“LAS EXPERIENCIAS DE PADRES CON HIJOS DISCAPACITADOS”
LIVED EXPERIENCES OF MEXICAN-IMMIGRANT PARENTS OF CHILDREN WITH IDENTIFIED DISABILITIES

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This dissertation, by Christina Cortez, has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Santa Barbara in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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Abstract

A nurturing and engaging environment within the family often leads to enhanced student performance. Nonetheless, the education system continues to struggle to connect with families from racially, ethnically, and culturally diverse groups, particularly parents with limited English proficiency or those who have children in special education programs. Amplified difficulties may arise because children with identified special needs—such as physical impairments, learning deficiencies, or developmental disabilities—require additional support, interventions, parental support, and/or services. As the nation attempts to mainstream children in public education and provide them support, Mexican immigrant families in many cases remain underrepresented, or they fall into greater risk due to financial instability, poor communication, and cultural barriers. This qualitative research utilizes a phenomenological approach to explore the experiences of Mexican immigrant families who have identified special needs children; specifically, the study seeks to draw out information regarding possible added hardship and burden compared to their White counterparts. A review of the literature will bring an awareness of the existing hardships or obstacles, as well as possible future actions of intervention within the special education systems when interacting with these families. This will point to supportive social transformation for those lacking social and economic privileges, as well as modify and possibly identify missing links among the broken chain of services in special education, allowing for new provisions to serve children with identified special needs. This information will also be useful to implement acculturation and empowerment tools to support families of children with identified special needs. This dissertation is available in open access at AURA, http://aura.antioch.edu/ and OhioLINK ETD Center, https://etd.ohiolink.edu

Keywords: Mexican immigrant parents of children with disabilities, Latino, Hispanics, special education, multicultural education, culturally sensitive care, cultural development of teachers and paraprofessionals, acculturation, assimilation.

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Glossary of Key Terms

Free Appropriate Public Education (FAPE)

Section 504 of the Rehabilitation Act of 1973 is a federal law enacted to protect the rights of students with disabilities who are enrolled in public schools that receive federal funds. Section 504 requires school districts to provide a free appropriate public education (FAPE) to identified or otherwise qualified students with a disability. Students with disabilities may receive instruction accommodations and assessment (United States Department of Education [USDOE], 2010). Section 504 provides that:

> No otherwise qualified individual with a disability in the United States shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (USDOE, 2010).

The Americans With Disabilities Act (ADA)

The Americans with Disabilities Act (ADA), is a four-part legislation (A-D) enacted in 1990 to ensure students with disabilities are provided with free appropriate public education. (Americans With Disabilities Act, 1990).

Individuals With Disabilities Education Improvement Act (IDEIA)

The reauthorized Individuals With Disabilities Education Improvement Act (IDEIA) signed into law in 2004, by President George W. Bush, ensures that all children with disabilities develop an Individualized Education Program so that students with specialized needs, who are entitled to a free appropriate public education, can meet their unique needs and to prepare them for further education, employment, and independent living. IDEIA ensures that students are identified and assessed if they are not making age-appropriate academic progress, and it is important to consider not only the impact on the child's grades, state standardized test scores, and academic progress but also whether there is an impact in the child's intrapersonal and social skills development, emotional/behavioral progress, adaptive skills, developmental milestones, or activities of daily living, as well as their executive functioning skills such as planning and organizing (USDOE, 2010).

Individualized Education Program (IEP)

An Individualized Education Program (IEP) is a legal document that guides a unique development plan of specialized education for a child, in keeping with IDEIA and Free Appropriate Public Education (FAPE) laws and regulations. In other words, the IEP is a "living document" specifying the child's condition, which may be substantiated either using a battery of specialized assessments executed by a school psychologist or through a substantiated medical diagnosis. This document identifies the child's current performance, their learning strengths and weaknesses, and their learning style as it relates to their academic performance. In addition to specifying special education and related services, inclusion of participation with nondisabled children, participation in state and district-wide tests with modifications (or if otherwise, noting why it is not appropriate), the dates and places of meetings held, and the need for transition services. It must specify the appropriate interventions, specific services and accommodation, and/or modifications to the child's learning environment. The IEP also addresses any teacher and parent concerns for the student and provides the opportunity to introduce the IEP team, which is made up of parents, special and regular education teachers, school psychologists, other services-related personnel, school administrators, and students (when appropriate) to dialogue and develop the special educational time-sensitive goals and recommendations suggested for the child. This document is revised multiple times throughout the year and the child's life in public education and until the child reaches the age of majority (USDOE, 2010).

Multicultural Education

Banks (2007) described multicultural education as a concept of reform and a process that is dedicated to giving all students an equal opportunity to learn.

Disability

Under the ADA disability is a legal term. A person with a disability is defined as someone who has a physical or mental impairment that substantially limits one or more major life activity, or who has a record of an impairment, or who is perceived as having an impairment (Americans With Disabilities Act, 1990). These are categorized as such: (a) *Specific Learning Disabilities* (*SLD*); examples include orthographic processing disorder and auditory processing disorder; (b) *Other Health Impairment* (*OHI*) is an umbrella term covering conditions that limit a child's strength, energy, and alertness such as attention deficit/ hyperactivity disorder; (c) *Autism Spectrum Disorders* (*ASD*) is a category that encompasses developmental disabilities, which covers a wide range of symptoms, but it mainly affects a child's social and communication skills, as well as behavior, sensory processing, attention, and cognitive development; (d) *Emotional Disturbance* (*ED*)*,* is a category comprised of various mental health related issues, such as anxiety disorder, schizophrenia, bipolar disorder, and depression, among others; (e) *Speech and Language Impairment* is the term that covers difficulties with speech and language, commonly identifying students with articulation, pronunciation, and enunciation problems, such as dysarthria and apraxia of speech; (f) *Visual Impairments including Blindness* is the category identifying children with visual impairment of either one or both eyes, with partial or complete blindness; (g) *Deafness* is the diagnosis given to students with who cannot hear most or all sounds, even with the assistance of a hearing aid; (h) *Hearing Impairment* is the term that is not encompassed under “deafness” since there is a hearing loss, but it can change over time. It identifies children who are hard of hearing. This is not to be confused with language or auditory processing, which are cognitive in in their function; (i) *Deaf-Blindness* is the medical diagnosis in which a child is identified being both severely deaf and blind, and where their needs require programs specifically designed with both disabilities; in other words, a child who is “Deaf-Blind” cannot be provided services under one category “Deafness” or “Blindness” because these categories independently do not adequately meet the child’s needs; (j) *Orthopedic Impairment* refers to the child’s lack of function with physical ability, such cerebral palsy or other congenital abnormality like an absence of limb, or disease such as tuberculosis, or other medical consequence such as an amputation or severe burn; (k) *Intellectual Disability* is the category that identifies children with below-average intellectual ability; an example may be developmental delay or genetic disorders such as Down syndrome and fetal alcohol spectrum disorder; (l) *Traumatic Brain Injury* is the term that describes the event of an injury directly to the brain by some physical force, causing temporary or sometimes permanent damage.

Special Needs

Special needs, defined more narrowly, are assessed or otherwise identified disabilities that meet specific medical or educational criteria. Special needs and disabilities are interchangeable terms employed in the literature, which refer as “*an environmentally contextualized or health-related limitation in a child's existing or emerging capacity to perform developmentally appropriate activities and participate, as desired, in society”* (Halfon et al., 2012). However, it should be noted that a “disability” does not define a child; rather, it is an important characteristic in the life of that child, much like temperament and/or personality. Some disabilities, depending on the condition, may improve with adequate support and interventions within Specialized Education after being identified or otherwise assessed.

Table of Contents

CHAPTER 1: INTRODUCTION

Migration occurs for many reasons. Some flee from violent conflict or persecution as refugees, while others, in part due to global economic discrepancies, emigrate to pursue a better future. Often these immigrants withstand unfair conditions and unequal power relationships as they become established in the community. Given these dynamics, families of children with disabilities struggle with numerous out-of-the-ordinary challenges (Breitkreuz et al., 2014).

Between 2000 and 2010, one of the largest and fastest growing minority groups within the United States were Hispanics (United States Census Bureau [USCB], 2018). The U.S. Census defines Hispanic or Latino as a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race (USCB, 2018). The Hispanic population proliferated 43%, rising from 35.3 million in 2000 to 50.5 million in 2010, and accounted for more than half of the 27.3 million growth of the total population in the United Sates (USCB 2018). As the population grows, Hispanics have become the largest minority group, thus increasing the number of children of Hispanic immigrants attending schools.

Immigrant families have faced social and economic disadvantages upon arrival in the United States, including limited familiarity with English, a lack of community and school ties, lower levels of in-classroom participation, and fewer financial resources (Matthews et al., 2017; Kao and Tienda, 1995; Zhou, 1997). Furthermore, past researchers and practitioners alike have theorized and found children of immigrants to be at an especially high risk for delayed special education placement with disabilities. Moreover, another implication is that longitudinal special education placement patterns with Hispanics have received scant attention (Björquist et al., 2017; Morville & Erlandsson, 2016).

Problem Statement

The question posed in this study is "What are the experiences of immigrant individuals who have children with identified special needs?" The objective of this study is to explore the subjective lived experiences of immigrant parents who have children with identified disabilities to explore the phenomenon based on collected qualitative data.

A possible positive outcome from this research could include a contribution to the psychological literature about the experiences of immigrant individuals who have children with identified special needs, as well as the application and value of their shared commonalities. Lastly, by exploring this phenomenon, special considerations may be taken by policy makers, advocacy groups, human rights organizations, and scholars that have power and influence over these issues to engage in systems of inclusion to assist in identifying the difficulties of these individuals and their children.

Purpose

With this population growing so rapidly, children with identified special needs remain underrepresented and underserved. These issues will lead to greater problems if strategies are not implemented and enforced. These figures speak to the level of disparities that exist, but they do not elucidate the reasons why many do not have the support needed. With children having disabilities belonging to the category of intellectual disability, specific services may be available to them regardless of insurance status, and the education is required to communicate the need and relate the parents. However, service providers within the education system will not challenge parents about their cultural superstitions, burdening feelings, and/or alternative options available to them.

Call to the Topic

By having a better understanding of the experiences of the immigrant families, their children will have a better opportunity to be heard, understood, represented, and supported. Having high aspirations for their children's school success in the United States, many Latinos are challenged with the lack of information, knowledge, and/or skills that are fundamental to direct their children through the school systems (Hughes et al., 2002).

Relevance to Clinical Psychology

The literature review will explore the ongoing hardships immigrant families of Mexican descent experience when raising children with disabilities. The purpose of this study is to shed light on these lived experiences, which can inform us about how to make a difference and lessen the disparities. Matters such as these are relevant to social justice and social transformation within the scope of psychology because they can foster awareness about underrepresented individuals, and the right to pursue liberation and allow voices to be heard. The findings of this study could potentially provide opportunities to implement culturally informed practices for educator and paraprofessionals alike to adapt competency practices when engaging multicultural populations. And third, this also creates an opportunity for mental health services to foster well-being with higher quality health care for immigrants and their children, who are America's children.

Parameters for Literature Review

The parameters for the literature review research were not limited to online sources such as PubPsych, PsychINFO, EBSCO Publishing, JournalSeek, WorldCat, OhioLINK, and

Google Scholar between 2000-2010 within the United States of America, more specifically with relevance in public education the state of California.

Key words and compound terms such as: Immigrant Mexican immigrant parents of children with disabilities, Latino and Hispanic parents of school age children, Hispanic children with disabilities, special education, multicultural education and culturally sensitive care, cultural development of teachers and paraprofessionals, acculturation, and assimilation. Other methods utilized for research information included printed literature and textbooks.

CHAPTER II: LITERATURE REVIEW

Special Education Services

Though few places in the world have programs, regulations, and culturally receptive instruction, the United States is one of the few countries where programs such as the Education for All Handicapped Children Act of 1975 exists (Langdon, 2009). The Individuals with Individuals With Disabilities Education Improvement Act (IDEIA), established in 2004, ensures that all children with disabilities who meet specific criteria in Education Code qualify for an Individualized Education Program (IEP). An IEP grants access to special education programming with the appropriate scaffolding or differentiation needed due to a child's specific disability. The Education Code and FAPE have minimum standards and requires specialized services in order to meet student's unique learning needs due to that disability. Prior to IDEIA, over four million children with known disabilities were denied appropriate access to public education. Many children were denied entry into public school altogether, while others were placed in segregated classrooms, or in regular classrooms without adequate support for their special needs (USDOE, 2010).

The IDEIA was aligned with the 2001 No Child Left Behind Act (NCLB), while NCLB seeks to improve the education of all children, it places emphasis on children from low-income families whereas IDEIA focuses on the individual child and seeks to ensure specialized services for children with disabilities so that they may benefit from education (Langdon, 2009). Once identified, each student receives an Individualized Education Program (IEP) to be assessed individually around the students' needs and must be truly personalized (Langdon, 2009). The IEP is designed to generate the opportunity for parents, teachers, school administrators, related services personnel, and students themselves if and when suitable to work unanimously to expand on the educational outcomes of children in special education (Langdon, 2009). Langdon (2009) emphasized that in Subpart 3, Section 671, under Parent Training and Information Centers, new required activities include the following:

> 1) Providing training and information to parents to enable their children to meet developmental and functional goals and challenging academic achievement goals and be prepared for independent living; 2) By providing training and information to meet the needs of low-income parents and parents of children with limited English proficiency; and 3) By helping parents participate in school activities that benefit their children; and helping parents understand, prepare for, and participate in resolution sessions.

Multicultural Education

As the statistics show growing Hispanic populations, for teachers, therapists, and other education professionals working with these populations, there is a growing necessity learn as much as possible about a given Hispanic group, above all, to avoid generalizations and to keep mind that it is impossible to know everything about a given culture (Langdon, 2009). Moreover, implementations of programs are needed to foster education as well as incorporate knowledge available from other service providers about who they serve, including immigrant families who have children with disabilities (Lindsay et al., 2012). There are a number of moral and practical factors of major importance related to supporting Hispanic parents caring for children with disabilities. These may be in the form of delivering training and providing culturally appropriate education to special education professionals. As well as proving supportive programs, adapting regulations, and or by having culturally receptive contact with Hispanic parents it enables and helps their children to meet their developmental, educational, and functional goals (Langdon, 2009; Magaña et al., 2016).

Banks (2007) described multicultural education as a concept of reform and a process that is dedicated to giving all students an equal opportunity to learn. According to multicultural education advocates, giving all students an equal opportunity to learn demands giving time and awareness for all students' cultural, racial, and ethnic backgrounds to inform the development of learning within classroom activities (Banks, 2007). It may not be the case that the host culture deliberately diminishes the cultural value of these populations, but rather, it may be that the education sectors at large have limited knowledge and familiarity about immigrant families' needs and their social and language constructs (Banks, 2007). This lack of knowledge and familiarity may consequently result in excluding and isolating these individuals from other cultural, racial, and/or ethnic backgrounds. As such, multicultural education is also categorized as a school reform activity that involves an emphasis on both knowledge assembly and content integration (Banks, 2006). This reform is envisioned as a continuing exercise, rather than a final static outcome, that promotes improving teachers' critical mindfulness of worldviews opened within their own education and learning (Banks, 2006). Obiakor (2007) further added that this era of accountability in which schools are challenged to leave no child behind makes schools more responsive to students' needs, including those with identified special needs who are linguistically and culturally diverse.

Povenmire-Kirk et al. (2010) conveyed that public special education today faces several problems. Some of these challenges include serving effective educational interventions and strategies for acculturating children of Hispanic backgrounds. More specifically, challenges that these individuals encounter are (a) the availability of interpreters or translated materials and other communication barriers, (b) the need for an identification along with a Social Security number to access federal programs that incorporate educational and rehabilitation services, and (c) facility of culturally appropriate practices or culturally knowledgeable professionals (Povenmire-Kirk et al., 2010). This information could underscore the need for more support in forms of effective education interventions and strategies for acculturating children of Hispanic backgrounds. As such, this body of literature could provide an outline of the ways in which interventions could be enhanced such as addressing the need for interpreters or translated materials to cater to the needs of children of Hispanic backgrounds (Povenmire-Kirk et al., 2010).

Hibel and Jasper (2012) noted that children of immigrants who have learning disabilities are at especially high risk with reduced special education placement. The authors delved into this topic given that special education placement patterns have received scant attention (Hibel & Jasper, 2012). The authors of the study examined temporal patterns of special education placement among children of immigrants, focusing on the timing of special education placement for learning disabilities among first- or second-generation children compared with their third-plus generation peers (Hibel & Jasper, 2012). The findings of the study provided empirical evidence that children of immigrants face comparatively lower odds of receiving early special education intervention services (Hibel & Jasper, 2012). This relationship is explained by the frequent participation of children of immigrants in English as a second language programs in the early grades (Hibel & Jasper, 2012).

As such, Hibel and Jasper (2012) argued that the current special education placement patterns among children of immigrants reveal a significant time-delayed pattern of special education placement for those with learning disabilities as opposed to other less evident physical disabilities. They theorized that this pattern could be attributed to children of immigrants' high frequency of language minority status, as well as English as a Second Language (ESL) service receipt in the early years to be the drivers of first- and/or second-generation and language minority children's delayed special education placement with learning disabilities (LD) (Hibel & Jasper, 2012). The researchers' findings indicated that immigrant students experience a different pattern of special education risk during elementary school than native children or children of third-generation immigrants (Hibel & Jasper, 2012). It was also found that children in immigrant families face comparatively lower odds of special education placement with LD in the early grades but begin to demonstrate a higher risk as the school years progress (Hibel & Jasper, 2012). Further, the findings of the study supported Hibel and Jasper's (2012) theory and are consistent with research indicating that schools use ESL programs as an alternative to special education during the first years of elementary school, not in a purposeful way, but in a general phenomenon (Hibel & Jasper, 2012). Students identified for ESL service receipt, most of whom (76% in this sample) are the children of immigrants, are significantly less likely to be considered for special education receipt until the third grade (Hibel & Jasper, 2012). However, there is the need to rule out language acquisition as a factor when considering special education placement, which compounds learning issues. Moreover, it can be very difficult to determine whether a child who is learning English is struggling academically due to a true learning disability or because instruction has been in a language that they have little foundation in, or have minimal understanding of. If a language issue is the case, the child can be provided additional interventions for language before special education is provide or considered in a valid manner.

