, self-identified unmet needs and the like.

Interviews were recorded on a voice recorder upon gaining permission from participants. Recorded interviews were later transcribed using a personal lap top and programs for audio such as VLC and iTunes. Time spent per transcription varied from two hours to two days. Data analysis took place after all interviews had been transcribed. Transcriptions were carefully reviewed, and common themes were identified. Themes were color coded. Common themes that resulted from the study included: challenges faced by parents of children born with developmental disabilities; barriers to accessibility of -services, programs and resources, as well as, identified unmet needs for both parents and their children. Two other themes that came up in the study were, social workers' role in the accessibility to services and the agencies and services that parents had found to be beneficial.

## Presentation of Findings

### Demographics

The nine participants that took part in the study were Latino women who ranged in age from early thirties to early fifties. Three quarters of the women (6) were monolingual -speaking only Spanish, the majority (8) of the participants were married, there were 2 participants that had divorced and later re-married. The average amount of years participants had been married for was 20 years. On average, the number of children born to participants was three, but ranged from one child to five children. Although most participants had only one child who had been diagnosed with a developmental disability, one participant had two children that had been born with a developmental disability. While most participants were Latino women who were nationals from Mexico or Guatemala, the majority (5) of participants were naturalized U.S. citizens. There were a couple of participants partaking in the study who disclosed being undocumented.

As far as educational level is concerned, most participants (5) had completed a high school education. Three of the participants in the study pursued higher education and two obtained a bachelor's degree. Two participants had completed a middle school education and two others stated only attending elementary school. Previous work history included working at warehouses, retail, or working other regular nine-to-five jobs such as working as a teacher's aide or substitute teaching. Some of the parents (2) were stay-at-home mothers, yet, others were employed through In-Home Support Services

(IHSS) as caregivers to their children. In most cases, participant’s husbands were the ones working a full-time job outside the home.

<u>Age</u>	<u>Legal Status</u>	<u>Marital Status</u>	<u>Education</u>	<u># Children</u>	<u>Employed</u>	<u>Ages of Children</u>	<u>Types of DD</u>
50	Naturalized US Citizen (Mexican)	Married	Bachelor's Degree	3	Y	21	Down Syndrome
45	Mexican Citizen	Married	Elementary	4	Y	9 & 12	Autism /ADHD
46	Naturalized US Citizen (Guatemalan)	Married	High School	2	Y	27	Down Syndrome
49	Naturalized US Citizen (Mexican)	Married	Some college	5	Y	19	Down Syndrome
56	Naturalized US Citizen (Mexican)	Married	Highschool	3	Y	13	Microcephaly, Dwarfism
50	US Citizen (Mexican)	Married	Bachelor's Degree	3	Y	25	Cerebral Palsy
30	Mexican Citizen	Married	Elementary	2	N	6	Autism
	Naturalized US Citizen (Mexican)	Separated	Middle School	3	Y	19	Cerebral Palsy



43							
49	Guatemalan Citizen	Married	Middle School	3	N	21	Down Syndrome

The ages of the children whose mothers participated in the study, ranged from ages 6 to 27. The severity of the diagnoses varied from child to child -some children were more functional than others. Four children had been born with Down Syndrome. The majority of the children who had Down Syndrome were mobile, however, in every case, speech was underdeveloped. Three other children whose mothers participated in the study had been diagnosed with Autism, two of the children who had an Autism diagnoses had a dual diagnosis - both children also had been diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Additionally, two children had been born with Cerebral Palsy. The child who was the most functional out of the two had also been diagnosed with a learning disability. The remaining child was diagnosed with Dwarfism and Microcephaly, her diagnosis was the most severe out all of the children whose parents participated in the study, she and one of the children who had been diagnosed with cerebral palsy needed the most specialized care. When participants were asked about their reactions to finding out their child's diagnoses, all expressed that they had experienced a difficult, painful and

emotional time coming to terms with the fact their children had a developmental disability.

## The Challenges Faced by Parents of Children Born with Developmental Disabilities

### Knowledge about Diagnoses

All of the participants disclosed that during pregnancy, none of their doctors had notified them about their child's developmental disability. Most of the participants were unaware about their children having a developmental disability until after birth. Mothers of children who had been diagnosed with Autism reported that behaviors and attitudes that were displayed by their children such as difficulty with social interactions and high sensitivity to noise, were the indicators that prompted them to have their children evaluated. The children in this study who were diagnosed with Autism were diagnosed during early childhood.

Although most parents had gathered basic knowledge about their child's developmental disability, most expressed a desire to learn more about their children's specific diagnosis. Participants agreed that having access to programs or services that would educate them more about their child's developmental disability would help them become more familiar with the characteristics of their

child's diagnoses, which would also contribute to them having a better disposition to care for their children more effectively.

### Care Needs

In making comparisons between the children who did not have a developmental disability and the children who had a developmental disability diagnosis, all participants agreed that the needs and care requirements for their children who had been diagnosed with a developmental disability were much higher. Notable distinctions were made about their children's independence as they grew and developed. Children that did not have developmental disabilities, although they required some parental assistance, became more independent in daily tasks, such as using the bathroom, showering, dressing, practicing personal hygiene and feeding themselves. Whereas, the children who had a developmental disability diagnosis required their parent's assistance and needed constant supervision.