According to other researchers, there is a lack of principal preparation to meet the special education needs of Hispanic children (McHatton et al., 2010; Roberts & Guerra, 2017). Roberts and Guerra (2017) and McHatton et al. (2010) indicated that principal preparation programs have ineffectively laid the foundations on the responsibility of the instructional leader, especially regarding students with disabilities. McHatton et al. (2010) added that merely 49% of school principals received a little special education instruction and not more than 30% received education on the learning characteristics of students with disabilities. This research focused on the need for more principal preparation programs with appropriate special education knowledge to ensure that they function as effective instructional leaders for Hispanic students with disabilities, which current preparation programs are not doing (McHatton et al., 2010; Roberts & Guerra, 2017).

Immigrant parents understand and make sense of special education based on their own cultural and school experiences such as getting an education, specific skills, self-esteem, self-actualization, employment, and social relations (Kim & Kim, 2017). According to Jung (2011), immigrant parents have different ways of dealing with children with disabilities. Thus, culturally and linguistically diverse (CLD) parents are often treated as unprofessional or passive regarding the education of their children with disabilities (Jung, 2011; Kim & Kim, 2017). Jung (2011) reported that CLD parents struggle to participate in their children's special education determination due to a lack of information regarding the concept of special education programs and services. Furthermore, information about procedural safeguards, the whole Individualized Educational Plan (IEP) process, and the selection of educational goals are inaccessible to immigrant parents who are caring for children with disabilities (Jung, 2011). Thus, this body of knowledge could call out the need for more efforts to improve the establishment of communication and mutual partnerships between schools and CLD families/parents who are caring for children with disabilities (Jung, 2011; Kim & Kim, 2017).

Rivera et al. (2016) similarly stated the same conclusion and noted that in order to generate continued success within and outside of the classroom when dealing with the educational outcome of students with disabilities, family input on educational decisions is needed. The authors further added that due to the specific nature of a child's disability, there is less access to the general curriculum, appropriate services, materials, and meaningful collaboration between families and educators, which highlights the need for stronger collaboration between culturally and linguistically diverse families/parents and educators (Kim & Kim, 2017; Rivera et al., 2016). The authors proposed a culturally responsive framework for facilitating academic instruction for culturally and linguistically diverse students with disabilities in order to increase access and academic outcomes for this specific population (Rivera et al., 2016). Moreover, the authors suggested that special educational initiatives should increase access to general education curriculum and parental involvement in order to further enhance academic outcomes for culturally and linguistically diverse students with disabilities (Rivera et al., 2016). This information could provide empirical information relating to the need to enhance educational outcomes of students with disabilities, especially those who are culturally and linguistically diverse.

Providing culturally sensitive care is an important element that should be included in family-centered educational and health care services. Lindsay et al. (2012) noted that there is gap in terms of understanding the experiences of educational and health care providers working with immigrant families raising a child with a physical disability. The authors indicated that this is vital to address given that health care and community service providers encounter several challenges in providing care to immigrant families raising a child with a disability. The authors further noted that service providers could make more efforts in improving their services to better meet the needs of immigrant families (Lindsay et al., 2012).

With the objective of enhancing services to better meet the needs of immigrant families, Lindsay et al. (2012) outlined the following challenges faced by service providers: (a) lack of training in providing culturally sensitive care; (b) language and communication issues; (c) discrepancies in conceptualizations of disability between health care providers and immigrant parents; (d) building rapport; and (e) helping parents to advocate for themselves and their children (Lindsay et al., 2012). This information could provide initial information regarding the need for clinicians to be cognizant of how culture influences the care they provide to clients. Also, this body of literature could underscore that more training opportunities are needed for enhancing culturally sensitive care, especially when dealing with immigrant families raising a child with a disability (Lindsay et al., 2012).

Fellin et al. (2015) added to this and noted that the use of culturally sensitive care should be incorporated in services for immigrant families with children with disabilities. The authors argued how it enhances positive experiences of immigrant families, and that these positive experiences often include parents’ access to resources and experiences with health care professionals who are sensitive to the beliefs, values, and worldviews of the families (Fellin et al., 2015). Moes and Frea (2000) and Zakirova-Engstrand and Granlund (2009) added to this, stating that culturally sensitive care reflects an eco-cultural approach to treatment planning. In this eco-cultural approach, there is careful consideration of the immigrant family's social and physical environments, including socioeconomic factors, the supports available to the family and child, and the family's cultural values and beliefs in the treatment approach. In this way, the family's context and goals are included in treatment planning (Fellin et al., 2015). This body of literature could provide empirical evidence regarding the ways in which health care services for immigrant families could be enhanced through the approach of culturally sensitive care and an eco-cultural approach (Fellin et al., 2015).

Björquist et al. (2017) arrived at a similar conclusion and noted that there are specific needs of immigrant youths with disabilities that should be addressed by institutions. The authors of the study indicated that caregivers or health care workers felt unfamiliar with the term intellectual disability. Their findings also revealed that there is a need for parents to have more knowledge and information about the child's disability or condition and of available service for their children now and in the future (Björquist et al., 2017). Further, the respondents in the study reported that there are six types of needs when dealing with children with disabilities: (a) information, (b) support, (c) explaining to others, (d) community services, (e) financial needs, and (f) family functioning (Björquist et al., 2017). These findings could provide an empirical basis regarding the need for more training and knowledge to be given to parents and/or caregivers of children with disabilities, especially in their transitional stages such as adolescence (Björquist et al., 2017). As such, to require a mandated diversity integration, more training is needed for enhancing culturally sensitive care among school officials, teachers, and specialists (Lindsay et al., 2012).

Several researchers also have reported that there is a lack of studies that focus on ethnic minority groups such as Hispanic individuals in the context of children with disabilities. It is said that immigrants are rarely represented in disability research, especially in a Hispanic context (Björquist et al., 2017; Morville & Erlandsson, 2016). In a recently published literature review, it was found that ethnic minorities are not represented in health care research due to a lack of functional methods and time-consuming processes for all involved (Morville & Erlandsson, 2016). This body of literature may provide a small window for future research to expand with immigrants of Hispanic descent in the context of caring for children with disabilities. King et al. (2015) further underscored the need for more effective communication and client engagement in delivering culturally sensitive care to immigrant parents of children with disabilities. This is especially because delivering pediatric rehabilitation services to immigrant parents of children with disabilities requires the practice of culturally sensitive care (King et al., 2015). The authors indicated that there is a lack of studies that examine the specific nature of culturally sensitive care in pediatric rehabilitation, especially the notions of effective communication and client engagement (King et al., 2015; Kummerer et al., 2007). The results of the study revealed several themes that are important in delivering culturally sensitive care, which include the importance and nature of effective communication and client engagement in service delivery involving immigrant parents (King et al., 2015).

The results of the study showed that there are four main types of strategies to engage immigrant parents: (a) understanding the family situation, (b) building a collaborative relationship, (c) tailoring practice to the client's situation, and (d) ensuring parents' understanding of therapy procedures (King et al., 2015). Future research could illustrate the importance of effective, two-way communication in providing the mutual understanding needed by therapists and other service providers to engage parents in the intervention process (King et al., 2015). The findings could also provide empirical information regarding different engagement strategies that could be utilized by therapists in delivering services to immigrant parents, which could also result in a collaborative relationship and good quality, family-centered care (King et al., 2015).

Kummerer (2012) proposed a number of promising strategies for collaborating with Hispanic parents who have children with disabilities. In the context of a family-centered speech-language intervention, many factors including cognitive, linguistic, and cultural influences need to be integrated. The author proposed general strategies such as establishing a trusting relationship, valuing parents as experts of their children, creating mutually constructed goals, accommodating families' schedules and roles, individualizing intervention in the home language, and encouraging parental education and advocacy (Kummerer, 2012). The intent of these strategies is to guide understanding of communication disabilities among Hispanic children and service providers with information on implementing evidence-based practices, which could be utilized in delivering effective and necessary services for immigrant parents who have children with disabilities (Kummerer, 2012).

In delivering family-centered and culturally sensitive care for diverse families caring for children with disabilities, cultural brokering is an approach for intervention of families of children receiving special education and special health care supports (Lindsay et al., 2014; Pang et al., 2019). Pang et al. (2019) reported that within the past decade, cultural brokering has been increasingly used in health care and education as an intervention to provide appropriate and effective services to culturally diverse families. The authors of the study define cultural brokering as an intervention to support connection, link or mediation between groups or persons of different cultural backgrounds for the purpose of reducing conflict or producing change. With children with disabilities belonging to culturally diverse groups is effective in engaging parents to build connections and collaborations with schools and other service agencies and to be more confident in navigating educational and health care systems (Pang et al., 2019).

Lindsay et al. (2014) also delved into this topic of cultural brokerage and culturally sensitive care for children with disabilities. The authors proposed the role of a social worker in providing culturally sensitive care to immigrant families raising a child with a physical disability (Lindsay et al., 2014). The results of the study showed that social workers' understanding of culturally sensitive care involved being aware of their biases and how their own cultural or professional orientation may influence their interaction with patients, thereby addressing the needs of children with disabilities who come from various backgrounds (Lindsay et al., 2014). The authors also noted that the social workers faced challenges such as language barriers, discrepancies between clinicians' and patients' cultural orientation, gender and generational differences, lack of knowledge of resources, and difficulties building rapport and trust (Lindsay et al., 2014).

Social workers can overcome these challenges, building rapport and trust by working as cultural brokers to link immigrant families to resources and to mediate differences between patients' and clinicians' cultural orientations (Lindsay et al., 2014). As cultural brokers, better health outcomes can be attained for their children with disabilities (Lindsay et al., 2014). Reviewing current approaches of cultural brokerage may be the most effective way to link immigrant families and their children with disabilities to needed educational and health care systems (Pang et al., 2019). Additionally, this scope of research could provide an initial context on how social workers play a critical role in providing culturally sensitive care to immigrant families raising a child with a disability (Lindsay et al., 2014).

Understanding the Needs of Immigrant Parents

In terms of understanding the needs of youth with special needs, parents, educators, and other professionals, Povenmire-Kirk et al. (2010) surveyed six Latino youth with disabilities (three male and three female, ages 14 to 18 years) and school and transition professionals to identify the youths' needs while transitioning from school to adulthood in Oregon. The researchers utilized a theoretical research model that included community context, cultural context, and individual factors to identify available transition services and barriers faced by this population. Students who were either enrolled in high school or no longer attending high school were recruited. These individuals had an identified disability and qualified for transition services under the Individuals With Disabilities Education Improvement Act (Povenmire-Kirk et al., 2010).

The second group studied was educators and transition professionals who were recruited from the school district to include a wide range services that cater to Latino youth with disabilities (Povenmire-Kirk et al., 2010). A total of 22 school professionals participated in the research, which also included seven high school special education teachers, five administrators or program coordinators, three case managers or school counselors, three transition specialists, two school psychologists, and two multicultural or home school liaisons (Povenmire-Kirk et al., 2010).

Results were broken down by themes wherein five categories were identified: (a) language issues, (b) concerns regarding documentation and citizenship, (c) lack of culturally appropriate practices, (d) barriers to family participation, and (e) limited school and community resources (Povenmire-Kirk et al., 2010). These five categories are what needs to be addressed given that they are major contributors to the challenges that Latino youth with disabilities face. The findings in this study also encouraged the need for modifications for Latino students' service delivery of their transition living due to their disabilities. As such, these changes are needed within the individual and school district levels. The authors argued that the vast majority of Latinos who have disabilities generally live below the poverty level and receive lower wages than those with higher education and partake in less enrollment than their postsecondary education than their same-age White peers. Their results also showed that immigrant families often do not receive services available to meet their needs (Povenmire-Kirk et al., 2010).

Pisula (2011) suggested there are three main factors that contribute to higher stress levels among parents of children with autism: (a) the impact from the child's autism characteristics and symptoms, (b) lack of adequate professional support and unsatisfactory relationships between parents and professionals, (c) societal views toward individuals with autism and a lack of understanding of autism and the experiences that families go through.

Balcazar et al. (2012) conducted a case study that was part of a project funded by the USDOE under the Americans With Disabilities Act (ADA). The ADA research project was primarily implemented to further the application of the ADA law within the metropolitan cities where Latino communities reside. In their research all of the families had immigrated within the last five years. Six parents of children, between the ages of 5 and 12, with hearing impairments were the sample of their research. They attended advocacy trainings as the focus of this case study. These families were first-generation Mexican immigrants who did not speak English while they were learning American Sign Language (ASL). The children attended a primary school that specialized in serving populations with hearing impairments.

The authors, Balcazar et al. (2012), found that many barriers exist, as well as factors that delay services; the concern to facilitate availability in the native language of immigrants, with deep understanding of the immigrant's culture is reflected. The researchers found that Latino immigrant families who have children with disabilities experience a number of causes of oppression during their integration into the United States. Additionally, Latino immigrant families who have children with disabilities face unfair social structures that reflect values foreign to theirs, which may influence their personal perceptions, which causes a cycle of oppression that is problematic and hard to eliminate (Balcazar et al., 2012).

Other important considerations are the active collaboration process of liberation in this population started by self-awareness from their personal narratives. The narratives allowed and enabled immigrants with disabled children to overcome multiple oppressions by analyzing their dilemmas and conditions because they later resulted in the formation of a community-university partnership. In their findings, the authors discovered that the immigrant parents had limited advancement classes in ASL for themselves to communicate with their deaf and hard-of-hearing children (Balcazar et al., 2012).

Arcia and Johnson (1998) explored the values of Mexican immigrant mothers that they used to guide their children and their understanding of how children acquire those values. Fifteen mothers were given a Q-sort task of parental values and interviewed at length using a semi-structured format. They hypothesized that the women's values would be defined by their cultural background, their personal experiences, and by their children's unique characteristics. The highest ranked items were these five:

> to have a sense of right and wrong, to be a good student, to be obedient, to be responsible, and to be respectful and the least desirable characteristics included: wanting to be the best or the first, being independent, being close to the family ("apegado"), and wanting to know how or why things happen. (p. 84)

The authors' analysis of the transcribed narratives of the mothers showed significant childhood development themes within a cultural model that is specific to them. This model diverges from that of modern experts' views. This may be because they are influenced by Westernized ideas and values. Their findings showed that obedience, responsibility, and respect are three characteristics considered to be synonymous. This raises questions about parents' understanding of their children's development with relation to special education placement. This also raises questions regarding Hispanic parents' sense of compliance that Western beliefs have toward Native American, African, and Hispanic cultures (Arcia & Johnson, 1998).

As previously discussed, parental involvement is essential to educate special needs children. A critical discourse analysis was conducted to see if any contrasting educational policy statements from the British Columbia Ministry of Education and the Vancouver School Board exist (Lai & Vadeboncoeur, 2013). The purpose was to explore the views of immigrant parents about their sense of their involvement in their children's education at home and at school (Lai & Vadeboncoeur, 2013). Ten semi-structured interviews were gathered, six of ten participants were recruited through letters the school district sent to the district parent support group, and four were directly referred by school staff.

According to Lai and Vadeboncoeur (2013) their data "highlight important contradictions between the ideal intent of policy and the positioning of parents as subordinate and inexpert within policy documents and between policy and practice" (p. 888). Furthermore, Lai and Vadeboncoeur (2013) found that

> parents are given mixed messages regarding their children's special education ranging from, their involvement is an important part of a partnership and legally required, AND that they ought not do or ask for too much, and; from the second theme, that their knowledge and input is valuable, AND that they are not professionals and are inexpert at much of what is valued by the school. While not every parent wants to or can offer themselves as partners, as teaching resources, the participants in this study did want to and were able to contribute their knowledge and time, but this was seen as being over-involved. (p. 888)

Limitations of Lai and Vadeboncoeur's (2013) study include the small sample size, the lack of generalizability crossing borders from Canada to the United States, and the individuals being heteronormative. That is, the individuals belonged to a particular social class and geographic location, and followed cultural norms such as where the father is the breadwinner and the mother stays home to raise children, as well as Chinese, English language, and Euro-Canadian cultural locations (Lai & Vadeboncoeur, 2013). Furthermore, the participants in this research were of middle and upper-middle socioeconomic status and had the time and financial resources to support their children's needs (Lai & Vadeboncoeur, 2013).

Health Care Accessibility

Other findings that contributed to the parental aggravation were instability of family structure, geographic variations, hardships with wages and/or employment, social support, parental well-being, faith and religiosity, and relationship quality. All of these challenges equally impact the quality of education, level of efficacy, availability of services for care, and well-being the children of immigrants with identified special needs require to flourish as productive independent citizens in their own community (Singh & Lin, 2013).

Immigrant children in the United States historically experience lower-quality health care. In their study, Singh and Lin (2013) argued for promoting health policy programs to promptly address these profound social disparities in disability and health care access. Cultural awareness backed with research and case studies have shown to be essential in this social transformation process. This study establishes the known hardships of the immigrant parental experience as well as the necessity for outreach efforts by clinicians, other mental health professionals, school systems, and social workers for implementing programs that will aid and provide a less aggravating parental experience for those immigrant families (Singh & Lin, 2013).

The U.S. Census Bureau's American Community Survey (ACS) for 2008–2010 databases did not include the type of disability (sensory, mental, or physical) for both children and adults in the microdata sample. This limitation reflects not only the type but also the severity of disabilities. Additionally, even though the ACS did include a series of immigration-related issues such as citizenship/naturalization status, English language ability, length of U.S. residence, and age at entry into the United States, ACS did not have data on the legal status of individuals who immigrate, which could greatly influence their eligibility for health insurance.

Kan et al. (2016) underscored the importance of addressing the special health care needs of immigrant children by focusing on increasing its accessibility among this population. By using the 2011 National Survey of Children's Health, the results of the study showed that foreign-born children with special health care needs were less likely than children with special health care needs with U.S.-born parents to have a medical home (adjusted odds ratio = 0.40, 95% confidence interval). Further, the results of the study revealed that foreign-born children with special health care needs most often lacked care coordination as compared to children with special health care needs with U.S.-born parents (Kan et al., 2016). Underscoring the disparities in medical access and presence for immigrant children with special health care needs calls for more attention to be focused on immigrant children and their families.

Garcia-Ramirez et al. (2010) also argued that there is a pronounced need to face issues that arise among Mexican immigrants rearing children with disabilities. The authors of the study indicated that issues of Mexican immigrants rearing children with disabilities are mostly due to their low socioeconomic-status, their uncertain eligibility for services available, the general low level of education, knowledge about their child's disabilities and limitations, and the lack of effective communication barriers between school officials, physicians, and other health care providers. The researchers conveyed that many immigrants are much more aggravated than their counterpart natives by having children with disabilities (Garcia-Ramirez et al., 2010).

Acculturation

As the immigrants move through the acculturation process, many continue to experience personal adjustments on many fronts. In terms of culture shock, Fee (2011) outlined five stages of acculturation: (a) a honeymoon period, rather like a foreign vacation, where the person retains the home culture; (b) a second stage marked by irritation with confusing cues, for example, how to interpret an unfamiliar traffic sign; (c) a third stage that integrates these cues but is characterized by anger at the differences; (d) a fourth stage, recognizing the positive and negative elements of both cultures; and (e) a final, bicultural stage where the person can navigate both cultures in some comfort (Fee, 2011). In such cases, the first usual stressor to take place in all immigrants is the outcome from culture shock experienced when they encounter new customs, values, and behaviors. It need not matter if the immigrants are affluent or of low socioeconomic level, or healthy or ill (Fee, 2011). There was the overwhelming lack of familiarity with a new country—new driving regulations, different medical systems, different schools for the children, changed holidays, absent family and friends. One newly arrived teacher got two traffic tickets within the first 2 weeks and had to appear in court for failing to stop at a flashing yellow light (Fee, 2011).

Lequerica (1993) discussed important findings for practice among professionals to become knowledgeable about immigrant stress. The author found that immigrants experience constant feelings of being overwhelmed, being lost and bewildered, as well as living in poorer conditions in greater metropolitan cities that are large, crowded, and noisy. The survey of the immigrants found that many form *barrio communities*, as part of their "community", which is an establishment process. This is supported by the microsystem theory in which the individual's interrelationship between themselves and their immediate physical and social environment is created with a sense of belonging and connection with their place of origin, as well as with other individuals from that place. However, it was mentioned that because immigrants may be living in cloistered groups, this could add to their self-exclusion and disengagement from the greater community and from the mainstream of the new society in the long term. The findings indicated that factors such as being foreign, being unacquainted, having to secure housing for their families, and having great differences in climate, customs, and responsibilities that are attributed to each of the sexes in the new community profoundly disorders the immigrant’s sense of self and belonging. When new immigrants cloister together, factors such as lower socioeconomic status can factor an additional impact to their adjustment. Immigrants typically bind together with those of familiar background, extended families, friends, or other connections in the same native language, customs, and lifestyle to decrease their stress and troubles. The author argued that fostering acculturation and integration is something that must come from the community members themselves because profound generalizations and stereotypes are shown to hinder the ability to connect with others and disable the ability to understand and have empathy with others (Lequerica, 1993).

The participation of experienced professionals and paraprofessionals in the field that are familiar with the language and culture of the immigrant family and that are equally knowledgeable about health care is essential, but it is more essential to facilitate the access of immigrant families and children with disabilities to better physical and mental health care.

Another study by Khanlou et al. (2017) stated a similar conclusion and noted that families of children with disabilities suffer from higher levels of stress and isolation due to increased caretaking burden and difficulty navigating systems of care in a new country. Millau et al. (2016) concluded similarly and noted that immigrant families of children with disabilities such as autism spectrum disorders (ASD) face significant challenges in accessing and using rehabilitation services appropriate for their child’s disorder. Compared to families native to their host country, the stress experienced by these families in relation to their child's condition is magnified by their immigrant status (Millau et al., 2016). As such, the authors of the study compared self-reported parenting stress levels among 24 mothers and 17 fathers who had immigrated to Canada to income-matched, Canadian-born parents. Overall, the findings of the study indicated that immigrant parents have higher stress levels than Canadian-born parents (Millau et al., 2016). Even though the study did not focus on Hispanic immigrant parents, these findings could highlight the necessity of using supplemental and specialized stress measures when working with immigrant families, for whom stress associated with the immigration process may compound or manifest separately from parenting stress and in caring for children with disabilities (Millau et al., 2016).

Luu and Neece (2019) noted similarly and found that minority parents of children with disabilities are at risk for especially high levels of parenting stress due to the additive stress of adapting to a new culture and parenting a child with special needs. Further, results indicated that the relationship between acculturation and parenting stress depended on the level of family support. That is, low levels of acculturation are associated with increased parenting stress at high levels of family support, however, not low levels of family support (Luu & Neece, 2019).

Millau et al. (2016) further added that the cultural influences on the perception of disabilities such as ASD, children's birthplace, and parents' roles in childrearing also impact stress. A study by Valicenti-McDermott et al. (2015) reported significantly higher parental stress for immigrant parents who care for children with ASD as compared to U.S.-born mothers. In addition, it was found that parental stress was related to child irritability, which often resulted in sleep difficulties. As such, targeting child irritability may be particularly important in reducing parental stress. Further, this body of literature could provide insightful information regarding the sources of stress that are experienced by families/parents who are caring for children with disabilities, and the additive stress that is faced by immigrant parents (Khanlou et al., 2017). As such, this study merits the need for more development support and peer support programs to address the needs and stressors that are specifically faced by immigrant parents who have children with disabilities.

Su et al. (2018) also investigated immigrant mothers of children with developmental disabilities and their stressors. The authors of the study found that immigrant mothers of children with developmental disabilities face challenges that contribute significantly to their stress. Such stressors include accessing services for their children, having limited financial resources, occupational unemployment, excessive paperwork, long waiting times, language barriers, limited knowledge of social services, emotional strain, transportation difficulties, dispersed services, and feelings of loss of face (Su et al., 2018). Due to the stressors that immigrant mothers of children with disabilities face, timely access to effective supports across service sectors is required. According to several researchers, immigrant mothers of children with disabilities face many access barriers that are further compounded due to acculturation stressors and learning to navigate new education, social, and health sectors (Dodds et al., 2018; Khanlou et al., 2017). Therefore, promoting equitable access requires that the challenges immigrant families face in accessing supports and services for their children with disabilities be fully understood.

Khanlou et al. (2017) delved further into this topic and aimed to study the barriers to services faced by immigrant mothers of children with autism in Canada, which are sources of stress for this population. The findings of the study indicated that immigrant mothers of children with disabilities face structural support challenges, such as delays in diagnosis, fragmented and dispersed services, as well as instrumental challenges due to loss of social ties and stigma. The findings also revealed that immigrant mothers often lack support from partners and have negative perceptions of services, which were identified as emotional and perceptive challenges and sources of stress for this population. These empirical findings identify barriers that immigrant mothers face when accessing services and support for their children with disabilities. This is vital to address given that they are shown to be major causes or factors of stress for this minority population group (Khanlou et al., 2017).

Students with disabilities who come from diverse backgrounds, such as Hispanic, face challenges and potential educational disparities beyond their special educational needs. With the objective of enhancing educational outcomes for this population, several researchers have emphasized the need to build capacity to engage culturally diverse families through interprofessional partnerships and training, especially when dealing with students with disabilities (Stronach et al., 2019). For example, proposed recommendations for engaging English language learning (EL) families include providing adequate training and professional development for educators and collaborating with all stakeholders and families. The authors underscored that more training and development for special educators is necessary in order to improve communication and engagement with immigrant and refugee families of children with disabilities, as well as providing training and developing resources to foster effective communication between schools and EL families of students with disabilities. In fact, the findings of their study showed that 88% of the interpreters and educators strongly agreed that they gained knowledge from the training and that they felt more equipped in addressing the special educational needs of children with disabilities. Although this study does not focus on the Hispanic population of children with disabilities, this could provide initial evidence on the need for more training and development for special educators when dealing with children with disabilities coming from various backgrounds (Stronach et al., 2019).

Language Barriers

Johnson et al. (2009) found that undocumented immigrants do not reach out to disability programs for support, possibly due to reasons such as lack of knowledge of services available, paucity of translated materials, and lower levels of acculturation.

Al-Hassan and Gardner (2002) appealed for more emphasis to be placed on giving information to Spanish-speaking parents, both written and oral, in ways that help them understand. The need for school documents to be translated, with interpreters, with simple reports, and with icons, with positive and direct body language, and verifying that the message was understood correctly, is an essential part of communication when interacting with Spanish-speaking communities. With the pressure rising and problems mounting within the immigrant communities, the risk grows for these populations to not receive the services they need. In order for teachers and other professionals to become familiar with these populations, some researchers encouraged reading about specific cultures as an effective way to learn. It is also beneficial to ask bilingual parents for their input on the process, encouraging and welcoming parent participation in the classroom and appreciating and being sensitive to others' cultures. According to these researchers there are many methods that immigrant families can use to participate in the educational process, as well as specific tactics that give professionals ideas. The authors suggested considering building a positive relationship between parents and professionals in the education field by being open to dialog, as well as staying informed and avoiding assumptions (Al-Hassan & Gardner, 2002).

The findings of Harper et al. (1999) advocated to support the academic needs of minority children with disabilities who require specific effective teaching models, as well as other considerations for applying peer-tutoring programs. The authors also highlighted that peer-tutoring programs are effective in stimulating minority children with disabilities in the educational and social integration into general education venues. O'Keeffe and Medina (2016) similarly added that offering peer-tutoring programs is an effective instructional strategy that school educators can use in inclusive settings in order to support the unique needs of culturally and linguistically diverse exceptional students. The authors also indicated that it is appropriate for both typical and atypical learners in a whole group setting, but they are particularly useful for helping students meet the challenges associated with diversity and disability in an environment that is generally geared toward their White, typically developing peers (O'Keeffe & Medina, 2016).

As stated by Lai and Vadeboncoeur (2013), the collaboration has been slow to progress because of the limitations between school professionals and parents in relation to the understanding, knowledge, and awareness on both parts.

With the objective of increasing communication levels between Hispanic immigrant parents and information on therapeutic interventions, Lajonchere et al. (2016) explored the strategies for disseminating information on research on disabilities such as ASD to Hispanic parents. According to the authors, low-income Hispanic families experience multiple barriers to accessing evidence-based information on their children's disabilities (Lajonchere et al., 2016). The authors proposed a mixed-strategy intervention to create access to information in published biomedical research articles on disabilities by distilling the content into parent-friendly English- and Spanish-language ASD Science Briefs (Lajonchere et al., 2016).

These findings provide empirical evidence that in order to promote culturally responsive intervention, there should be more information about the therapy process to be provided to Mexican immigrant mothers in their native language. These findings of limited knowledge and lack of clear communication amid parents and families add additional challenges to educating and servicing immigrant children with identified special needs.

Perceptions of Disabilities

Kummerer et al. (2007) conducted a study regarding speech-language therapy and treatment along with immigrant mothers caring for children with disabilities. The authors of the qualitative study explored mothers' perceptions of their children's communication disabilities, emergent literacy development, and speech-language therapy programs (Kummerer et al., 2007). Fourteen Mexican immigrant mothers and their children (age 17–47 months) who were receiving center-based services from an early childhood intervention program participated in the research. The findings of the study showed that the majority of mothers perceived their children as exhibiting a communication delay. Causal attributions were diverse and generally medical in nature (i.e., ear infections, seizures) or due to familial factors (i.e., family history and heredity, lack of extended family). In this study, mothers focused and inquired about the time required to remedy their children's disability, as well as inquired on more information about the therapy process. Furthermore, the mothers expressed frustration at their frequent inability to understand their children's difficulties and the proposed plans of action in other health care venues, such as doctors' offices.

Through their study, Lajonchere et al. (2016) found that Hispanic parents showed an increased likelihood of experiencing confusion and difficulty making sense with relevant health information and retaining only short-term knowledge regarding therapeutic interventions and information regarding ASD. However, after 5 months, Hispanic families reported utilizing the information learned, wherein 90% wanted to read more science briefs related to their children's disabilities. This could provide empirical context regarding the ways in which communication levels between Hispanic immigrant parents and information on therapeutic interventions could be enhanced. This highlights the potential benefits of distilling research articles on disabilities into parent-friendly educational programs for underserved Hispanic parents, which could address their need for more information regarding the disabilities of their children.

Social Stigmatization

Goffman (1963) defined stigma as a discrediting attribute assigned by society to those who differ in some manner from society's expectations, customs, and norms. Social stigma is one of the causes linked to stress among Hispanic parents who care for children with disabilities. Hispanic families have distinct cultural beliefs about disabilities such as ASD (Khanlou et al. 2017; Cohen & Miguel, 2018). These beliefs often include social stigma, which leads to parents' emotional stress (Cohen & Miguel, 2018). Zuckerman et al. (2018) reported similarly, having developed an English/Spanish bilingual parent-reported scale of perceived community stigma toward ASD. The results of the study revealed that the perception of social stigma toward disabilities is linked to parent-reported stress levels (Zuckerman et al., 2018). Although the study did not focus on the Hispanic population, this could provide additional information regarding the factors attributed to stigma as an additional stressor for immigrant families who are caring for children with disabilities. As such, this could prove to be a callout for more efforts in reducing social stigma when it comes to disabilities of immigrant children (Cohen & Miguel, 2018; Zuckerman et al., 2018).

Young and Rabiner (2015) underscored the importance of strengthening relationships between mental health care providers and the community to reduce the stigma associated with seeking mental health treatment for children, as well as better educating parents about the potential benefits of treatment. In their study, the authors found that Hispanic parents report socioeconomic and stigma-related barriers as more inhibiting than did African American parents. According to their findings, these barriers prevent or delay Hispanic parents from obtaining health services linked to their children's disabilities. These barriers are associated with access to treatment and community engagement for immigrant parents raising a child with a disability.

Brassart et al. (2017) delved into this area of study with focus with the strategies for service providers to reduce stigma and enhance engagement with immigrant parents raising a child with a disability. The authors noted that service providers have a key role to play in the families' understanding of disability and in increasing the engagement process. Twenty-one semi-structured interviews were conducted with service providers from three large cities from Canada. The findings indicated three factors in order to address the barriers that diminish the social stigma and immigrant parents' engagement in their child's treatment: (a) overcoming the language barrier, (b) developing a shared understanding of the child's disability, and (c) helping the parents to understand the treatment process (Brassart et al., 2017). These findings underscore several adaptations needed within special education and health care for immigrant parents.

Fellin et al. (2015) also addressed the need to explore the ways that clinicians could implement service delivery models and reduce internal stigmatization and engage immigrant parents of children with a disability. The authors of the study aimed to examine the experiences of clinicians working with immigrant families raising a child with a physical disability as well as to examine the views and experiences of clinicians providing collaborative, culturally competent care. According to their findings, clinicians remove or create barriers for immigrant families in different ways, which impact their ability to provide culturally competent care for immigrant families raising a child with a physical disability. These findings merit the need for more institutional support for collaborative, culturally competent education of professionals who care for immigrant families.

Ijalba (2016) similarly suggested that Hispanic immigrant mothers who are raising a child with disabilities such as ASD often face additional stressors. The findings indicated a lack of awareness about disabilities such ASD influenced social isolation, which was identified as a source of stress for both Hispanic immigrant mothers and children with disabilities. This could be due to the fact that disabilities such as ASD are associated with fear or sadness and therefore raise the chances of alienation for this specific population. The results also revealed other stressors faced by Hispanic immigrant mothers including immigration status, economic hardship, and advice against using Spanish with their children. Thereby, the authors of the study proposed that more professional training and parent education is needed to facilitate early identification of disabilities to aid Hispanic immigrant mothers who are raising a child with disabilities (Ijalba, 2016).

Parents may feel branded by social disapproval as a result of their child's socially inappropriate behaviors, leading them to encounter social stigmatization. This experience of feelings shameful and guilty can lead parents to separate from their social circles due to lack of practical and emotional support, as well as judgment and blame placed on them for their child's nonnormative behaviors, in addition to the lack of public knowledge and understanding regarding the nature of ASD (Farrugia, 2009; Gray, 1993, 2002). To address the stigma and minimize the potentially hurtful encounters and exchanges that would arise from their child's socially deviant behavior, many parents decrease their exposure on public outings. Parents may also be selective about who they disclose their child's diagnosis to, and they may restrict their social lives with friends and family who they feel lack compassion and empathy for their child's condition (Farrugia, 2009; Gray, 1993, 2002). Experience with receiving overtly hostile looks and stares, as well as rude and unwanted advice from strangers about the way in which they should parent or correct their child's behavior may make parents feel particularly targeted, vulnerable, embarrassed, and angry (Gray, 1993, 2002).

In the first theme discussed in the research of Cohen and Miguel (2018), parents described instances where members of their community negatively evaluated them, their parenting skills, and their children's behavior. Parents also described their reactions to the negative evaluation and their efforts to educate community and family members. The researchers identified instances in which participants described rejection, ignorance, and negative evaluations from family and community members and mothers described situations when their upset children threw a tantrum in public settings (Cohen & Miguel, 2018).

Mental Health Difficulties

Additional research by Yu and Singh (2012) suggested that parental mental aggravation is correlated with a quality of life and stress levels that families face caring for offspring. In their research, the authors found that elevated parental aggravation has been formally correlated with maternal and paternal depression, ASD, learning disabilities, child obesity, maternal chronic illness, paternal alcoholism, single parenthood, family transitions, and identifying with Black heritage.

Parenting aggravation is associated with high parenting stress, and it has also been explored by Schieve et al. (2011), wherein the authors assessed aggravation levels among parents of children with and without ASDs. The results of their study revealed that high aggravation percentages were found among parents of children with a current ASD, while aggravation percentages were significantly lower for parents of children with no special health care needs. The authors noted that study in this area has not been explored in immigrant individuals of Hispanic background (Schieve et al., 2011).

Over the past decade parents from minority groups have had increased difficulty with accessibility to health insurance programs for their children with identified special needs. However, lapses in access and utilization, the degree to which individuals use services, still persist specifically for Hispanics (Locke et al., 2017; Roberts & Guerra, 2017). Further, current literature on childhood disability indicates that Hispanic children with disabilities experience a high number of unmet needs and significant barriers to obtaining health care (Fellin et al., 2015). Several researchers have found that Hispanic children are 14% to 40% less likely to receive special health care services than other ethnic groups (Locke et al., 2017; Roberts & Guerra, 2017; Singh & Lin, 2013). Singh and Lin (2013) sought to explore the discrepancies within the health insurance rates of children and adults within racial, ethnic, immigrant, socioeconomic status as well as the link between disability and being uninsured. Singh and Lin (2013) analyzed the data of 9,093,077 participants. Their expectations were drastically underestimated. They in fact found that 55% of Mexican immigrant children, 36.0% of Central/South American immigrant children, and 35.2% of Laotian immigrant children lacked health insurance, compared with 4.1% and 5.8% of U.S.-born White children and foreign-born Japanese children (Singh & Lin, 2013).