In regard to caring for their children with developmental disabilities, participants shared that their children required either, the same amount of care or, in most cases, needed extra care as they grew and developed. Additionally, participants stated that because their children's needs were much greater than those of children who did not have a developmental disability, they required more attention and special care in a school setting. Most participants were dissatisfied with both the amount of services available at schools and the frequency at which

services were provided. There was only one participant who stated being completely satisfied with the services her child had been provided with at school.

Depending on the diagnosis and on the severity of the diagnosis, some children were more functional and were able to do more daily tasks than others. For example, according to their parents, three out of the four children who had a Down Syndrome diagnosis were able to use the bathroom and dress themselves with minimal assistance, they were able to physically feed themselves, and they were able to carry out minor personal hygiene tasks. The same was true for the children with an Autism diagnosis.

Although children with a Down Syndrome and Autism diagnosis had low levels of communication, they were amongst the most communicative and the most functional in the group of the children whose parents took part in the study. Two children, one who was diagnosed with Cerebral Palsy and another who was diagnosed with Microcephaly were the least functional of the group. The symptoms of these children's diagnoses were severe. They were both bed ridden, did not communicate and were fed through a feeding tube; hence, their needs were greater, and they required around the clock care from their parents and nurses. One of the participants described the specialized care her child required on a daily basis. According to the participant, on a day to day basis, she spent her time:

Preparing her food, giving it through the catheter, connecting the ventilator, changing her, moving her around the clock, checking that she is

not urinated, checking the machines, changing her pampers... sometimes she has a lot of phlegm. I have to be alert at all times because her blood pressure could drop, or it gets too high. If it gets too high, she can have seizures (Participant 1, personal communication, February 2018).

### Emotional and Physical Effects

Upon asking participants how their child's diagnosis had affected them mentally, physically, and emotionally, most answered in a similar fashion. Mentally, most participants stated that they were not sufficiently prepared to care for their children. Most participants felt that they had not been educated thoroughly about their child's diagnosis, what the diagnosis meant, what to expect or how to take care of their children accordingly. Emotionally, parents described feeling sad, angry and confused as they processed their new reality; participants who were religious also stated that during this period of uncertainty and emotional angst, they found themselves questioning God. Physically, participants -especially those who had children with higher needs and who required medical attention- reported feeling exhausted, they gained or dropped in weight and, they frequently experienced sleep deprivation. When asked how her child's diagnosis had affected her physically, one of the participants stated, "The time she goes to school, it's the only time I get to rest... sometimes I find myself falling asleep while I'm eating" (Participant 2, personal communication, February 2018). Additionally, participants also disclosed that they seldomly had the time for self-care or leisure.

### Support Systems

All nine of the participants taking part in the study reported having a small support system. In every case, their support system was composed of their nuclear family -their husband and their biological children. A few other participants mentioned that apart from their nuclear family, their children's teacher, family friends or one or two other members of their immediate family also formed part of their support system. When asked about who she considered her support system, one of the participants responded with, "he is the [only] one that gives me support, practically" in reference to her husband (Participant 3, personal communication, February 2018). A larger or stronger social support system was one element that most participants had a need for but lacked. Several participants expressed that they would like it if more support groups were available for parents who had children with developmental disabilities. Most were interested in joining a support group and in interacting with other parents who had children with developmental disabilities.

### Barriers to the Accessibility of Services and Resources

Factors that participants identified as having an impact on their access to services and resources were language, lack of information about available services or resources, the willingness of service providers to educate participants about the services they and their children qualified for as well as their legal status. Location was also a factor that participants identified as a barrier to the accessibility of services and resources. Some participants had to travel

significant distances from their home in order to access services or to obtain resources offered in their counties. Other participants felt as it was more difficult for them to access or receive services simply for the fact they were Latinas. In regard to the attainment of services, one participant explained that “being Hispanic makes it more difficult” (Participant 4, personal communication, February 2018).

A couple of participants mentioned that they had felt discriminated by service providers because they were Latinas. Two of the biggest barriers to accessing services and resources were language and legal status. Half of the participants stated not being confident in their ability to speak English.

Participants believed that their inability to communicate in English not only made it more difficult for them to advocate for themselves and their children but in turn, made it increasingly more difficult for their needs to be met. Upon asking one participant about which barriers she had encountered in accessing services she responded with, “Well... the language, since we only speak Spanish. We always have to wait [for services], or there is a long wait time” (Participant 5, personal communication, February 2018).

Similarly, a couple of participants were unable to receive services due to being undocumented. Many of the programs and services available to parents -such as IHSS and respite are more difficult to obtain for parents who are undocumented.

### Identified Unmet Needs

When participants were asked a series of questions about the type of needs exhibited by their children, the majority of participants stated that their children would thrive if they had better access to services like speech therapy, physical therapy and other school programs or programs outside school that would allow them to socialize with peers that had the same or similar diagnosis. Participants stated being unhappy with the number and variety of programs available to their children. Furthermore, participants did not agree with the amount of time their children qualified for these services. On average, children were approved to receive services such as speech therapy or physical therapy for a period of six months; in addition, therapy was given only once or twice a week for a thirty to forty-five-minute session. Although participants saw improvements in their children after receiving these services, they found that many of them regressed or halted their progress once services ceased.

Participants, especially those who were parents to young adults, reported that there was a critical need for programs or services that were specifically designed for young adults who had developmental disabilities and who were no longer attending school. The participants who were parents to young adults stated that, due to their age as well as their mental and physical limitations, their children could not continue with higher education or hold a full-time job. Participants believed that there was a large need for day-programs that would make it possible for their children to invest their time in more productive and



beneficial activities outside their home. According to participants, such programs would permit their children to socialize with peers and to participate in activities that encouraged learning.

In regard to healthcare, participants expressed the desperate need for better healthcare services that were specialized for children who had a developmental disability. Services such as dental care and vision care that better adjusted for children that required careful attention and more delicate handling. Participants also reported the large need for more healthcare professionals that had the training and the expertise in working with children who had developmental disabilities. According to participants, healthcare professionals that specialized in working with children who had a developmental disability was scarce.

When asked about the type of services or programs participants had a need for as parents of children who had developmental disabilities, most reported similar needs. Participants reported that due to the physically and mentally taxing occupation of caring for children who had special necessities, a large need was expressed for more services that relieved parents from their high-stress parental duties and allowed them the time necessary to practice self-care. Participants stated not only needing more programs that were similar to Respite, they also emphasized that these programs should be available for a wider range of time. Participants who were familiar with respite care and who were currently utilizing

their services believed that the time they were given to utilize the service was too restrictive.

Psychoeducational groups were one other need participants demanded. Based on participant's responses, psychoeducational groups would educate them about their children's diagnoses and provide them with the tools necessary to create a thriving environment for themselves and their children. One other need participants reported having, was their need for support groups or other similar programs that a stated by participants, would make it possible for parents who had children with developmental disabilities to interact, de-stress and learn from each other.

### Social Workers' Role in Accessibility to Services

Participants were also asked about their past experiences with social workers in their role of helping them obtain services and resources. Overall, participants reported that they had had positive experiences with social workers. Participants shared that the social workers they had worked with in the past had been very helpful in providing resources, connecting them to other agencies/organizations or in helping them obtain services. The majority described social workers as pleasant, approachable, receptive and easy to work with. A couple of participants however, stated that they had one or two negative experiences with social workers. Their main complaints were related to the social

worker's negative attitude or indirect refusal to help, as well as their failure to follow-up or follow through in doing what they had told participants they would do. Generally, participants had more positive experiences than negative ones when working with social workers.

### Beneficial Agencies and Services

When participants were asked about agencies, community members or organizations in their community that had been helpful in providing services or other resources to them and their children, all participants mentioned the Regional Center. The Regional Center had proven to be a great resource for parents because it had played an essential role in connecting them to other services and agencies that had become indispensable to them and their children. For example, participants reported that Regional Center case workers had informed them about programs like In-Home Supportive Services, which allowed participants to stay home with their children while providing them with a steady income.

Respite was one other program that participants thanked the Regional Center for. Participants found Respite to be incredibly helpful as it temporarily relieved them from their responsibility of caring for their children -it allowed parents to practice self-care and to de-stress. In addition, the Regional Center also offered parents discounted Disneyland tickets which made purchasing

theme park tickets more affordable for parents who had tight budgets. Furthermore, the discounted Disneyland ticket program made it possible for parents and their children to spend quality family time together and at the same time, escape from their daily routine. A few participants mentioned specific people in their community such as friends or teachers who had been helpful in providing them with information about programs or services.

### Summary

The study consisted of nine Latino women, all of which were parents to a child or children who had a developmental disability. Participation in the study was strictly voluntary, the women who were interviewed had been gathered through snowball sampling and convenience sampling. Ages of the women who were participants in the study ranged from early thirties to early fifties. Participants were given the freedom to choose the time and place in which their interview would be conducted. Interviews ran between fifteen to sixty minutes long. Parents who participated in the study had children with differing developmental disabilities as well as different levels of severity. Common themes that resulted from the interviews were: challenges faced by parents of children born with developmental disabilities; barriers to accessibility of -services, programs and resources, as well as, identified unmet needs.

The study found that common challenges faced by Latino parents who had children born with a developmental disability were emotional and physical distress, lack of support, and insufficient knowledge about their child's diagnoses -a factor that further affected the quality of care parents provided to their children. Based on the results of the study, the biggest barriers to the accessibility of services, programs and resources were language barriers, legal status and the location of services. Moreover, the study found that participant-identified unmet needs were related to the scarcity of available services and the length of services. Additionally, the study yielded results regarding social workers' role in accessibility to services and agencies and services that parents have found to be beneficial.