Willis et al. (2016) explored gender differences in the relationship between dispositional optimism, coping, and depressive symptoms in Hispanic mothers and fathers of children with ASD. The authors of the study found that Hispanic mothers reported greater depressive symptoms and greater use of positive and support coping than Hispanic fathers (Willis et al., 2016). In addition, the authors of the study noted that positive and avoidant coping strategies mediated the association between optimism and depressive symptoms for both mothers and fathers (Willis et al., 2016). The body of research herein could provide in-depth context and empirical evidence regarding the need for more interventions for Hispanic parents caring for children with disabilities, in order to improve their optimistic outlooks, as well as their coping skills, which could reduce negative outcomes (Willis et al., 2016).

Severe stressors for parents are vital to address because they can lead to negative outcomes such as anxiety and depression, if left unresolved (Gatzoyia et al., 2014). The authors stated their conclusion and indicated that raising a child with disabilities is a severe stressor for parents, who often present high levels of depression. They added that a remarkable proportion of parents with an ASD offspring present clinically significant depressive symptoms, which were associated with illness perceptions relevant to the consequences and the chronicity of the disorder. This information shows the importance of supporting parents to deal with the consequences and chronicity of their offspring's disorder in order to reduce parental psychological distress. Yu and Singh (2012) and Gatzoyia et al. (2014) emphasized that the association of depressive symptoms and general psychological distress in parents of an offspring with disabilities is an area that has not been studied widely in immigrant individuals of diverse racial and ethnic backgrounds.

Burns (2018) and Neece et al. (2019) noted that parents of children with disabilities reported elevated mental health difficulties compared to parents of children without disabilities, which are largely associated with child behavioral problems. However, existing studies rarely focus on providing support for minority families from racial and ethnic backgrounds such as Hispanic culture. This should be addressed given that Hispanic parents of children with disabilities experience heightened risk for poor mental health outcomes due to additional stressors associated with minority status (Neece et al., 2019).

One of the ways to support immigrant parents caring for children with disabilities is through mindfulness-based stress reduction (MBSR) interventions (Burns, 2018; Neece et al., 2019). MBSR has been shown to be efficacious for reducing parenting stress and improving well-being in families of children with disabilities (Burns, 2018). As such, Neece et al. (2019) employed a mixed-method, waitlist-control design to examine the efficacy of MBSR for improving parent and child outcomes in Latino and non-Latino families. The results of the study indicated that MBSR is similarly efficacious for Latino and non-Latino families in improving parent mental health (parenting stress, depressive symptomatology, and life satisfaction) and reducing parent-reported child behavior problems (Neece et al., 2019). The authors also highlighted that support programs such as MBSR should be delivered directly in the Spanish language, rather than using translation services, for Spanish-speaking families in order to enhance its efficacy among this specific population (Neece et al., 2019). This study revealed the efficacy of standard MSBR for Hispanic parents of children with disabilities and underscored the potential benefits of disseminating this practice to traditionally underrepresented families (Burns, 2018; Neece et al., 2019). This body of knowledge could therefore be utilized as an avenue for supporting immigrant families who are caring for children with disabilities given its proven efficacy among this group (Burns, 2018).

Chan and Neece (2018) concluded similarly and argued that elevated parenting stress is concerning, not only because of the associated poorer physical and mental health outcomes for the parents but also because of its role in the development of behavior problems and subsequent psychopathology in their children with disabilities. As such, the authors of the study aimed to evaluate whether the effects of MBSR in the Hispanic population are maintained long term. The findings showed that immigrant parents who received MBSR reported significantly greater improvements in mental health outcomes as well as reduced negative child behaviors related to inattention and withdrawal compared to parents and their children in the control group (Chan & Neece, 2018). Finally, the study revealed that the positive changes resulting from the MBSR were maintained at a 6-month follow-up assessment. These findings warrant the efficacy of MBSR for immigrant parents in supporting their mental health outcomes, which in turn impacts the overall well-being of their children.

Javier et al. (2010) focused their research with immigrant status linked to issues such as health care access, health care utilization, and health status compared to U.S.-born individuals. The authors aimed to compare health care access, utilization, and perceived health status for children with special health care needs in immigrant and nonimmigrant families. The findings of the study indicated that, compared to children with special health care needs in nonimmigrant families, children with special health care needs in immigrant families are more likely to be uninsured (10.4% vs. 4.8%), lack a usual source of care (5.9% vs. 1.9%), report a delay in medical care (13.0% vs. 8.1%), and report no visit to the doctor in the past year (6.8% vs. 2.6%).

Additionally, children with special health care needs in immigrant families are found to be less likely to report an emergency room visit in the past year (30.0% vs. 44.0%), as well as more likely to report poorer perceived health status (33.0% vs. 16.0%). This further outlines the current barriers to continuing health care for children with special needs within immigrant families. These findings could also underscore the fact that children with special health care needs found in immigrant families are largely affected by family socioeconomic status, parent’s language, parental education, and employment opportunities. Given these barriers that immigrant families face, the need for more public health policies to improve access in existing insurance programs and provide culturally and linguistically appropriate care can likely decrease health care disparities for Hispanic immigrants (Javier et al., 2010; Singh & Lin, 2013).

In Singh and Lin’s research (2013) it was found that there are greater disproportions for health care found within Mexican immigrants: 58.3% of all, and 34.0% of Mexican immigrants with disabilities being uninsured (Singh & Lin, 2013). These numbers are catastrophic to speak of, and possible factors such as poverty, lack of opportunity for advancement in employment, or lack of employment-based health insurance may very well be attributed. The authors proposed that there should be a promotion of policy programs in order to promptly fill the gap in these profound social disparities in disability and health care access. Further, they also highlight the basic moral obligation to identify the limitations of integration and the factors of aggravation for isolation in immigrant families' experience. These statistical disparities can add aggravation and stress to any individual, more so for individuals who are a minority, are underrepresented, or are marginalized such that insurance is neither offered nor affordable.

Other Barriers

Considerable distrust for health care professionals and disability organizations may be perceived by Hispanic immigrants, adding to the long list of barriers already discussed. Alternatively, undocumented immigrant families may not want to call attention to themselves for fear of judgment or the involvement of Immigration and Customs Enforcement (Johnson et al., 2009). Without the proper documentation tied to legal residency, immigrants may fear being reported and consequently deported. There may even be the uncertainty and reluctance to actively seek services from agencies immigrants do not know or trust. It was also revealed that some programs available might not be accessible to the child because they or the parents are not eligible due to of lack of legal citizenship or absence of a Social Security number (Balcazar et al., 2012). A Social Security number provides the ability to sustain employment, collect Social Security benefits, and receive other governmental services.

Balcazar et al. (2012) organized a support group for immigrant parents and promoted advocacy and social justice, but when the immigrant parents disrupted the status quo, the university serving them suddenly closed their doors and threatened to report them to the Department of Immigration and Naturalization and their employers. The parents in their research group persevered and fought against threats of deportation mainly because knowledge and awareness was gained and the immigrant parents formed a grassroots organization to support them, with the guidance from the researchers. In the end, the immigrant parents were able to form their own organization to obtain continuous learning with ASL for their children (Balcazar et al., 2012). The Hispanic parents leading the grassroots organization received recognition by the State Vocational Rehabilitation Agency and were awarded for exemplary community service.

This research fostered change with current biased social structures that dominate cultural values and norms, which give influence to and for immigrants in general. Some agencies within this community offered added benefits, from providing advice and training on advocacy skills to analyzing and selecting issues, as well as being able to assist with action planning and teaching how to take actions to attain desired outcomes. However, without the funds to support, guide and explore unanswered questions, and bring awareness to the community through collaboration and exchange of knowledge, immigrants will continue to have limited information about the rights, benefits, and services available to them.

The research shows that more advocacy case studies are needed to help train and organize researchers and communities alike who could enhance the general liberation understanding the strengths, limitations, and process.

All of the identified factors compounding parental aggravation with delayed or inappropriate special education placement, multiple barriers to participation, linguistic limitations, economic hardship, cultural differences, and health care burden show the alarming need for educators and service-oriented professionals to take a step further to involve parents by informing them of their rights and seek their input by building trusting relationships. However, to truly be able to build trust, one must walk in another person's shoes for a day and appreciate the flavor of what it means to be a Mexican immigrant parent of a child who has an identified disability. This path into the lived experiences will give us that opportunity to walk alongside them as we investigate, understand their point of view, comprehend their perceptions, gain insights, and appreciate cultural and religious beliefs to inform culturally responsive education and intervention alike, as well as identify unmet needs.

CHAPTER III: METHODOLOGY

Qualitative Research

This chapter presents this research methodology: sampling procedures, recruitment strategies, and participant selection criteria. It is followed by detailed descriptions of data collection procedures and data management, as well as a discussion of ethical issues related to the study and the procedures for protecting research participants. Quantitative research evokes evidence-based facts that are responses derived from the scientific field, whereas qualitative studies produce phenomenological methods that explore the lived experiences of individuals who share a commonality in a phenomenon (Creswell, 2009). The study employed a qualitative methodology because I sought to understand participants' lived experiences. Qualitative research takes an interpretive approach to human experience and personal perception and is thus suitable for the present study, given the research aims, problem, and purpose of understanding challenges and potential supports for Mexican-immigrant individuals with children who have identified special needs (Yin, 2016). For this research project, a phenomenological exploration was utilized to create a detailed and systematic account searching for meaning that reports the consciousness and perspectives of Mexican-immigrant individuals with children who have identified special needs.

A qualitative phenomenological investigative approach was adopted to allow me to interact with the participants and to provide them an opportunity to vividly describe their lived experiences and perceptions, including the challenges they face in the process of establishing interpersonal trust. Dilthey (1976) emphasized,

> all science and scholarship is empirical but all experience is originally connected, and given validity, by our consciousness . . . it is impossible to go beyond consciousness, to see, as it were, without eyes or to direct a cognitive gaze behind the eye itself from this point of view our picture of the whole of nature stands revealed as a shadow cast

> by a hidden reality; undistorted reality exists for us in the facts of consciousness given by inner experience. (p. 161)

The tradition of hermeneutics research is that of interpretation. It was first developed in Protestant theology and then became a powerful tradition within philosophy and human studies, thanks to the works of Friedrich Schleiermacher, Wilhelm Dilthey, Martin Heidegger, Hans-Georg Gadamer, Paul Ricoeur, and others (Lindseth & Norberg, 2004). Hermeneutics is the art and science of understanding and interpretation that dates back to Western philosophy (Bauman, 2010). Since the ancient Greeks, this way of understanding the world has been occupied with the problem of understanding lived experiences of individuals from their perspectives. We could especially draw on the tradition of 1900 century European hermeneutics, i.e., the tradition of text and biblical interpretation, as it first emerged in Protestant theology. It has since become a powerful tradition within philosophy and human studies, thanks to the works of Friedrich Schleiermacher, Wilhelm Dilthey and Martin and evolved to modern day qualitative phenomenology (Bauman, 2010.

This phenomenological method was adopted to allow me to interact with the participants and to provide them an opportunity to vividly describe their experiences and perceptions, including the challenges they face in the process of establishing meaning and locus of experiences. This contributes to the body of knowledge that can inform policy makers, advocacy groups, human rights organizations, and scholars and grassroots organizations about the current unknown disparities. The intent of this study was to document the lived experiences of professionals in the sphere of special education when they have interacted with immigrant families who have children with disabilities. This system also gives the individual a free space to spontaneously use their own language and interpret questions and give direction of the interview process (Brenner, 2006); see Appendix B to view questions. Brenner (2006), indicated that the interview is an “interactional relationship such that both the informant and interviewer are engaged in an ongoing process of making meaning” (p. 357). These prerequisites became the directional influence that operationalized this method of research by going further into the individual’s narratives and being able to gather a snapshot of their specific experiences, opinions, and thinking patterns. This was captured through the production of our protocol and questions, as well as the evaluation of how to interpret and analyze the data before conducting the individual interviews (Kvale & Brinkmann, 2009).

Subjects

The participants were eight adults who are parents of children with disabilities and who are first-generation immigrants from Mexico or Latin America. The documentation was returned to me to be reviewed, and if the individual met the participation criteria, I would then schedule a personal (1:1) interview with each participant. The interview was composed of 10–12 questions.

Recruitment

Participants were recruited within the community’s special education classrooms. I contacted teachers and other paraprofessionals and requested for them to spread the word within their classrooms, providing general information to parents and family members and inviting them to call me to discuss the purpose of the study as well as provide a more detailed purpose for their participation. I then inquired with additional families through word-of-mouth to invite others to participate in this study. The interviews were conducted in a private office, a participant’s home, or a public library’s private study area. All participants were interviewed while maintaining discretion, anonymity, and confidentiality. The participants who agreed to participate in this research received a documentation packet containing a recruitment letter, which provides an introduction to the topic as well as a general orientation; a methodology description, a demographic questionnaire, a preview of the pre-constructed interview, and confidentiality and consent forms.

Participants were required to complete and return all paperwork in person, at the time of the interview, or do so in the convenience of their homes. The data collection interviews were scheduled at mutually agreeable times. All interviews were conducted 1:1, except were participants were couples or family members. A digital device was used to record the interviews to ensure accuracy of data collection and transcription. Interpretation of the data was conducted via standard procedures of qualitative data analysis.

Semi-Structured Interview Protocol and Questions

The interviewer's protocol can be thought of as semi-structured interview. Questions were consistent among interviewees but flexible in that each participant can answer the question based on their interpretation and not feel constrained by the interviewer's perceptions or biases. Interviewers attempted to minimize the need for a correct answer. The essential definition of a semi-structured protocol involves "asking all informants the same core questions with the freedom to ask follow-up questions that build on the responses received" (Brenner, 2006, p. 362). Specific questions were asked in order to direct the subjects to speaking about their direct experiences, and to recall any instances where they saw greater difficulties or obstacles.

The interview questions were posed for participant response. All interviews were recorded via digital voice recorder for accuracy of data collection and transcription. I took brief notes in addition to having the interview recorded, to include preliminary impressions and record observations on body language. This is important because there is much more information gathered from pauses, intonations, nonverbal emphasis, and gestures. Moreover, the participants affect being congruent or noncongruent. The formulation of the interview questions was conducted by me and was approved by the dissertation committee prior to commencing interviews. The questions were designed to elicit information to explore the main research question. The length of each interview is estimated to have a duration between 50 and 90 minutes.

Ethical Assurances, Limitations, and Delimitations

The dignity of each participant as well as the confidentiality of each individual's identity was protected. All participants' names were changed to pseudonyms and other identifying information was altered to keep anonymity. All data were kept in a secure location (a locked file box for transcribed narratives and personal notes, and a password protected computer file for the digitized contents).

The study is based on the assumption, which is largely substantiated by the research, that immigrant families face increased challenges in accessing services, interventions, and/or equipment compared to their native counterparts. Another assumption was that the participants who met the criteria for selection would offer valuable insights, knowledge related to their experience, and willingness to share their experience honestly and openly.

An important area of concern when conducting any research by interviewing people with hardships is that of vicarious traumatization, and/or of lived experiences being reactivated. To control for this possible effect, a thorough debriefing was offered, as well as references to affordable or free community and counseling services.

Commonly, the results and hypotheses within qualitative research are rarely generalized, and seldom do the apply as blanket statements about the general population. Specifically, the findings only apply to a specific population who fit under this current umbrella and meet the inclusion criteria. Their unique subjective experiences cannot be used to draw conclusions about the general population. Therefore, the purpose of phenomenology is about constructing knowledge rather than testing theories in seeking universal truths. Ideally, future research would include an account of individuals that are representative of the general population, encompassing race, religion, ethnicity, socio-economic status, sexual orientation, geographic location, etc., with sensitivity and care to not aggravate further. Additionally, this study abides by the standards published by the American Psychological Association in their 10 principles for the conduct of research with human participants (Blackstone, 1975).

Semi-Structured Interview Protocol and Questions

Consistent with phenomenological research protocols, these data were collected through direct contact, face-to-face organic dialogue, asking questions for clarification, and elaborating the meaning of data obtained, as well as for the identification of emergent data. All interviews were digitally audio recorded to ensure that I did not distract participants by taking notes during the interview process. The intention for using this method is not to generate new theories nor to generalize the results of the study, since they are specific to this population under these nuanced experiences and conditions. The findings will not seek to find a universal truth, but rather have a greater capacity to grasp a specific relationship between the immigrant parents who have children with disabilities and the special education system of the United States.

Analysis of the meanings of the interviews reflected the six steps of qualitative analysis as explained by Kvale and Brinkmann (2009).

1. Subjects' description of their lived experience is noted.
2. Subjects themselves discover new relationships or see new meanings in their experience.
3. During the interview, the interviewer condenses and interprets the meaning of what the interviewee describes and sends it back to him/her, which leads to a self-correcting interview.
4. The interviewer interprets the transcribed interview. This includes structuring the material for analysis, the clarification of the material, and lastly, the analysis involves summarization, categorization, narrative structuring, interpretation, and ad hoc methods.
5. Re-interviewing is performed, as a means of continuing the self-correcting interview.
6. Interpretations are extended to include action, which means interviewees begin to act from new insights they have gained as a result of the interview process.

Data Analysis

An important consideration is the process of data analysis in this research. Gordon Allport believed that "the outstanding characteristic of man is his individuality" (Allport, 1937, p. 3). Allport described "idiographic" to introduce a new individualistic phenomenon that is specific to a singular case and borrowed the word "nomothetic" from the German philosopher Windelband (1904), to characterize general laws. Idiographic analyses describe the *intraindividual variations* which are best suited for heteronormative clinical studies and person-specific research, providing specificity and aims to describe the meaning of unique, cultural, or subjective experiences. While nomothetic-aggregates describe the *interindividual variations*, or the intersection of themes among individuals establishing generalizations among these participants, not general laws. In other words, overarching themes or occurrences found within the shared experiences of the participants (Runyan, 1983).