Challenges that participants of the study faced as a result of being a parent to children with developmental disabilities included: the inability to properly care for their children due to a lack of knowledge about their children's diagnoses, difficulty meeting their children's special needs, as well as, difficulty handling the emotional and physical strains associated with caring for a special needs child. In addition, parents reported not having sufficient emotional or social support. Furthermore, some of the barriers that affected participant's accessibility to services and resources were language, legal status, lack of information about available services or resources, the willingness of service providers to educate participants about the services they and their children qualified for, as well as location.

Participants in the study identified several unmet needs experienced by themselves and their children. Based on participants reports, their children were in need for a larger variety of programs as well as better access to services like speech therapy, physical therapy and other school programs or programs outside school. Participants also expressed that their children's progress depended on the length of time and the frequency at which services were provided. Therefore, there was a large need for services that were provided for longer periods of time. Parents reported having a large need for support groups and programs that would provide them with the sufficient time for self-care. Lastly, participants reported that social workers who had an appropriate attitude and their best interest in mind were indispensable to their attainment of services and resources.

## CHAPTER FIVE

### DISCUSSION

#### Introduction

This discussion section will highlight the significant results of the study, the unanticipated results of the study, the limitations of the study and finally, recommendations for social work practice and research.

The interviews conducted with the nine Latino mothers who were parents to a child or children who had developmental disabilities yielded results that emphasized some of the most common barriers and needs experienced by this population. The results that were gathered from the study supported findings of previous studies in that parents who had children with developmental disabilities experienced higher stress levels as well as, higher mental and physical distress (Al-Kandari, 2014). Furthermore, due to factors such as language barriers, legal status and lack of education about their child's diagnosis, Latino parents who had children born with developmental disabilities exhibited a broader range of needs. Moreover, these same factors became the barriers that made it more difficult for Latino parents who had children with DD to access or obtain services, resources or programs that could be beneficial to them and their children.

An analysis of the results yielded common themes relating to: the lack of information parents felt they received from their children's healthcare

providers, the type and intensity of the care needs exhibited by their children and the emotional as well as the physical strains they experienced as a result of caring for their special needs children. Other themes that resulted from the study were, the type of barriers parents experienced in the accessibility to services, types and number of unmet needs, in addition to, how parents viewed the role of social workers in their attainment of services, resources or programs and, finally, the agencies, services and programs parents had found to be beneficial.

## Significant Results

### Mental and Physical Strain

Upon close examination of the results, it was found that Latino parents who had a child or children born with a developmental disability experienced higher levels of mental angst and physical strain. All parents who participated in the study had more than one child and had experienced parenting with children who did not have a developmental disability. Caring for a child with special needs demanded higher levels of physical activity and intense, close supervision around-the-clock. The severity of a child's diagnosis had a direct correlation to the physical strain experienced by parents and the time available for self-care that parents had for themselves. Parents who experienced a higher level of physical strain tended to have more symptoms of depleted mental health such as stress, anxiety, decreased sleep and weight gain.



## Implications and Recommendations

These findings suggest that parenting with a child who has a developmental disability is significantly more physically and mentally taxing than it is parenting with a child who does not have a developmental disability. Based on these findings, it could be gathered that parents who have a child or children with a developmental disability are in poorer states of physical and mental health than are their counterparts. Recommendations based on these findings would be to conduct additional research that would provide further understanding of the physical and mental impacts that caring for children who have developmental disabilities have on parents. New findings could also provide effective ways to address this issue.

## School Services

A prominent finding that resulted from the study was the dissatisfaction parents had with the variety of services available to their children in a school setting. There was also a dissatisfaction in the length and frequency in which these services were provided to their children. According to parents, schools needed to improve the number and types of services that were available specifically to children who had a developmental disability. Parents understood that the availability of more services meant that children like theirs, who had special needs, would be in a better position to receive a combination of

individualized services that would improve their areas of deficit. Similarly, parents felt that the length and frequency in which a service was provided severely affected how much or how little improvement their child made. Parents found that after their children stopped receiving services such as speech therapy, physical therapy or the like, improvements in that area either lapsed or ceased altogether.

#### Implications and Recommendations.

These results suggested that schools were either not working with parents to provide the best education possible to students with special needs or that schools were either underfunded or were not setting aside the funds necessary to provide appropriate services. One other implication based on these findings was that there were insufficient speech therapist, physical therapists and other professionals to satisfy the high demands for these services. Subsequent research is necessary to examine the impact that the length and frequency of services has on the progress exhibited by students who have a developmental disability. Additional research should be conducted to explore the views of service providers on the availability of services as well as their opinion on the scarcity of service providers. Possible findings of these studies could improve our understanding about the issues surrounding the need and provision of services.

## Mental Health and Support Systems

Other findings revealed that because parents had small support systems which usually consisted of their nuclear family - husband and other children, there was a large need for support groups. Based on participant responses, support groups would be helpful as they would provide parents with a safe space to express their hardships and concerns. Support groups would also provide parents with an opportunity to exchange parenting tips or advice with other parents in similar situations. In addition, support groups would serve as a therapeutic outlet with a high potential to improve a parent's mental health. Lastly, having more support groups that are specifically targeted at Latino parents who have children with developmental disabilities would expand a parent's support system.

### Implications and Recommendations

Implications amassed from these findings suggested that participants found it helpful to interact with other parents who experienced first-hand the hardships and challenges attributed to caring for a child with a developmental disability. One other implication gathered from these findings was that forming relationships outside of their immediate support group provided parents with the opportunity to step away from their parental responsibilities while at the same time providing them with a therapeutic alliance that stimulated emotional support. Recommendations for future research would include examining the differences in mental health between parents who attended support groups compared to those

who did not. In order to provide better, more comprehensive services, an additional recommendation for service providers is to gain a more concrete understanding about the impact support groups have on the mental health of this specific population. Moreover, new policy should be created to make it a mandate for parents with children who have a developmental disability to receive mental health services.

### Self- Care

Based on the results of the study, self-care was an essential factor in a parent's ability to care for a special needs child. Because of the high physical and mental demands that come with caring for a child with a developmental disability, time set aside for self-care was critical. Parents reported feeling renewed, refreshed and re-energized after they had given themselves the time to engage in an activity that interrupted their everyday routine. Parents who had utilized services like Respite understood that temporarily stepping away from their parental duties improved their physical and mental condition. Parents who had more time to care for themselves had higher energy and more higher levels of patience which then allowed them to better care for their children.

### Implications and Recommendations

Implications that were derived from the findings suggested that there was a direct correlation between the amount of self-care a parent engaged in and the

type of care they provided to their children. Therefore, it is understood that parents who are better rested and who devote a part of the day to their personal care are better able to provide their children with more meticulous care and further, dedicate more quality time to their children. More in-depth studies are necessary in order to fill in the gaps in the understanding service providers have about the role self-care plays in the lives of parents with children who have developmental disabilities.

### Barriers for Latino Parents

According to the findings of the study, participants felt as if their ethnicity and the fact that they looked Latino, had a deep impact on their accessibility and attainability of services. Some of the participants felt as if they faced more discrimination from service providers than women of other ethnicities. The inability to speak or understand English also made some of the women who participated in the study feel incompetent, both as a person and as a parent. Participants, all who were Latino women, would feel more validated if their culture and their language was celebrated instead of looked down upon.

### Implications and Recommendations

Results indicate that Latino parents who experience language barriers tend to lack confidence in service providers. There is a notable level of distrust which adds to the lack of credibility parents attribute to service providers. To

eliminate distrust, lack of confidence, and the lack of credibility parents have towards service providers it is recommended to service providers to practice with transparency and cultural competency.

## Unanticipated Results

### Education on Diagnoses

Results also demonstrated that participants felt that their children's healthcare providers had a significant role in educating and providing them with the information necessary to care for their children adequately. Participants felt that the lack of information they received regarding their child's diagnosis when their child was initially diagnosed, critically affected their understanding of their child's diagnosis, their understanding of their child's needs and, their understanding of their role as the parent of a child with a developmental disability. Similarly, parents were unhappy with the lack of specialized medical professionals and specialized medical services available for children who had a developmental disability. Being cognizant that the healthcare professionals treating their child has the knowledge, the techniques and the patience to treat their child appropriately, provides parents with the peace of mind that their child is receiving the best treatment possible.

## Resiliency

Although the majority of participants spoke or understood very little English, had a small support system and did not know where to go for services or resources, they were all resourceful, resilient women. All women understood that their children depended on them entirely and that it was their job to advocate for their children. Regardless of their difficulty in speaking the English language and despite legal status, these Latino women fought for their children and strived to provide their children with a better quality of life.

## Limitations of the Study

One of the limitations of this study was the use of a small sample size that was not representative of the population. Although the purpose of the study was to better understand the needs experienced by Latino parents who had children with developmental disabilities, only Latino women were interviewed. It is likely that the needs of Latino mothers would be different than the needs exhibited by Latino fathers. Yet another limitation of the study was that there was little variance in the developmental disabilities that were exhibited by the children of mothers who participated in the study. This narrowed the overall understanding of how the severity of different types of developmental disabilities impacted the intensity of care required by children. Similarly, the age range of the children that formed part of the study was very small, hence not enough to provide sufficient

information about how a child's needs change as they go through different developmental stages.

### Recommendations for Social Work Practice and Research

Findings of the study indicated that there was a large need for culturally competent service providers who had a better understanding of the factors and barriers Latino parents -especially those who had children with developmental disabilities- faced when it came to the accessibility of services, resources and programs. Participants also voiced their need for social workers who had a genuine interest in helping them obtain services and who were proactive in linking them to programs that would help them and their children.

In addition, participants appreciated social workers that were friendly, approachable, followed through with their assertions, were readily available and maintained continuous contact with them. Social workers who work with this population should be knowledgeable about the challenges implied in caring for a child with DD. In the same way, social workers should utilize a systems theory perspective to address issues experienced by this population in a more holistic fashion.