The research questions were framed within semi-structured interviews to explore the participants' lived experiences and knowledge (Creswell, 2009). Keeping with the philosophy of phenomenology, the interview questions are designed to be open-ended in order allow the key participants to tell their stories in their own words. This methodology also gives the individuals a free space to spontaneously use their own language and interpretation of questions and give direction to the interview process (Brenner, 2006). See Appendix B to view the questions. The analysis of interview transcripts and field notes was based on an inductive approach geared to identifying patterns in the data by means of thematic codes. Brenner suggests "Inductive analysis means that the patterns, themes, and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis" (2006).

Phrasing questions with specific terms and/or vocabulary allows potential themes and differences of the interviewees to be addressed with greater focus. It was also considered how the individuals might interpret certain questions and create their own meaning; therefore, flexibility allowed room for interpretation of, and space to consider, alternate views to respond to questions freely. During the process of analysis, it is important to pay close attention to themes that arise from the interviews (Berg & Lune, 2004).

In order to facilitate the process of inductive analysis, I coded from the derived data based on participants' responses such that the researcher's analytic lens does not override the participants' responses. The data was gathered from semi-structured interviews, which assisted me in exploring patterns and themes (Berg & Lune, 2004). The transcripts of data gathered were reviewed several times wherein I first checked if all data were complete and valid. The recorded sessions were later transcribed verbatim, and the transcripts were then coded and analyzed to find meaning, parallels, and variances within the interviewee experiences.

Next I proceeded to examine key themes through extensive coding of all documents. *Coding* refers to a qualitative description, which is most often a word or short phrase, that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data; it is described as the critical link between data collection and their explanation of meaning (Saldana, 2013). Axial coding was employed on the transcripts of all individuals. This system of coding describes a *category*, or property of characteristics or attributes and dimensions, and explores the relationships among the categories, as well as in context, it also touches on the conditions, interpretations, interactions, and consequences of a process (Saldana, 2013).

With the application of this data analysis method, I took the opportunity to focus on the identifying patterns of emotions, behaviors, and ideas and described nomothetic or group phenomena in each section-related topic. Each section provides a synopsis of the responses describing the individual as well as group variation around the norm. This provides the researcher with "within-person patterns" that are distinctive to each individual participant (Conner et al., 2009, p. 293). This phenomenological sampling method is appropriate for this study because it allows the researcher to assess for similarities within the group and between individual variables.

Strengths and Weaknesses of Qualitative Phenomenological Research

Consistent with the phenomenological approach, immersion with the participants and the data was important to this research (Sousa, 2014). The interviewing relationship consists of respect, interest, attention, and good manners, and as the interviewer, I remained alert to what is appropriate to the interviewing situation (Seidman, 2013). It is important to be aware of the possibility for exploiting the participant, and maintaining a formal interview relationship protected the participants from being negatively affected by the interview process (Seidman, 2013).

The strengths of qualitative phenomenological research studying the conscious and unconscious lived experiences of others can lead to the development of knowledge (van Manen, 1990). Moreover, the collected data are the participants' lived experiences as told by participants—such direct interaction allows researchers to engage in immediate follow-up questions during the interviewing process to elaborate on the responses. Phenomenological research captures subjectivity as its primary value, compared to quantitative research's emphasis on facts and a single universal truth. In this way, phenomenological research allows for the study of the human experience, which is not easily captured by the methods of the hard sciences. Finally, one of the most significant strengths of phenomenological research is that it allows for the meanings to unfold over time as the interview questions are asked and examined.

The findings of phenomenological research are not as generalizable as the findings of quantitative research, which is a weakness of this particular method. Phenomenological research also does accept the meanings that emerge to change over time, as well as multiple truths to emerge, and this is in opposition of the factual truth that comes from quantitative research. The sample sizes in phenomenological research are small and focused on homogeneous groups of individuals that specifically have experienced the shared phenomenon. Despite the limitations, this method appears to be the best suited for this study because it will examine the essence of the lived experiences of immigrant parents of children with identified special needs.

CHAPTER IV: RESULTS

The results of this phenomenological study are presented in this chapter. Participants were asked to expand on details and intricacies of their lived experiences, both prior to having a child with special needs as well as when they learned about the disability. And finally, participants were encouraged to expand on what factors contributed to their stress and report on what support they received. The questions are also integrated into each section. The responses were summarized, leaving out unnecessary, “Ums” and “Ahs,” pauses, etc., and analyzed according to the meanings as well as common themes as well as discussing singular cases. The narratives were integrated into corresponding sections by theme for their relevance.

With the first interview question I tried to outline the participant’s life prior to having a child born with special needs and describe how their life changed or was impacted. I also utilized this time to create an alliance and a sense of empathy so that the participant could feel at ease with freedom to elaborate their stories with full detail. In the follow-up questions, I made inquiries with the purpose of clarifying and/or diving further into the details of the specific conversation. This process encouraged participants to elaborate and provide many details about potential difficulties with emotional, psychological, interpersonal, health related, and other related processes as well as discuss coping mechanisms, support systems, the process of involvement in their child’s education, and their own conceptualization of their experience. I also noted the participants’ affective responses and reactions.

Furthermore, I inquired on how the participants used their personal agency or community resources to help mitigate their stress levels and relay the community resources to others in need. Other factors that were discussed were experiences related to special education, services, interventions, and tactics helpful in supporting their child and thus reducing their stress.

The eight parent participants were recruited throughout the Santa Barbara County and Los Angeles areas. All eight participants emigrated from Mexico and had been living in the United States between anywhere from 10 years to more than 18 years. All of the parents identified themselves as "Mexican Immigrants," and the participants' primary language is Spanish. The interviews were conducted in Spanish, without the need for an interpreter. Five of the parent sets were recruited from a contact in the regional center, and the other three parents were recruited through word of mouth by the parents of children with identified special needs. All parent participants ranged from ages 31 to 67 years of age.

The participants conveyed their stories cathartically, as a sort of therapeutic relief in being heard and being seen. All participants emphasized that they had much to say and conveyed their stories with a wide affectivity, ranging from the shock and psychological impact of learning about their child's disability or diagnosis, through navigating through the rocky and sometimes treacherous terrain that lay ahead of them.

Having established some rapport through the brief conversation in Spanish, over the phone as well as in the introduction phase, I made sure to engage the participants with full unconditional regard by using clinical reflective listening skills to increase trust and a feeling of security. The initial question was groundbreaking, as participants were asked to describe their experiences prior to having a child with disabilities. This question set the theme by providing them a blanket of trust that openly invited their feeling with support and understanding and therefore encouraged the parents to delve deeper into their psyche, their memories and recall anecdotes and events. Many participants elaborated responses that were uninterrupted. I later reviewed the responses for clarity and to get additional personal emphasis. I noticed that all participants had a urge to reveal their whole story, their grief, suffering, trials, and lessons as a cathartic retelling “from the beginning” of how they adapted, transformed, and survived the trials and finally came to terms with their child’s special circumstances. All participants shared a sense of urgency to share and recount their story which came with cathartic release of strong or repressed emotions. Each was allowed this process, to be heard in their entirety before jumping into the questions as to honor their person, their emotions and over all experiences and not be reduced to the relevant responses, but their whole story be heard.

Individual Essential Descriptions

“Alberto” is a 67-year-old Hispanic male. He lives in the vicinity of Norwalk, CA, and was widowed six years prior. He is a retired plumber. His adult daughter, “Alma,” also participated in the interview. She is in her mid-40s and is employed with the Regional Center. Alberto and his family immigrated from Mexico to the United States in 1997. Alberto has a son who suffered from a severe form of meningitis infection and consequently encephalitis, and thus suffered significant cognitive damage and is in a vegetative state. “Dieguito’s” health has deteriorated over the years, and he is the only member of the family that remains undocumented. He is undocumented due to his inability to appeal legally and due to the family’s lack of financial meant to access to legal aid and support him to gain his citizenship.

“Bertha” is a 54-year-old is Hispanic female. She is a housekeeper who resides in the greater metropolitan area of Los Angeles, CA. Bertha’s son, now 16 years old, was born with

Anotia, a congenital deformity where there is an absence of the outer projected portion of the ear and an absence or deformity of the ear canal, causing deafness. She immigrated from Mexico to the United States in 1996 with her husband, who passed away suddenly when their son was 6 years old.

"Felicia" is a 52-year-old Hispanic female. Felicia immigrated from Mexico to the United States in 2004 with her now ex-husband. She is now a homemaker; she was previously an agricultural worker. Felicia lives in northern Santa Barbara County, CA. Felicia's daughter, 15, was born with a congenital visual impairment and is legally blind. Felicia remarried in 2007 after she divorced the father of her children because he was abusive and violent.

"Margarita" is a 43-year-old Hispanic female. She immigrated from Mexico to the United States in 1998 and is a stay-at-home mother. She lives in the metropolitan area of Los Angeles with her husband and children. Her son, 16, has Down syndrome.

"Marina" is a 36-year-old Hispanic female. Marina immigrated from Mexico to the United States in 2002. She remains a stay-at-home mother. She lives in the metropolitan area of Los Angeles with her husband and two children, a 13-year-old daughter, and a 10-year-old son diagnosed with an autism spectrum disorder. His autism is considered to be on the severe end of the spectrum with cognitive and developmental delays.

"Renata" is a 46-year-old Hispanic female. Renata immigrated to the United States in 2004 and lives in the metropolitan area of Los Angeles, CA. She married and is a stay-at-home mother of an adopted boy, age 13, who suffers from severe emotional disturbance/cognitive and developmental delay due to child abuse and neglect from his birthparents. Renata's son was 14 months old when they adopted him.

"Vicente" and "Ana" are a Hispanic couple aged 38 and 36 years, respectively. They immigrated from Mexico to the United States in 2003 and 2004, respectively. Vicente is a full-time chauffeur who works for a private company, and Ana is a stay-at-home mother of four children. Their daughter, age 13, suffered hypoxic ischemic encephalopathy at birth, which is oxygen deprivation and damage, causing her to have severe cognitive and developmental delays.

"Victoria" is a 31-year-old Hispanic female who immigrated from Mexico to the United States in 2000 and is now permanently separated from her husband. She is a hospitality housekeeper in the metropolitan area of Los Angeles, CA. Her daughter was born premature with a type of congenital heart disease. She underwent numerous surgical procedures and high-risk medical interventions with the purpose of saving her life. Due to the heart condition, in-utero and post-birth, she suffered oxygen loss to her brain and major organs. Victoria's daughter is now 15 years old, and her intellectual function and adaptive behavior are significantly below the expected level for her age, otherwise referred to as cognitive and developmental delays.

Immigrant Parents' Conceptualization of Their Special Needs Child

A major theme that emerged for all the participants in this study was the stressor acquired by their shock in learning about their child's condition, one participant, "Alberto" explained:

> *Yo tenia mi trabajo, mi esposa, teníamos tres niños, jugábamos deportes y todo era normal, todo era alegría, y todo estaba bien hasta que se enfermo mi hijo, Roberto. Después fue tristeza, nunca pensé que[el] fuera a enfermarse.* [I had my job, my wife, we had three kids, we played sports, everything was normal, and everything was joy and everything was fine until my son Roberto became ill. It was sadness, I never thought [he] would become ill.]

The loss of a life that was once considered "normal," "tranquil," and "calm," unburdened by a "problem" was reported unanimously until each participant learned about their child's diagnosis or disability. For most participants, sharing the feeling of being "unprepared" came with grief, a sense of powerlessness, helplessness, loss for their free lifestyle, and the loss of their child's full ability. As well as bearing the burden of having a child be dependent upon others, or not having full physical autonomy. Similarly, Participant "Bertha" expressed:

> *Bueno, mi vida era tan normal como la de los demás, ¿Verdad? Yo no valoraba todas las partes de mi cuerpo. Me parecía tan normal que mi hija halla nacido "normal", con sus manos, sus pies, sus ojos, sus oídos, su todo, y bueno, no había ningún problema, hasta que nació el. Nunca pensé que me sucedería a mi, yo no savia nada [sobre su incapacidad], no savia lo que haría, o a quien iría [para obtener ayuda]. Fue muy difícil para mi y mi familia. Pero con el tiempo, hemos aprendido mucho con el, tuvimos que aprendes a hablar el lenguaje de signos, a tomar clases de… bueno, casi todo lo que se nos recomendó por que el no oía nada. Aprendimos a involucrarnos con todas las personas que no oyen, y con los que se comunican con el leguaje de signos, con… con todos.* [Well, my life was as normal as everyone else's, right? I didn't really value every part of my body. It seemed so normal to have my first daughter be born "so normal" with her hands, her feet, her ears, her everything, um well, there weren't any problems, until, well he was born. I never thought that was going to happen to me because I knew nothing [about his disability], I didn't know what I was going to do, with whom I should go [for help]. I was really hard for me, and my family. But overtime, we have learned a lot with him, we had to learn to sign, take classes of… well, mostly all the things that were recommended since he had no hearing. We learned to get involved with everyone who can't hear, with those that sign, with… with all of them.]

Participant "Marina" said:

> *Bueno, el fue nuestro segundo bebe, ya teníamos a nuestra hija. Mi embarazo de ella fue muy fácil, y cuando nació ella yo no me sentía estresada por que tenia a una baby muy tranquila. Mi vida era muy calmada. Mi vida era muy calmada, todavía me estaba adaptando a ser mamá por que yo tenia veinte años cuando la tuve. Ella nació y tres meses después me embaracé con mi hijo, y allí fue cuando mi vida comenzó a cambiar por que no estaba mentalmente preparada para tener al segundo bebe, antes de el, todo era calmado y normal, yo trabajaba y tuve que parar por el.* [Well, he was our second baby, we already had our daughter. My pregnancy with her was really easy, and when she was

> born I didn't feel stressed since she was such an easygoing baby. My life was really calm, but I was still adapting of being a mom and life because I was twenty when I had her. She was born and three months later I got pregnant with my son, and that's when life started to change since I wasn't mentally prepared to have a second baby, before him, everything was calm and normal, I worked, and I had to stop to be there for him.]

The heartfelt loss and grief experienced by these parents is best described in their own words. In general, the shock or initial sad surprise amalgamated into grief from the loss of the "normal life once lived" transitioned as the participants' perspectives transitioned into that of sadness, difficulty, powerlessness, helplessness, fear, guilt, shame, doubt, struggle, anxiety and depression and physicals symptoms such as partial facial paralysis, and total physical paralysis.

Participants were asked to describe their response/reaction to learning about their child's diagnosis. Participant "Bertha" recounts her learning about her son's diagnosis of having been born with a birth defect, without ears, and being totally deaf, "La impotencia, la batalla, la culpa de no saber como ayudarlo" [The powerlessness, the struggle, the guilt of not knowing how to help him].

Participant "Margarita" relates as she learned that her son was born with Down syndrome,

> *Por decir así, [nuestra vida] era normal porque yo veía a otras personas [con discapacidades] y yo las veía de lejos, yo veía niños que necesitaban ayuda. Yo estaba bien porque tenía en mi familia yo no tenia a ninguno [con discapacidad]…Yo ya tenía hijos y pues no, ninguno estaba enfermo, todo estaba muy bien en la vida, como quien dice, sencilla, sencilla, normal. Y ya desde el día que…el día que nació cambió la vida para nosotros. Desde ese día que nació.* [So to speak, [our life,] it was normal because I would see other people [with disabilities] and I would see them from afar, I would see that they needed help. I was fine because in my family there was not any one [with a disability]… I already had kids, and no one was ill, everything in life was good, as one could say, simple, simple, normal. And from that day…the day he was born, life changed for us. From the day that he was born.]

Participant “Marina” shares the same sentiment, the loss of normalcy of a healthy, fully abled child when learning that her second child, a boy, was diagnosed with autism and developmental delay,

> *Para mí ha sido, y todavía es muy duro… lo psicológico y duro (llora) para mí, lo duro es entender y saber que mi hijo no va a llevar una vida como yo lo quisiera para el, “normal”.* [But yes, for me it has been… and it still is very psychologically hard for me (cries), the hard part was understanding and knowing that my son would not have a life like I’d like for him, “normal”.]

All of these participants echoed in their experiences. The word “normal” came up 21 times in the initial phase of the interview, making it the most common description of what life was like before they had a child with a disability. Living through a “normal” life before grappling with the notion that their child was limited or burdened by an illness or handicap, robbed of a common life. And later coming to terms with the condition fate chose for them and their children. All of this being increasingly difficult in a foreign country with a foreign language and customs.

Parents sought to integrate the stressful existential framework through their religious beliefs, through their faith and hope. All participants asked for divine intervention for “strength,” “patience,” and “stillness” to integrate this new parental role. Many asked themselves “what to do” and “why me?” as they were walking on uncharted territories in being parents of a child with special needs. But all members of this research asked for Divine intervention, for the healing of their beloved child. The participant “Margarita” relates:

> *Fueron muchas cosas, pues desde detenerme y pensar como… el cambio, no era como otros niños, normal, fue entender que el necesitaba ayuda, pero que no era, no era como otros niños nomas. Entonces, tener que aprender a vivir con el y mas por que me lo dieron con oxigeno. Aprender a llevarlo al doctor con oxigeno. Tener un hijo [discapacitado] y aprender de sus necesidades. Y pues como yo soy católica, decía entre mi, por algo (Dios) me lo dejo, nos lo dejo.*

> *Entonces sobrepase mi tristeza, me anime porque decía yo, si lo tengo es por que tenemos que cuidarlo, tenemos que ver por el.* [There were many things, well, from stopping to think how… the change, he wasn't like other children, normal, it was coming to an understanding that he needed help, he just wasn't like other children, just that. Then, having to learn to live with him, because of his oxygen tanks. To learn to take him to the doctor's office with his oxygen [tank]. Having a [disabled] child and having to learn about his needs. And well, I'm catholic, I would say to myself, "there's a reason why He (God) left him in our care, He left him to us". So, then I overcame my sadness, I boosted my own mood, I'd say to myself, "there's a reason I have to look after him, if I have him, it's because we need to take care of him, we have to look after him".]

This is supported in the literature. Hoffman (1961) explained that Catholicism sees all persons as possessing an immortal soul. Moreover, "pain and suffering in this context are found with widespread acceptance in Catholic theology" (p. 53). Perhaps, Catholic parents accept handicaps as a part of a divine plan that is acceptable to believers as "martyrdom" or "Sainthood" or being "chastised" for their sins, as a punishment of sorts. At any rate, the combination of medical, religious, and folk beliefs were found to be the possible cause of their child's handicap, but all parents asked for "strength."