Social workers should seek to empower their clients by acknowledging the amount of work and dedication they put forth in caring for their children. Further studies are necessary to fill in the gaps in our understanding of the challenges



that plague this population. Moreover, additional research could help highlight or identify more effective tools parents could adopt or activities they could participate in that would empower them, increase their confidence in their parenting abilities and create a healthier more thriving environment for themselves and their children.

### Conclusion

This article has examined the needs of Latino parents who have a child or children with developmental disabilities. The article sought to explore the challenges and barriers that impede access to programs, services and resources that could help address the needs of this population. This article also examines the common types of needs faced by Latino parents as well as the type of needs experienced by their children. It has been gathered from the results of the study that because caring for children who have developmental disabilities is mentally and physically demanding, the needs experienced by parents of children with special needs are much higher. Parents to children with developmental disabilities invest a large portion of their time to caring for their children; because of this, little time is available for parents to practice self-care, this contributes to the deteriorating mental and physical health of parents. Furthermore, language barriers and legal status are two factors that make access to services more

difficult for Latino parents. Implications of the study suggested that Latino parents lacked confidence in service providers.

This article also presents findings that highlight the services and programs parents found essential to the well-being of their children and themselves. Additionally, this article explored the role social workers play in the attainability of services. Moreover, this article reviews implications of the study as well as recommendations for policy, practice and future research. The intention of the study is to provide service providers with a deeper understanding of the challenges and needs experienced by Latino parents who have children with developmental disabilities in order to ensure effective provision of services. In addition, this study seeks to amplify the challenges and needs of this population in order to create the awareness necessary to better address and further improve the quality of life for parents and children. Additional studies should be conducted with this population to address the gaps in the findings.

APPENDIX A  
INSTITUTIONAL REVIEW BOARD APPROVAL

**CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO**  
**SCHOOL OF SOCIAL WORK**  
*Institutional Review Board Sub-Committee*

Researcher(s) Lizbeth Quintero  
Proposal Title Needs and Challenges Experienced by Latino Parents of Children with Developmental Disabilities  
# SW1809

Your proposal has been reviewed by the School of Social Work Sub-Committee of the Institutional Review Board. The decisions and advice of those faculty are given below.

Proposal is:

- approved
- to be resubmitted with revisions listed below
- to be forwarded to the campus IRB for review

Revisions that must be made before proposal can be approved:

- faculty signature missing
- missing informed consent  debriefing statement
- revisions needed in informed consent  debriefing
- data collection instruments missing
- agency approval letter missing
- CITI missing
- revisions in design needed (specified below)

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James Chang \_\_\_\_\_ Date 1/19/2018  
Committee Chair Signature

Distribution: White-Coordinator; Yellow-Supervisor; Pink-Student

APPENDIX B  
INFORMED CONSENT



California State University, San Bernardino  
Social Work Institutional Review Board Sub-Committee  
APPROVED 1/19/2018 VOID AFTER 1/18/2019  
IRB# SW1809 CHAIR *Jane Clark*

College of Social and Behavioral Sciences  
School of Social Work

**INFORMED CONSENT**

The study in which you are asked to participate is designed to examine the needs and challenges experienced by Latino parents who have children with Developmental Disabilities living in Riverside County or San Bernardino County. The study is being conducted by Lizbeth Quintero an MSW student under the supervision of Dr. Herbert Shon in the School of Social Work, California State University, San Bernardino. The study has been approved by the Institutional Review Board Social Work Sub-Committee, California State University, San Bernardino.

**PURPOSE:** The purpose of the study is to examine the needs and challenges experienced by Latino parents who are parents to children with Developmental Disabilities.

**DESCRIPTION:** Participants will be asked questions regarding severity of child's diagnosis, services/resources parents have received in the past, satisfaction with previously receive services/resources, satisfaction in working with other professionals – teacher or social workers, the challenges of raising a child with Developmental Disabilities, self-reported needs that relate to effective parenting, and some demographics -amongst a few others.

**PARTICIPATION:** Your participation in the study is completely voluntary. You can refuse to participate in the study or discontinue your participation at any time without suffering consequences.

**CONFIDENTIALITY:** Your responses will remain confidential and safeguards will be utilized to protect your confidentiality.

**DURATION:** It will take approximately 60 minutes to complete the interview.

**RISKS:** There are no foreseeable risks to the participants.

**BENEFITS:** There will not be any direct benefits to the participants.

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**CONTACT:** If you have any questions about this study, please feel free to contact Dr. Herbert Shon at (909) 537-5532 or e-mail him at CSUSB Email: [herb.shon@csusb.edu](mailto:herb.shon@csusb.edu)

**RESULTS:** Results of the study can be obtained from the Pfau Library ScholarWorks (<http://scholarworks.lib.csusb.edu>) at California State University, San Bernardino after December 2018.

This is to certify that I read the above and I am 18 years or older.

Place an X mark here \_\_\_\_\_

\_\_\_\_\_ Date

I agree to be tape recorded: \_\_\_\_\_ Yes \_\_\_\_\_ No

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**CONSENTIMIENTO INFORMADO**

El estudio en el que se le pide que participe está diseñado para examinar las necesidades y los desafíos que experimentan los padres Hispánicos que tienen niños con discapacidades de desarrollo, que viven en el Condado de Riverside o San Bernardino. El estudio está siendo dirigido por Lizbeth Quintero, una estudiante de MSW bajo la supervisión del Dr. Herbert Shon en la Escuela de Trabajo Social de la Universidad Estatal de California en San Bernardino. El estudio ha sido aprobado por el Subcomité de Trabajo Social de la Junta de Revisión Institucional, California State University, San Bernardino.

**PROPÓSITO:** El propósito del estudio es examinar las necesidades y los desafíos que experimentan los padres Hispánicos que son padres de niños con discapacidades de desarrollo.

**DESCRIPCIÓN:** Los participantes recibirán preguntas sobre la gravedad del diagnóstico del niño, los servicios / recursos que han recibido en el pasado, la satisfacción con los servicios / recursos anteriores u otros profesionales, los desafíos para criar a un niño con discapacidades de desarrollo, necesidades auto informadas que se relacionan a una crianza efectiva y algunos datos demográficos.

**PARTICIPACIÓN:** Su participación en el estudio es completamente voluntaria. Puede negarse a participar en el estudio o suspender su participación en cualquier momento sin sufrir consecuencias.

**CONFIDENCIALIDAD:** Sus respuestas permanecerán en confidencia y se utilizarán salvaguardas para proteger su confidencialidad.

**DURACIÓN:** llevará aproximadamente 60 minutos completar la entrevista.

**RIESGOS:** No hay riesgos previsibles para los participantes.

**BENEFICIOS:** No habrá ningún beneficio directo para los participantes.

**CONTACTO:** Si tiene alguna pregunta sobre este estudio, no dude en ponerse en contacto con el Dr. Herbert Shon al (909) 537-5532 o envíela por correo electrónico a CSUSB Correo electrónico: herb.shon@csusb.edu

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**RESULTADOS:** Los resultados del estudio se pueden obtener de la Biblioteca Pfau ScholarWorks (<http://scholarworks.lib.csusb.edu>) en la Universidad Estatal de California, San Bernardino después de diciembre de 2018.

Esto es para certificar que leo lo anterior y que tengo 18 años o más.

Coloque una marca X aquí Fecha \_\_\_\_\_

Acepto grabarme en cinta: \_\_\_\_\_ Sí \_\_\_\_\_ No

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APPENDIX C  
DEBRIEFING STATEMENT



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### **DEBRIEFING STATEMENT**

This study you have just completed was designed to investigate the needs and challenges experienced by Hispanic parents who have children with Developmental Disabilities. We are interested in assessing the types of needs and challenges reported by Hispanic parents who have a child or children with Developmental Disabilities. We are also interested in understanding how addressing the needs of Hispanic parents to children with Developmental Disabilities will improve a parent's mental, emotional and physical health as well as their parent-child relationship. What the needs and challenges are and the factors that act as barriers to addressing them. This is to inform you that no deception is involved in this study.

Thank you for your participation. If you have any questions about the study, please feel free to contact Dr. Laurie Smith at Phone: (909) 537-3837. If you are interested in seeking mental health services you can contact one of the crisis walk-in clinics in San Bernardino County at phone: (909) 421-9495; Riverside County at phone: Riverside County at phone: (951) 358-6858 or call Los Angeles County at phone: 1-800-854-7771 to obtain more information. If you would like to obtain a copy of the results of this study, please contact the ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) after September 2018.

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### **DECLARACIÓN DEL STUDIO**

Este estudio que acaba de completar fue diseñado para investigar las necesidades y los desafíos experimentados por los padres Latinos que tienen niños con Discapacidades de Desarrollo. Estamos interesados en evaluar los tipos de necesidades y desafíos informados por padres latinos que tienen un niño o niños con Discapacidades de Desarrollo. También estamos interesados en comprender cómo atender las necesidades de los padres latinos a los niños con Discapacidades de Desarrollo mejorará la salud mental, emocional y física de los padres, así como también la relación entre padres e hijos. Cuáles son las necesidades y los desafíos y los factores que actúan como barreras para abordarlos. Esto es para informarle que no hay ningún engaño involucrado en este estudio.

Gracias por su participación. Si tiene alguna pregunta sobre el estudio, no dude en ponerse en contacto con el Dr. Laurie Smith al Phone: (909) 537-3837. Si está interesado en buscar servicios de salud mental, puede comunicarse con una de las clínicas sin cita en el Condado de San Bernardino al teléfono: (909) 421-9495; en el condado de Riverside al teléfono (951) 358-6858 O en el condado de Los Angeles al teléfono 1-800-854-7771 para obtener más información. Si desea obtener una copia de los resultados de este estudio, comuníquese con la base de datos de ScholarWorks (<http://scholarworks.lib.csusb.edu/>) después de septiembre de 2018.

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APPENDIX D  
RECRUITMENT FLYER

## **¿Es usted un padre Hispano de un niño con una discapacidad de desarrollo?**

### **Nos gustaría aprender más sobre:**

- Su experiencia en el cuidado de su hijo/a
- Programas y servicios a los cuales le gustaría tener más acceso u obtener.
- Los estragos que sostiene en obtener servicios para usted y para su hijo/a.