"Victoria" relates,

> *Desde un principio todo fue…fue difícil para que ella pudiera salir adelante. Me preguntaba, "¿por que otros padres tienen a sus niños sanos?… van, vienen, es una felicidad salir de hospital con su bebe y (Llora) es…es lo difícil para mi. (llora) "¿Porque, si otras mamás podían, por que yo no (Llora) podía? Pues, siempre la traía yo en brazos, muy apegada, siempre con ella… Dios me la mando así a mi, entonces yo le pedía fortaleza para sacarla adelante.* [From the beginning everything was... it was difficult to get ahead. I wondered, "Why did other parents get healthy children... they come, they go, there's the happiness in leaving the hospital with her baby and (she cries) it's ... it's the difficult thing for me (Cries). "Why, if other moms could, why wasn't I able to? (Cries) Well, I always carried her in his arms, very attached, always with her...God sent her [my child] to me like that, so I ask him for strength to get her ahead.]

A few other parents felt guilt, remorse, and even shame in thinking that they had somehow caused the disability of their child. One parent related that her own mother had recommended her to wear a safety pin on her pregnant belly as a good omen to protect her child. Here is what participant Bertha said:

> *Bueno, cuando el nació, el doctor me dijo, "¿quiere ver a su hijo?" Y yo le dije, "¿Sí?" y el contesto "Tengo que decirle que tiene una deformidad." Eso fue cuando comenzó la pelea dentro de mi. Al principio pensaba que era un castigo. También pensé que era por que había…bueno (llora) yo me sentía frustrada, y con culpa. ¿Pensaba que era por que no me puse el seguro cuando me dijo mi madre que lo hiciera? ¿Tal vez era por que me puse el seguro un día y no otro, porque me olvidé de ponérmelo? No lo se, me sentía muy culpable, muy mal. No entendía por que sucedió, fue muy difícil.* [Well, when he was born the doctor told me, "Do you want to see your son?" And I said "yes?" and he answered, "I need to tell you that he has a birth defect." That's when all the fighting inside of me started. At first I thought it was punishment (from God). But I have learned so much from him (referring to her son). I also thought that it was because I had…well, (cries) I felt frustrated and I felt guilty, I thought that it was because I hadn't placed the safety pin on me when my mother told me to do it? Maybe it was because I put it on one day, and forgot to the next because I had forgotten? I don't know, I felt very guilty, and badly, I didn't understand why it happened and it was very difficult.

Similarly, participant Marina resonated in her experience of sadness and grief as well as melancholy in realizing her son's delays, and consequently his diagnosis. As she reported, they started to notice that their son was significantly delayed, so they sought professional help to discern the situation. Marina recalls,

> *Empezamos a ver que no estaba hablando como un niño de su edad. De ahí nos mandaron con la psicóloga, le hicieron su evaluación y nos dijeron que él tenía autismo, pues en su momento yo no sabía ni siquiera la palabra "autismo, ni siquiera que era… pues fue devastador para mí. Fue más que para mí, que mi esposo, yo lloraba en estos días. Me decía a mi misma, "¿cómo le explicó a la familia?", "¿qué les digo?", "¿Si me preguntan qué es…?", "¿qué les voy a decir?", si ni yo misma no sabía, ni mi esposo... Eso fue lo bueno, como lo tomo el, más... como más tranquilo. Es decir, bueno, el decía, "¡No importa, sabemos lo que tiene y ahora podemos ayudarlo!" También lo asimiló, lo asimiló más rápido que yo… y otras veces yo lloraba. Hasta la fecha todavía me pone un poco triste. Después del diagnostico empecé a buscar en la librería cosas para saber cómo… en los libros. Pero sí. Para mí ha sido, y todavía es, muy duro lo psicológico y duro (llora) para mí lo duro es entender y saber que mi hijo no va a llevar una vida como yo lo quisiera para el, normal. Es decir, es un niño normal para mí, pero la vida que yo quisiera... para que él pudiera comunicarse de una manera más abierta de una conversación con él, simplemente es con él. El hablar es nada*

> *más contestar, "si/no". Pero, el nos corta. Yo quisiera que llevara una vida como la de mi hija, o sea, con más amigos, él no tiene amigos. O sea que sí considero que tiene personitas que a el le interesan, pero que te digan que "fue un amigo que me interesa", lo duro es eso, el saber que él toda la vida va a depender de nosotros. Tenemos que saber de que nunca va a tener una vida cien por ciento normal. Eso es lo que a mí se me hizo muy duro, ver que ha avanzado bastante, pero pues, se me hace como que aún le falta mucho a mi hijo. Yo soy… se me ha hecho duro asimilarlo… asimilarlo que no va a tener la vida… (Solloza y suspira).* [Then we started to see that he wasn't speaking like a child his age. From there we were sent to the psychologist, they did evaluations on him, and she told us, "he has Autism", well in that moment, I didn't even know the word "Autism", I didn't know what it was…. it was more devastating for me than for my husband, I cried for days. I would tell myself, "how do I explain this to my family?", "what do I tell them?", if I didn't even know what it was, nor my husband… That was the good thing, the way he took it…like with a little more tranquility. So, to speak, well, he would say "it doesn't matter, we know what he has and know we can help him"! He also assimilated it…he assimilated it faster than I did, and I cried other times. To this date it makes me a little sad. After the diagnosis I started to look in the library for things to learn how…in books. But yes, for me it has been… and it still is and still is very hard, psychologically… (cries). The hard part was understanding and knowing that my son would not have a life like I would like for him, normal. He is a normal to me, so to speak, but the life that I would like for him to have…for him to be able to communicate, to have a more open conversation with him, with him, simple, with him. His communication is just answering, "yes/no". But he cuts us off. I would like for him to carry on with a life like my daughter's, that is, with more friends, he doesn't have friends, he has no friends. That is, he has little people that he is interested in, but to hear, "he is a friend that I'm interested in", the hard part is knowing that his whole life he will depend on us. We have to know that he will never have a life one hundred percent normal. That's what has made it harder for me, seeing that he has made so much progress, but it seems to me like my son still has a long way to go. It is very hard for me to assimilate it… assimilate that he won't have the life… (cries and takes a deep breath].

The parents shared process of assimilation and acceptance in varied ways. Many mothers expressed greater difficulty to emotionally overcome and assimilate having a special needs child than their male counterparts. Overall, all parents experienced varying degrees of grief. All experiences were within the five stages of grief (denial, anger, bargaining, depression, and finally acceptance) as a part of the framework of adjustment. The participant's grief was compounded by not knowing and understanding their child's diagnosis and prognosis. In addition to overcoming and or enduring the associated hardships with specialized interventions, adapted transportation, etc.

"Felicia," an atypical case, had other priorities in her life: survival. She and her husband lived in Mexico and later immigrated to the United States where she gave birth to her third daughter who was also born with the same congenital visual impairment as the older daughter. Felicia expressed an urgency in retelling her story, summarized into survival and escape from a life with a batterer. It seemed insurmountable; as an illiterate immigrant who did not know how to drive, she was afraid and was far away from a familiar community. Felicia struggled to survive as her husband beat her and her children with baseball bats, machetes, and other large objects.

Participant Felicia's response;

> *Yo tengo una historia muy larga, si me pongo a decirle hoy, para mañana no termino. Yo eh tenido una vida muy difícil. Yo, en México ya tenia hijos con el mismo problema de "Lucero", las muchachas se quedaron allá… ellas hacen todo sola [son autosuficientes] pero su papá nos pegaba, nos golpeaba. Y cuando nos venimos [a U.S.] seguimos con lo mismo, puro pelear, y pelear, y este…y una ves me golpeo con un bate de béisbol, muy feo, nos decía que nos iba a matar a todos. Y luego a mis hijos les pegaba, los agarraba y les pegaba y les decía; "los voy a matar!" Ellos estaban muy asustados, espantados. Y me decía que yo no podía hacer nada, me amenazaba con el cuchillo, el machete y lo que fuera. Luego de que nació Lucero, a los tres meces se fue con otra [mujer]. Al mes regreso y me busco, pero mi hijo grande llamo a la policía por que me quiso ahorcar. Pero ya de allí…bueno lo sacaron por que me golpeo estando la niña chiquita y se lo llevaron todavía diciendo; "te voy a matar!" Entonces en eso, me fui y puse quejas [reporte de policía] y me fui a una casa hogar. Allí estábamos, el me amenazaba, pero luego con el tiempo se fue y nos dejo, desde que le echamos la policía. Cuando la niña nació, el no vio por ella. Yo solita la saque adelante. Y ella dice "Yo tengo padre". Pero nunca me estrese por ella, por que estaba mi hija así [siega]… no, nunca me preocupe por ella por eso, solo por lo de los papeles, por que no se leer, tenia que preguntar. Pero pues, ya me acostumbré, para llenar papeles solo pregunto y les digo que necesito que me ayuden. Pero lo de ella lo veía muy normal, por que ya tenia dos hijas, así como ella.* [I have a very long story, if I tell you today, by tomorrow we will not have finished. I've had a very difficult life. In Mexico, I already had children with Lucero's same condition [total visual impairment]. They stayed in Mexico…

> they do everything alone [are self-sufficient] but their father used to hit us, he hit us. When we came [to the United States] it continued, just fighting and fighting. He hit me with a baseball bat, very badly, he would tell us that he was going to kill us. Then he also hit our kids, he hit them, and he would tell them, “I’m going to kill you”. They were very scared, spooked, and he would tell me that I couldn’t do anything. He would threaten me with a knife, with a machete or anything at all. When “Lucero” was born, he…when Lucero was 3-month-old, he left with another woman. A month later he returned, and he looked for me, but my older son called the police because he wanted to strangle me. Since then… well, they took him away because he hit me while the baby was so little, they took him away while yelling; “I’m going to kill you!” It was then that I went to go live in a Women’s shelter. While were there, he would still threaten me, he left some time later, he left us and since we [continued to] called the police on him. When the baby was born he didn’t provide for her. I did it [I raised her] all alone. And she says; “I don’t have a father”.]

When probed with questions regarding her emotional process of learning her daughter’s impairment, Felicia seemed unchanged as she recounted her story. She denied any stress this associated with that experience. Being a domestic violence victim left no room in her inner world for her to process her daughter’s visual impairment. If it was there, it was repressed in her deepest corner. Instead she shrugged and related that her “story was long and much more complicated to finish in one day.” This participant had perhaps already normalized her daughter’s visual impairment through her experience of her older daughter’s visual handicap, earlier in Mexico. To her, they seemed to be doing fine since they had remained in Mexico, and had grown up to become self-sufficient, alone, without any support, education, or interventions or any professional help, as Felicia retold. Felicia expressed that having her children and herself be tormented by her husband was much more distressing. Perhaps, in order to survive and maintain a functional role, she compartmentalized and/or repressed that aspect of her experiences.

At any rate, Felicia ended that relationship with the help of authorities and a women’s shelter, and later remarried. Her story is unique; although not unique to the experience of domestic violence among the participants of this research, she was unique in the sense that she was not emotionally affected in learning about her daughters' visual condition. Despite her being from humbler beginnings, being illiterate as well not being able to drive, many portions of her story are exceptional from that of the other participants, and these differences are discussed later in their corresponding sections. Although Felicia's affect was unchanged, she recounted that she had experienced many physical ailments. These may be the product of the stress incurred in dealing with the compounded issues she experienced.

Mental Health and Stress-Related Health Problems

When asked to describe the stressors they have experienced, both currently and in the past, many parents described both personal stress which manifested itself psychologically, physically, emotionally, and participants also described the stress partners and spouses experienced. When presented with the question to describe the stressors she had experienced, both currently and in the past, participant Renata said:

> El, (mi esposo) tiene diabetes, le dio en el transcurso de los problemas con el niño, y yo me enferme de cáncer, tenia que ayudarme en la casa y con los niños. A el si le afecto el estrés en ese aspecto. Y yo soy diabética desde hace muchos años, pero lo tengo controlado y el (esposo) no. [Him, (my husband) has diabetes, he developed it through the problems with our son, and I got sick with cancer, he had to help at home, with the kids. The stress affected him in that aspect. And I've been a diabetic for many years, but I have it under control and he [my husband] doesn't.]

Participant Bertha declared:

> *Nunca me enfermo, pero emocional si me dio depresión, acumulado con la operación del niño y la muerte de mi marido… fue el luto. Solo lo eh echo a un lado, por que todavía sique a un lado, si a amenorado, pero sigue allí y no lo quiero mover por que es muy doloroso. No hay que tocarlo, es mucho. Pero mucho estrés y muchas lágrimas. Fue de mucha lucha, por que no savia nada de esa rama. Lo que fue peor, me fui a san José a operar al niño y falleció mi marido, el niño tenia seis años, justo el día de su operación del niño el [mi*

> *marido] murió de un "stroke", por estrés. Entonces fue… navegar el duelo, y ayudar al niño, poniendo cada cosa en su lugar, mi marido ya murió y la batalla sigue con mi niño. (solloza y pausa, voz tiembla) Tuve que posponer mi dolor, mi pena, mi tristeza por seguir ayudando a mi niño, en cuestión de tres semanas, estuve lejos de mi marido cuando el murió. Yo estaba en shock. Ya después del entierro fue…fue la recuperación emocional, física, psicológica, todo…pero después que fallase mi marido, como no estuve cercas de mi marido, no tuve la oportunidad de estar con el en el hospital, nada…el duelo. Entonces cuando llegamos a casa, allí si me vino mucha depresión, como unos seis meses, empecé a caer y caer.* [I never get sick, but emotionally, I did get depression, accumulated by my child's operation and the death of my husband…the mourning. I just have set it [grief] aside, because it still there, it has decreased, but it's still there and I don't want to move it because it's very painful. I don't want to address it because it's painful, it's a lot.] What was the worst, is when I went to San Jose so my son could have his surgery, that day my husband died, our son was six years old, just on the day of his surgery, he [my husband] died of a "stroke", due to stress. So, it was navigating my grief, and helping my child, sorting things out, my husband was already gone but the battle continued with my child. (Sobs and pauses, voice trembles) I had to postpone my pain, my sorrow, my sadness to continue helping my child, in a matter of three weeks, I was away from my husband when he died. I was in shock. After the funeral I was ... it was an emotional, physical, and psychological recovery, everything... all after my husband passed, since I was not able to be close to my husband, I did not have the opportunity to be with him in the hospital, nothing... the grief! So, when we got home, then became very depressed, like for about six months, I started falling and falling.]

Bertha describes her story as she experienced her unfortunate luck when her husband passed away while she was away in San Jose at their son's scheduled ear surgery. Bertha experienced both an outward struggle in having to drive herself and her son back, while internally she was devastated in learning about her husband's unexpected death. Bertha described being informed that her husband had suffered a stroke and had passed away. She explained that they only gave her a two-week grace period to postpone her son's surgery. Physicians were able to modify his rib cartilage and transform the tissue into ears for him, while they also made other medical interventions to help him have partial hearing. Bertha described feeling tormented because she was not able to be with her husband at the hospital as he took his last breaths. Bertha expressed that she sort of compartmentalized her pain and grief to support her child and that after falling into a depressive state, she pushed herself to recover.

Participant Felicia said:

> *Pues, el estrés fue mas por el maltrato, pero después fue por dinero, para sobrevivir sola, con mis niños, y con Lucero, pero ahora con mi marido, el me apoya, no tengo que trabajar y estoy al pendiente de ellos [los niños]. En ese tiempo me dolía mucho la cabeza, se me torció la cara, pero ya se me esta quitando, casi ya no se me nota. Pero por lo [su discapacidad] de ella, no nunca me estrese por ella. ¿Porque esta mi hija así?¡No! Nunca me preocupe por ella, por eso, solo por lo de los papeles, por que no se leer, tenia que preguntar. Pero pues, ya me acostumbré, para llenar papeles solo pregunto y les digo que necesito que me ayuden. Pero lo de ella lo veía muy normal, por que ya tenia dos hijas, así como ella.* [Well, the stress was more because of the abuse, but later it was for money, to survive alone, with my children, and Lucero, but now with my husband, he supports me, I do not have to work, and I am involved with them [the children]. At that time my head hurt a lot, my face was twisted, but it is already being removed, it is almost no longer noticeable. But have never stressed [over her disability]. Because she is that way? No! I have never worried about that, about her, only about papers [referring to school and doctor's forms and documents] because I don't know how to read, I had to ask. But, well, now I'm used to it, when I need to have forms filled out I just ask, I tell them that I need help, but in regards to her [condition] I see it very normal, because I already had two older daughters like her.]

Felicia experienced what would be a survival trial in a domestic violence relationship. Once she managed to separate and make it alone, she endured a financial struggle on a single income as well as navigating life being illiterate and unable to drive. Later she met her current husband, whom she described as a "supportive." She said that she previously experienced physical ailments, where her stress manifested itself in many headaches, and a partial facial paralysis, which had subsided. Felicia related that she never felt stress about her daughter's condition, although she was diagnosed with type 2 diabetes.

Similarly, participant Margarita said:

> *Pero en ratos si me ponía triste y me estresaba cuando estaba sola por que veía a mis otros hijos a futuro [y a el no]. Pero yo sola lo asimilaba, lo procesaba, y si me sentía sola me levantaba y me decía, "¿para que? "¿de que me sirve estar así?*

> *Y para que el [niño] no lo sintiera, yo me hablaba a mi misma y a el le decía, "¡tu estas bien, tienes manitas, tienes tus deditos!". O sea, para que el contara sus fortunas y no sus faltas, y bueno, todavía le digo "¡tu estas bien!" Aunque dentro de mi yo se que no, pero soy optimista y le digo que el tiene todo, le cuento que el puede caminar, y comer, y pues todo…a aunque yo veo que no…pues para ayudarlo, para animarlo.* [But at times I did feel sad and stressed when I was alone because I saw my other children in the future [but not my son]. But I assimilated it alone, I processed it, and if I felt lonely I would pick myself up and I'd say to myself, "What for?" What is the use of being like this? So that he [my son] would not feel it, I would speak to him and I'd say, "you are fine, you have little hands, you have your little fingers!" that was so that he would count his fortunes and not his faults, and well, I still tell him "you are fine!" Although inside of me I know that he isn't, but I am optimistic and I tell him that he has everything, I tell him that he can walk, and eat, and well everything ... although I see that not ... well, to help him, to encourage him.]

Margarita describes the process of her first experiencing sadness and then stress as she negotiated her son's condition, as well as the factors that contributed to her grief by uplifting herself, being optimistic, and focusing on their blessings rather than their shortcomings. She explains that she also motivated her son and elaborated that even though she tried to convince her son, she could not convince herself that he was "fine." She was unable gain a new sense of normalcy.

Participant Marina said:

> *Pues yo creo que a mí…la depresión...con él me dio cuando empezamos a ver que a el le faltaba… le faltaba algo. No sé por qué me llegó la depresión y hasta que ya empecé a asimilar lo que me dijo el doctor, "¡era así y así iba a ser y usted tiene que ayudarlo!", pues empecé a salir de la depresión con el tiempo. Más de seis meses, más o menos. Hasta que yo salí de la depresión, cuando empecé a tomar medicamento y me puse a estudiar. Dejé toda mi vida y dejé de trabajar, dejé de estudiar en el colegio y me dediqué a ellos [mis niños]. Ya fue cuando mi esposo…que ni siquiera sabía que estaba pasando por depresión hasta que estaba tomando medicamentos, le dije, "estoy pasando por esto y que no es justo que tenga que pasarlo sola". Le pedí ayuda, que me apoyara más con ellos [los niños]. Y ahí fue cuando empezó a ayudar más él, y pues mi hija también [ayudaba] y así me metí a estudiar otra vez y a trabajar. Físicamente, me daban espasmos musculares, porque yo lo cargaba. Hasta que tenía como 5 años, se tiraba al suelo con berrinche. Entonces para mí era más fácil levantarlo, cargarlo. De ahí tuve que ir al doctor como unas dos veces y me dieron relajantes musculares porque tenía espasmos. Aquí en esta parte, (señala) como*

> *en el cuello y en hombro, que eran como bolitas de cansancio. Eso fue lo único que me produce estrés. Pero si me afectaba verlo tan frágil. Pero nunca perdí la esperanza de seguir adelante con el.* [Well, I think that I... the depression... because of him, I had it when we started to notice that he was missing... something was missing. I don't know why I got depression, until I started to assimilate what the doctor told me, "it was like that and that's how it was going to be, and you have to help him!" So, I overcame the depression over time, more than about six months, more or less. Until I came out of depression, when I started taking medicine and started studying. I stopped my life, I stopped working, I stopped studying at the college and I dedicated myself to them [my children. That was when my husband… who didn't even know I was feeling depressed until I was taking medication. I told him, "I'm going through this and it's not fair that I have to go it alone". I asked him for help, to help me with them [the children]. And that's when my husband started helping me more, and well, my daughter too [helped] and so I went back to school to study, and back to work. Physically, I had muscle spasms, because I would carry him. Until he was about 5 years old, he would throw himself on the floor with a tantrum. So, it was easier for me to lift him, carry him. From there I had to go to the doctor, twice, and they gave me muscle relaxers because I had spasms. Here in this part, (signals her neck) as in the neck and shoulder. It was like little balls of fatigue. That was the only thing that causes me stress. But it did affect me to see him so fragile. But I never lost hope of getting ahead with him.

Margarita retells her experience, grappled by depression in her realization that her son had failed to meet his developmental milestones. She noticed that her son was delayed with age appropriate abilities. And so, they sought an expert's opinion early on and learned that he was diagnosed on the autism spectrum disorder (ASD). She expressed being baffled by the name and meaning of the term "autism," as well as his prognosis. Marina recalled that she overcame her battle by seeking medical help and was prescribed antidepressants. She added that she also disclosed to her husband, who ignored the fact that she was taking antidepressants, that she was "suffering alone" and asked him to take some of the domestic and childrearing responsibilities from her. As she started to assimilate the situation and his condition, she gained the motivation to learn about ASD by researching it at her local library and obtaining as much information and knowledge as she could. Additionally, Margarita reports that she experienced muscular spasms and pain in her back and shoulder as a result of “fatigue” and from picking up her child after he threw tantrums.

Participant Ana said:

> *Si, el nivel de estrés, por decir del 1 al 10, el nivel lo pondría en 10, el más alto. Yo a veces sí me siento como al 10. Si hay ocasiones que si gana [el estrés]... cuando estaba ella más chiquita, yo creo que era el 10, porque él (Vicente) estaba trabajando, pues yo estaba aquí con todos y yo creo que era cuando estaba más deprimida porque estaban los cuatro, peleaban, eran chiquitos.* [Yes, the stress level, to say from 1 to 10, the level would put it at 10, the highest. I sometimes do feel like 10. If there are occasions that it [stress] wins…when she was younger, I think it was 10, because he [Vicente] was working, because I was here with everyone and I thought it was when I was most depressed because all four were all four would fight, they were small.]

Vicente explained**:**

> *Yo diría que el estrés era más significante, ya que no…no tenían, no sabíamos ni de grupos de apoyo. A duras penas conocíamos lo que era el Centro Regional, la falta de experiencia de ser padres de un niño regular, menos de niño especial. Pues no sabes qué hacer en el momento y luego por encima, yo por mi parte, atendiendo las necesidades especiales de mi niña, mi esposa y sus ataques de ansiedad y la depresión. Ahí sí, yo diría que el estrés de 10 subía al 12 pues por estar atendiendo las necesidades de ella, porque a veces los ataques de ansiedad que le daban a mi esposa me la dejaban paralizada, a veces por días a la vez y al tener que estar ateniéndose interrumpían en mi trabajo. Fue un momento de sobrevivir, hay que oprimir todo, evitarlo, hacerlo a un lado, trabajar lo que se puede y me ponía… me enfocaba en ellos. Tal vez ya ahora lo puedo superar y como cuando mi esposa pone la olla que después empieza a salir del vapor cuando ya está listo y toda la presión se acumulo. ¿A lo mejor la presión que sentía en ese momento ya se acumuló?* [I would say that the stress was more significant, since they didn't… they didn't have, we didn't even know of support groups. We hardly knew what the Regional Center was, the lack of experience of being parents of a regular child, much less of a special needs’ child. Well, you don’t know what to do in the moment and then on top of that, on my part, attending to my daughter’s special needs, my wife and her anxiety attacks and depression. Then, yes, I would say that the stress went from 10 up to 12 because I was attending to her [my wife’s] needs, because sometimes the anxiety attacks, they left my wife paralyzed, sometimes for days at a time and having to attend to her would interrupt my work. It was a time of survival, you just have to suppress everything, to avoid it, put it aside, work as you must, and I would... I would focus on them. Perhaps now I can overcome it, like when my wife puts on the pressure cooker pot, it starts to let out the

> steam later, when the pressure is accumulated. Maybe the pressure I was feeling at that time has accumulated?

As the parent's adaptation, acceptance, and change of perspective came gradually, they settled into their routines, and the habitual care with the intricacies of caring for a special needs child. Participants bonded with their infants and realized they needed additional supervision and care. All the women in this study resigned from their employment to become their child's main caregiver. They transformed into their child's source of motivation and their advocates, until their child gained a routine through school. They also discuss the stress and process of coming to terms with the issue of being undermined by medical staff. As Alberto's son became increasingly ill with pneumonia, the medical staff bypassed his consent to give his son a G-tube. He elaborated on his feelings of anger and despair that he felt as well as how he learned to cope with the change. Here is Alberto's and his daughter Alma's experience:

> *Ha sido también estresante para el [mi papá] porque al principio le molíamos su comida y nos sentábamos y le dábamos de comer. Pero llegó el momento en que, este su cerebro no mandaba la señal para pasar. Entonces se nos enfermó varias veces de neumonía… [It was also stressful for him [my dad] because at first we used to puree his [Dieguito's] food and would sit down and feed him. But the time came when his brain did not send the signal to swallow.*

Alberto interrupted: *Si neumonía*. [yes pneumonia.]

Alma continued:

> *Entonces, la última vez que se enfermo mi hermano de neumonía, porque cuando se nos enfermaba mucho, le decían a mi papá que había que darle de comer por sonda, pero mi papá nunca lo quería. Entonces, a la quinta ves que se nos enfermó de neumonía le dijeron que…* [Then my brother, the last time my brother became very ill with pneumonia… because he was ill a lot, they would told my dad that he needed to be fed through a G-Tube, but my dad didn't want that. Then, on the fifth time that we became ill with pneumonia, they told him that…]

Alberto interrupted:

> *"¡No! No me dijeron nada, no mas me…me lo entregaron con él "G-tube", la sonda. Sentí mucho coraje y desesperación. Y de momento me molesté porque debían tener mi consentimiento. Ya en varias ocasiones querían, y yo le dije, "¡No, yo puedo le doy en la boca!" ¿Pero mire cómo son las cosas? ¡Después de reflexionar y todo, dije, "¡Pues Dios tiene su plan!" Porque yo tenía una persona a la que le pagaba porque nos atendieran, pues a la familia y sobre todo a mi hijo. Ella era la que le hacia la comida, le daba de comer, se ocupaba de todo eso. ¡Y fue el día que ya no podría pagarle también! Todo se juntó, todo se juntó. Cuando paso eso con Dieguito, me molesté. Pero ahora vendito se Dios, que bueno que paso así, por que mire por lo menos tengo esa tranquilidad. Le pongo la máquina y la máquina lo esta alimentando las 24 horas, gota por gota, gota por gota. Pues ya no tengo preocupación… ahora que mi hija y mi nieto estén al pendiente de todo.* ["No! No, they didn't tell me anything, they just… they just placed the "G-Tube" on him and handed him over to me like that. I felt a lot of anger and despair. And for a while I was upset because they didn't ask for my consent. Several times they pressed that he should get it, and I said, "No, I can feed him!" But look at how things turned out? After reflecting and everything, I said, "Well, God has his plan!" Because I used to have paid help, who care of us [prepped meals and cleaned], for the whole family and especially my son. She made him food, fed him, took care of all that. And it was that day that I couldn't pay her too! Everything was piling up. When that happened to Dieguito, I was angry. But now, blessed be God, how good it is that it happened that way, because I look at how… at least I have that tranquility. I put the machine on, and the machine feeds him 24 hours [a day], drop by drop, drop by drop. Well, I have no concern, now that my daughter helps with everything.]

Alberto endured the difficulties of having an increasingly ill child, as well as the pressure of the medical staff insisting on the need of G-tube and the powerlessness, anger, and despair as he learned that his wishes had been ignored. It seems, at least retroactively and from his point of view, that he may have not been given enough information to understand how the G-tube would facilitate his son's nourishment and avoid his probability of falling ill again as a consequence of his son's diminished ability to swallow. At any rate, his lack of fluency of English may have been another contributing factor to the poor communication with the medical staff.

Victoria declared, "*Hay veces que me da ansiedad, y tomo medicina, me calma, o como antes me sentía muy sensible, nerviosa, y quiero dormir, dormir, dormir… como depresión.*"

[There are sometimes I get anxiety, and I take medicine, it calms me down, and since I was very sensitive before, very nervous, all I wanted was to sleep, sleep, sleep... like depression.]

The participants share the following experiences in varying degrees; distress, shock, pain, grief, sorrow, helplessness, despair, anguish, fear, stress, sadness, guilt, shame, fear of being punished, nostalgia and loss simplicity of life, enmeshment with their special needs child, social isolation, powerlessness, an "internal battle," anger, preoccupation, panic, nervousness, anxiety, and depression. All of the participants experienced the normalization and assimilation through their unique validation of the meaning of having a child with special needs.

All participants looked to their Higher Being for solace; many offered *ofrendas*. Ofrendas can be either an altar constructed for prayer and spiritual guidance; or a ritual practice such as masses, prayers, or gifts with items such as food, drink, flowers, meaningful gifts; or a multitude of mementos, which may serve different favors or can be a sign of thanksgiving (Congdon et al., 1999). The participants in this research offered candles and flowers or pilgrimages to Mexico City, to visit the Basilica of Our Lady of Guadalupe in homage or asking for favors of well-being and protection for their children.

Financial Stress

All of these cases illustrated ways in which multiple themes converged as a result of parental stress. The participants identified a number of complications ranging from affective and anxiety disorders from the emotional impact, to physical ailments, social stigmatization about their child's disability, isolation and absence of supportive figures, difficulties with school networks and legal status problems impacting health care coverage, as well as stressed interpersonal relationships among partners and children, along with household financial struggles as sources of their distress. Participant Alberto said:

> *Me siento, muy desesperado, impotente, me pongo a llorar, y también con la economía, tener el dinero suficiente para la renta, siempre buscando como hasta el ultimo minuto. Cuando Dieguito se enferma, si me estreso mucho, ahora me preocupo mas, pensando negativamente, pesimista…Si me da ansiedad, por que cuando llega ella [mi hija], me siento tranquilo. Yo quisiera ver a un psicólogo para que me controle.* [I feel very desperate, impotent, I start crying, and also with my finances, having enough money to pay our rent, always looking [for money] until the last minute. When Dieguito gets sick, I get stressed a lot, now I worry more, think more negatively, pessimistic...it makes me anxious, when she [my daughter] arrives, I feel calm. I would like to see a psychologist to help me control it.]

Participant Ana said:

> *Nosotros estamos rentando [casa] y aparte de eso también a veces no la vemos muy difícil porque como a él (Vicente) le pagan una vez al mes, no rinde, no rinde, no rinde.* [We are renting [the house] and apart from that we also sometimes have a hard time because as he [husband] is paid once a month, it's not enough, not enough, not enough.

Vicente explains:

> *También está el problema del Seguro Social, pero por lo mismo, hasta que no cumpla 18 años autocalifica pagar el Seguro Social. Mientras tenemos ese estrés, del dinero.* [there is also the problem of Social Security, but for the same reason, until he turns 18 she qualifies to get Social Security. Meanwhile, we have that stress, about the money.]

Special Education

An important theme that emerged among participants is that many parents found delays with Special Education placement with the children who had evident if not significant cognitive or physical impairments. The parents experienced ranging levels of stress due to not having their child evaluated and placed in Special Education within a reasonable amount of time. "Bertha's" story, for example, demonstrates how she struggled with her son's education. Bertha's son was born with a birth defect, causing his missing ears and impairment in his hearing. Bertha, like many of the other parents, struggled with their school district, not knowing the English language and navigating the system that was foreign to them. She, like the others, was diligent to inquire and find support groups to gain information to advocate for her child's educational rights. Some of the parents resolved to pressure with lawsuits, and some actually obtained legal aid to represent them in court so that their children would be provided public Specialized Education and the appropriate services and/or interventions.

Bertha described what she encountered when she enrolled her son in the neighborhood elementary school. She stated that she appealed the placement in General Education where they did not offer him any Sign Language. The school did not respond to or to provide a resolution. She explained that he was the only child in that school district with a hearing impairment. As time went by, she grew restless and took it upon herself to inquire what steps to take to help her son. She gained assistance from a local support group and joined them. She declared that they provided her useful information to advocate for her son. In this support group, not only did she find validation and emotional support but she was also provided with legal information regarding her son's educational rights and direction with the protocol to follow. Bertha added that the support group encouraged her to communicate with the school district in writing, so she did. She wrote letters and requested that the school accommodate her son's needs. Yet the school did not resolve the issue, and her son continued in General Education. She persisted, and ultimately decided to hire an attorney to represent her. However, they never went before court because the school district quickly fulfilled his needs by arranging his transfer to another district. Here is what "Bertha" had to say:

> *Mucho, mucho [estrés], porque para mi, cada día que pasaba [sin educación especial], era como un día perdido para el niño, que yo no luchaba por él, porque yo no quería que ni un día se le pasara a él, ni un día. En la escuela no le daban ayuda especial…en el grupo de apoyo me orientaron de los derechos y como mandar cartas al distrito, pero nada que hacían, como el era el único niño [sordo]. Hasta que conseguimos abogado y pronto que el distrito le pago a otro [distrito] para que lo recibieran con la ayuda que necesitaba.* [But a lot of stress and a lot of tears. It was a lot of struggle, because I didn't know anything about that branch. A lot, a lot [of stress], because for me, every day that passed [without special education], was like a lost day for my child, it was another day that I did not fight for him, and I did not want another day to go by, not a day. At school they didn't give him special help… through the support group they gave me guidance about our rights and how to send letters to the district, but they did nothing, since he was the only [deaf] child. Until we got an attorney then quickly the school district paid another [school district] to take him and support him with the help he needed.]

"Marina" experienced a similar battle where the school district denied speech therapy to her son who is cognitively and developmentally delayed. She expressed that the battle took three years. At every IEP she would appeal their decision, until finally she expressed her dissatisfaction about their decision of not providing the speech therapy intervention her son needed by mentioning hiring an attorney to appeal this. Marina relates that after that specific discussion, the school district quickly paid for his transfer into a school for special needs children, where they accommodated his speech therapy and he learned to speak.

Marina's stated:

> *Cuando estaba chiquito no le querían dar servicio de lenguaje en Linwood, por que dijeron que supuestamente "su nivel cognitivo era muy bajo". Fue una pelea de tres años, decida yo, ¿Cómo va a aprender a hablar si tu no le das el servicio?". Y finalmente hasta después de transferirlo le dieron la intervención de lenguaje, y siento que fue lo que le a ayudado mas. Tubo un gran cambio, el si aprendió a hablar palabras en cuestión de semanas. Me repetirá la pregunta que yo le hacia, junto con su respuesta, (ríe). Pero si, el pleito era en cada IEP, yo presionaba y nada, hasta que mencionamos que iba a llevar un abogado, entonces me dijeron, "es por el distrito, y el departamento educación especial que no querían ayudarlo". Pero, por fin, ellos pagaron la transferencia de escuela, a una para niños especiales y le dieron la terapia del habla. Todo eso fue*

> *un alivio, finalmente ves su cambio y menos estrés para todos.* [When he was little, Linwood school did not want to give him speech services, because they said that "his cognitive level was very low," supposedly. That was a three-year battle, I'd say, "how is he going to learn to speak if you don't give him the service?" And finally, only after he was transferred, they gave him the speech intervention, and I feel that it has helped him the most. There was a great change in him, he learned to speak, first just a few words, in a matter of weeks. He would repeat back the whole question, along with his answer, (laughs). But yes, the battle was at every I.E.P., I pushed and nothing, until I mentioned that I was going to bring an attorney, they said, "It's the district, and the Department of Special Education that didn't want to help him". But finally, they paid his transfer to a school, one that is for special needs children, since like my son, and they gave him speech therapy. All of that was a relief, we finally saw the change in him, and we were all less stressed.]