**Información sobre la investigación:** Una estudiante de la Universidad de San Bernardino está llevando a cabo una investigación para obtener más información sobre padres Hispanos que tienen hijos con discapacidades de desarrollo. El objetivo del estudio es aprender más sobre las necesidades, preocupaciones, estragos y deseos de padres Hispanos en referencia al cuidado de sus hijos con discapacidad de desarrollo.

**Elegibilidad:** Participantes tendrán que ser padres Hispanos que tengan hijos con alguna discapacidad de desarrollo.

**Compensación:** Participantes recibirán una tarjeta de Starbucks por \$5.00.

**Contacto:** Favor de comunicarse con Lizbeth Quintero. Mande un mensaje al siguiente correo electrónico: [005054773@coyote.csusb.edu](mailto:005054773@coyote.csusb.edu) o llame al Tel: (951) 442-7765 si le gustaría participar en el estudio o si tiene alguna otra pregunta. Muchísimas Gracias



APPENDIX E  
INTERVIEW GUIDE

## INTERVIEW GUIDE (English)

1. How old are you?
2. At what age did you have your child?
3. What is your nationality?
4. What is the highest degree or level of school you have completed?
5. What is your marital status?
6. Are you currently employed? What was your previous job?
7. Could you tell me more about your child's diagnosis?
8. What is the severity of your child's diagnosis?
9. What were your initial thoughts, emotions etc. experienced when you were informed your child was going to be born with a developmental disability?
10. What is something you would have liked to know before your child's birth regarding special cares for your child?
11. (if they have other children) How is caring for your special needs child different than it has been caring for your other children.
12. How has your child's diagnosis affected you, mentally, physically, emotionally?
13. How does a regular day of caring for your child look like?



14. How has the level of care changed as your child develops?
15. How would you describe your social support system? Who is part of your social support system?
16. Could you tell me about your past experiences in working with social workers as it relates to your child? What would you have changed?
17. What factors have made it difficult for you to access services or resources that could be of help to you and your child?
18. What are services or resources you do not have access to but think would be beneficial for you and your child?
19. If you could receive assistance via a service or resource what service or resource would it be? What is the reason?
20. What agencies, organizations or people in the community have provided services/resources that have helped you in meeting your needs and your child's needs. What have you liked about them?
21. What other needs have you experienced as a parent to a child with a developmental disability?
22. In an ideal scenario what services or programs would you have liked to receive for you and your child?
23. How would receiving more professional support, services or programs help you and your child?

## GUÍA DE ENTREVISTA (Spanish)

1. ¿Qué edad tiene?
2. ¿A qué edad tuvo a su hijo/a?
3. ¿Cuál es su nacionalidad?
4. ¿Cuál es el grado o nivel más alto de escuela que ha completado?
5. ¿Cuál es su estado civil?
6. ¿En qué país nació?
7. ¿Está empleado/a actualmente? ¿Cuál fue su trabajo anterior?
8. ¿Podría decirme más sobre el diagnóstico de su hijo/a?
9. ¿Cuál es la severidad del diagnóstico de su hijo/a?
10. ¿Cuáles fueron sus pensamientos, emociones, etc. iniciales cuando le informaron que su hijo iba a nacer con una discapacidad de desarrollo?
11. ¿Qué es algo que le hubiera gustado saber antes del nacimiento de su hijo con respecto a los cuidados especiales requeridos por su hijo/a?
12. (si tienen otros hijos) ¿Cuál fue la diferencia entre el cuidado de su hijo con necesidades especiales a comparación de sus otros hijos?
13. ¿Cómo le ha afectado el diagnóstico de su hijo/a, mentalmente, físicamente y emocionalmente?

14. ¿Cómo es un día regular conforme al cuidado de su hijo?
15. ¿Cómo ha cambiado el nivel de cuidado a medida que su hijo se desarrolla?
16. ¿Cómo describirías su grupo de apoyo social? ¿Quién es parte de su grupo de apoyo social?
17. ¿Podría decirme sobre sus experiencias pasadas al trabajar con trabajadores sociales?
18. ¿Qué factores le han dificultado el acceso a servicios o recursos que podrían ser de ayuda para usted y su hijo/a?
19. ¿Cuáles son los servicios o recursos a los que no tiene acceso, pero cree que serían beneficiosos para usted y su hijo?
20. Si pudiera recibir asistencia a través de un servicio o recurso, ¿qué servicio o recurso sería? ¿Cuál es la razón?
21. ¿Qué agencias, organizaciones o personas en la comunidad han proporcionado servicios o recursos que lo han ayudado a satisfacer sus necesidades y las de su hijo/a? ¿Qué le ha gustado de ellos?
22. ¿Qué otra necesidad ha tenido como padre de un niño con una discapacidad de desarrollo?
24. En un escenario ideal, ¿cuáles servicios o programas le gustaría recibir para usted y su hijo/a?
25. ¿Cómo le ayudaría a usted y a su hijo a recibir más apoyo profesional?

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