These struggles were overcome by the parents' advocacy for their children. They acted on their child's best interest and pushed for services according to their child's capability. These mothers were successful in challenging the school districts and specialists to obtain the support and specific interventions their children needed.

One parent encountered ongoing difficulties with the school's decision to cut his daughter's speech therapy, and despite him voicing ideas to support his daughter, he felt dismissed and consequently stressed by the lack of support he felt his daughter was getting. Victor recounts his experience with special education,

> *Otra cosa es que nos estresa es que…. conociéndola como su padre…es que no le ofrecen servicios de "speech" por el diagnostico de retraso mental que dicen que tiene, pero se basan solamente en los exámenes de psicólogos que tienen, que son solo captan su habilidad en ese momento, pero nosotros la conocemos mejor, y sabemos que ella batalla con pronunciar los sonidos de las letras, ella no puede coordinar bien los músculos para pronunciar y la anunciación de las palabras, y eso hace que ella se esfuerce demasiado y eso le afecta a la larga, si no hay terapia [del habla] y ella se frustra y se atrasa mas. Hemos notado que lo que mas le ha ayudado son los cantos con el Karaoke por que le interesa y la motiva. En la ultima junta de IEP si lo mencionamos todo esto a los maestros y no le dieron mucha atención.* [Another thing is that we are stressed about is that… knowing her, as her father…is that they do not offer speech services due to the diagnosis of mental retardation they say she has…But they are based only on the psychological tests they have, which are only capture her ability in that moment, but we know her better, and we know that she struggles with

> pronunciation and annunciation of the letter sounds, she cannot coordinate her muscles well enough to pronounce words, which causes her to try too hard, which in the long run affects her if there is no [speech] therapy and she gets frustrated and falls further behind. We have noticed something that has helped her more is singing with the Karaoke because she is interested, and it motivates her. At the last IEP meeting we mentioned all of this to the teachers, but they didn't pay much attention.]

One parent fought the system to remove his son from the Special Education system altogether. Alberto was married, and he and his wife were dissatisfied with the level of care their son was getting. It is unclear if he was placed in a "special day class" or what level of intervention he was getting. Their son was wheelchair bound and was not able to communicate by any means. Alberto's son suffered from severe cognitive and developmental delays as a result from enduring encephalitis after battling a meningitis infection as an infant.

Participant Alberto said:

> *La verdad, nunca estuve conforme con el sistema de educación especial. Por que empezamos a notar que el niño se enfermaba mucho, Y entonces mi esposa dijo, ¡No, yo no quiero que valla, solo lo quieren por el dinero!". No le hacían nada, tal y como lo mandaba, lo regresaban…orinado, lleno de popo, sin cambiar el pañal. Fue una lucha sacarlo. Entonces ella hablo con su doctor, y el le ayudo, hicieron un plan de poner un pañal con una marca, o su firma en el panal, y notar cuando regresaba sucio. Mi esposa pidió una junta, y las personas encargadas le preguntaron, "¿por que?", y mi esposa le dijo sobre el pañal con su firma. Entonces el doctor firmo para que el niño estuviera en la casa, y mi esposa se hiso responsable, fue todo un caso esa pelea. Con varios trabajadores sociales, y vieron que el sufría mas en la escuela. También el chofer del camioncito, le dijo a mi esposa, en días de lluvia y tormenta. "no los recogen hasta que llega el camión". Ósea, que se mojaban. No lo cuidaban bien, y así autorizaron que no fuera a la escuela. Mandaban a una enfermera a la casa por un tiempo, eso fue todo.* [Actually, I was never satisfied with the Special Education system. Because when he was little we started to notice that our son would get sick often, And then my wife said, "No, I don't want him to go, they just want him for the money!". But they did nothing to him, just as he was sent to school, he returned... urinated, full of poop, without changing his diaper. It was a struggle to get him out. So she talked to our doctor, and he helped her, they made a plan to put a diaper with a mark, or his signature on the inside of the diaper, and note when he came back dirty. My wife asked for a meeting, and the

> person in charge asked why, my wife told her about the diaper with her signature. So then doctor signed for our boy to be cared at home. My wife became responsible, it was a real case that battle. With several social workers, and they saw that he suffered more at school. Another thing, the driver of the bus told my wife, that when it rained and stormed, "They didn't pick them up until the bus arrived, then they pick them up". In other words they [the kids] would get wet. They did not take good care of him, and so they authorized for him to not to go to school. They sent a nurse home for a while, that was all.]

Implicit, here, is the solution Alberto and his wife created to the inadequate care: keeping him home permanently. Alberto reports that they were increasingly concerned with the poor quality of care his son was getting in the public school. As they observed that their child was becoming more ill as time passed, they also started noticing that he was consistently and severely soiled upon his return from school, with his original diaper untouched. After seeing that he was still in the original diaper with which he was sent to school, they started to place a special mark, their signature on the inside of the diaper, visible only when removed. Alberto recounted that this inconspicuous mark would be there along with their extremely soiled child. After many of these occurrences, they began to document the occurrences. Alberto and his wife looked to the family's physician for aid. Alberto expressed that their doctor helped them make a plan. And together they appealed to remove his placement in public education and bring him home instead, where, "they sent a nurse home for a while, that was all." Alberto expressed that he and his wife suffered in seeing their son in such poor condition, so they maneuvered to remove him from Special Education all together.

Social Stigmatization

These parents are challenged in numerous ways. On the one hand, they struggle with their children's health-related issues as with challenges of nonconventional social behavior that result from the disability. On the other, they are challenged by social stigmatization and stereotypes as well as their own internal prejudices that result from misconceptions about disabilities. In a third component, with the added social stigmatization, people make assumptions about the labeled group and apply those assumptions indiscriminately to all the individuals in the designated group. T If they had helped me understand hus continue the process, as people socially or emotionally distance themselves from the labeled group, positioning the designated group, to some extent, as fundamentally different from other people (Farrugia, 2009). Meanwhile, the majority of these parents also encountered systemic difficulties with their school districts in obtaining special education placement for their child.

Moreover, a few others battled their own partners at home, in domestic violence. One mother, a victim of an emotionally abusive partner, described that her husband was entirely against special education placement for their daughter, who suffered from cognitive and developmental delays. The participant, "Victoria," reported that her daughter did not start special education until she was in the third grade because her husband thought it would be detrimental for her to get help. She expressed that he would often put her and her daughter down, but despite his abusive behavior, Victoria braved her partner and consented their daughter's special education placement and took the front of what would be his reaction. Participant Victoria expressed,

> *El papá no quiso que [ella] estuviera en educación especial, me decía ¡No, que ella no esta loca, y no necesita eso!" y con sus maltratos, le decía a la niña "que tienes tapado el cerebro". Hasta que nos separamos, me daban dolores de cabeza. Entonces ella no comenzó con educación especial hasta en tercer grado, por que el [papá] no quería. Yo lo tuve que autorizar. Se enojo tanto, me decía "¡eso es peor, la van a hacer todavía peor!". Bueno, pero si estaba afectada, parte de su cerebro no podía… si necesitaba la ayuda.* [Her father did not want [her] to be in Special Education, he said, "No, she is not crazy, she doesn't need that!" and with his abuse and mistreatment, he would yell at her, "What? Is your brain is blocked?". Until we separated, I'd get headaches. So, she didn't

> start Special Education until she was in third grade, because he [husband] didn't want to. I had to authorize it. He got so mad, he said to me "that's worse, they are going to make it even worse!" Well, but she was impacted, part of her brain couldn't…she did need the help.]

"Margarita" talked about how she has overcome her own views toward handicaps and social stigmatization as she used to keep her son hidden away at home. She described that she believes people see her son, who was born with Down syndrome, as "defective" and a punishment on her, although this may have been her own projection of her initial feelings and internal prejudices. She did report that initially it was too difficult to deal with stranger's "glares and comments." However, Margarita learned to accept her son, unconditionally, and is not ashamed to go into the community with him. "Margarita" conveyed her transformation:

> *Yo misma, antes no lo entendía, ahora ya lo entiendo. Ahora veo otros niños y digo "es normal". Pero para la gente que no tiene…o que no sabe la experiencia de uno. Hasta ahorita todavía se le quedan viendo a mi hijo, y es donde piensa uno ¿Por qué?, ¡si también es una persona! Es triste. Otras personas lo ven como un defecto, o un castigo, y para mi no es un castigo, el es igual que cualquier otra persona, y mi hijo brinda muchísimo mas amor con todos.* [Like myself, I didn't understand it before, now I understand it. Now I see other [handicap] children and I say, "they are normal!". But for people who do not have... or who do not know one's experience. Even now people still look at my son, and that is where I think "Why ?, if he is also a person! It is sad. Other people see him with a defect, or a punishment, and for me he is not a punishment, he is the same as any other person, my son offers much more love toward others.]

"Vicente" explains that he and his wife, "Ana," have also struggled with social stigmatization and their own internal prejudices. Vicente described that learning to accept their fate and their daughter's limitations as well as assimilating the situation has helped them to overcome their internal prejudices. Vicente added that he felt regret each time in not being able to be present to defend or explain the situation in the instances when strangers rudely commented or stared, because he was away at work.

> *Pero lo mas grande [estresante] es que cuando otras personas reaccionan negativamente hacia ella, y tristemente muchas veces no podía estar yo allí con ellas para defenderlas o explicar la situación. Mas que nada, lo que a cambiado ah sido nuestra aceptación y asimilarlo. [*But the greatest [stressful] thing is that when other people react negatively toward her, I've sadly I wasn't able to be there to defend them or explain the situation. More than anything, what has helped more is our acceptance, and assimilating it.]

Isolation

To avoid and minimize the potentially hurtful social encounters and verbal exchanges that arise from their child's socially deviant behavior, many parents decreased their outings in the community with their child.

Participant Margarita reported:

> *Si sentíamos como que la gente volteaba y lo veían y pensaban "¡Ah mira, su niño está enfermo!". En ese tiempo no era bonito salir con el, por que la gente de afuera no entiende.* [I did feel like people would turn around and look at him and think "Oh look, her child is handicap!" During that time, it wasn't nice to go out with him, because people do not understand.

Participant Felicia expressed:

> *Yo no, no busco ayuda afuera en la comunidad, no. No salgo, yo solo de la tienda a mi casa. Ni con mi familia o mis hermanas.* [Not me, I'm not looking for help outside the community, no. I don't go out, I just go from my house to the store. I don't even go with my family or my sisters.

Participant Victoria states:

> *No, nunca e tenido ayuda de nadie. Aquí estoy siempre, no tengo amistades, no salgo, siempre eh estado sola. Nunca e tenido a nadie, y ni mis hermanos… siempre [están] trabajando. No me relaciono con otras personas. Si me ofrecieron en el Centro Regional, para cuidarla, como para salir a pasear y despejarme y relajarme, como a un viaje o algo así, pero no. Siempre me desanimo, me da miedo, pienso en ella, y siento remordimiento y culpa. Yo no eh tomado ayuda profesional, solo pienso que por ella debo de luchar.* [No, I have never had help from anyone. I am always here, I have no friends, I do not go out, I've always been alone. I have never had anyone, not even my brothers…they [are] always working. I do not relate with other people. They offered me services at the Regional Center, with childcare, so that I could go for a walk and clear my head and relax, or for example be able to take a trip or something. But I always disheartened myself, it scares me, I think about her,

> and I feel remorse and guilt. I have not had professional help; I just think that I must fight for her.]

Participant Bertha said:

> *Me aislé un tiempo, me puse mucho a trabajar a ocuparme en las cosas de mis hijos. Entonces no socialice mucho. Ahora, veo como todo muy guardadito, y me da miedo hablar de eso, hasta la fecha.* [I isolated myself for a while, I'd work a lot, I'd keep myself with the children's matters. I dedicated myself to my children and my work, so I didn't socialize much. Now, I see everything has been very guarded, and I'm afraid to talk about it, to this day.]

Vicente and Ana declared that the support group they joined two years prior helped them integrate into the community. They claimed their change in becoming more open and gaining friendships. They also expressed that their special needs child developed socially and interpersonally and integrated with others through the participation of the support group. Vicente stated;

> *Antes de meternos a el grupo de apoyo todos nosotros éramos muy aislados, y hemos cambiado mucho en ese aspecto. Ella se a abierto mucho y a echo muchas amistades, se integro en el grupo, y nosotros también.* [Before we joined the support group we were all very isolated, and we have changed a lot in that regard. She has opened up a lot and made many friends, she integrated into the group, and we did too.]

Health Care Accessibility

Trauma and resilience travel together in the journey of life. So too, most of these participants normalized and assimilated their trauma in having a special needs child and adjusted their lives to better suit. The road to adjustment has been treacherous for many of them, managing significant difficulties, barriers, and added responsibilities of rearing a child with a disability. For a few, the adjustment journey to arriving at acceptance is still in motion. One such barrier found were difficulties with Medi-Cal and/or Social Security benefits due to issues such as transportation, illiteracy, lack of knowledge about the criteria or in maneuvering the application process, as well as their illegal immigrant status. For example, "Alberto" stated,

> *El problema mas grande que hemos tenido es que el niño no es legal aquí (*United States*), entonces no califica para muchos programas, como no tiene [numero de] seguro social. El no tiene un autor legal, necesitamos un abogado para que nos ayude a hacer el papeleo de autor legal. Yo realmente no tengo la forma de pagar eso… con migración, no se ni donde investigar. Eso nos a causado estrés, por que no recibe toda la ayuda que nosotros quisiéramos para el.* [The biggest problem we've had is that our child is not legal here (in the United States), so he doesn't qualify for many programs, since he does not have a Social Security [number]. He does not have a Power of Attorney; we need an attorney to help us with the legal paperwork to assign his Power of Attorney. I really don't have a way to pay for that…with migration, I don't even know where to investigate. This has caused us stress, because he does not receive all the help that we would like for him.]

Alberto explains that his son reached the age of majority, and he remains the only family member in the family who is undocumented because they are unfamiliar with the process to obtain his legal residency, as well as the funds to process the application. Another barrier is that they do not have a power of attorney for his son, who is completely incapacitated and noncommunicative and requires a high level of medical attention. Alberto reports that his son does not have many services and interventions such as physical therapy that they would like for him.

For "Vicente" and "Ana" it is a similar situation. Although they are legal residents, they are unfamiliar with the application process and criteria for eligibility. With the unfamiliarity, they take whatever information is given to them with face value. Vicente explains:

> *No recibo ayuda [asistencia económica] tampoco, ni de seguro ni de nada, porque supuestamente dicen, "¡no califica hasta los dieciocho!". Pero dicen que por el [Vicente] gana mucho, no calificamos ni para medicamentos. Tengo el problema de Medi-Cal, que ya me lo cortaron otra vez, y apenas si nos alcanza para lo básico. También nos han dicho que no podemos sacarle [beneficios de] seguro social hasta que tenga los dieciocho años.* [I don't get help [financial

> assistance] either, or social security [benefits], or anything, because they say that, supposedly; "she doesn't qualify until she's eighteen!". But they say that [my husband] earns a lot, and we don't qualify even for medications. I have a problem with Medi-Cal right now, which is that we've been terminated again, and we barely have enough money for the basics. We have also been told that we get her Social Security [benefits] until he is eighteen years old.]

Acculturation

On top of the immense lack of understanding in maneuvering a new county, the lack of familiarity about new customs, language, medical coverage systems, school systems, and interventions for the children, among those with a lower socioeconomic status, there is an added hurdle of limited literacy and illiteracy.

Felicia described her regrets in misunderstanding the support she was offered when she arrived, as the special education staff suggested that she go to school to learn to read and write. She expressed her wish that they had emphasized how much it would help her to be literate. Felicia is a legal resident, but she described that in not being literate, and not knowing the English language, she is unable to start her citizenship application, which requires individuals to have a basic level understanding of the English language and answer questions in English, according to her.

> *Si me hubieran ayudado a entender [lo importante de aprender a leer] seria como, tener mas información seria mas fácil para mi, pero como no se leer, pues se me hace muy complicado a mi. Si me ofrecieron programas para leer, si hubiera yo ido, pudiera por lo menos defenderme de los papeles (se ríe), tal ves eso [seria de utilidad para otros]. Se me hacia como que no iba a aprender. Pero si me hubiera ayudado para ir por mi ciudadanía, porque hay que saber ingles, y no, no se nada, nunca fui. [*If they had helped me understand [the importance of learning to read], it would be like having more information, it would have been easier for me, but as I don't know how to read, it is very difficult for me. They did offer me programs to learn to read, if I had gone, I could at least defend myself from the papers (nervous laughter), perhaps that [could be useful to others]. It seemed to me that I was not going to learn. But that could

> have helped me toward my citizenship, because you need to know English, and no, I don't know anything, I never went.]

Felicia lives in a rural area where there are fewer programs and outreach groups that support immigrants in their process of acculturation. With her illiteracy limitation, she also faced a difficulty in obtaining her driver's license, which she is eligible for as a resident. However, she described her stress in having to constantly ask others for transportation:

> *También lo que me estresa más, que yo no se manejar, y eso fue, o es lo que a sido mas duro, necesito buscar alguien de la familia, o en la escuela quien, en la escuela me ayudan mucho con lo de las citas de Lucero.* [What stresses me out more, is that I do not know how to drive, and that was been and still is the hardest, I need to look for someone in the family, or at school they have been very helpful toward me with Lucero's appointments.]

Maternal Role, Parental Alienation, Enmeshment, and Parentification

The discourse of mothering advances expectations for parent involvement based on an idealized image of a patriarchal Christian family values, with a husband, wife, and children. That assumes particular gender roles, in which the husband works, and the wife stays home to raise children (Lai & Vadeboncoeur (2013).

All participants coincided with the phenomenon of resigning their employment and becoming their children's caregiver. The maternal roles may very well be attributed to the cultural and traditional gender roles, as one participant describes her conversation with her domestic partner. Participant Felicia said;

> *Después de que me junte [con mi pareja domestica], ya no trabaje, me quede en la casa, no eh trabajado y el no quiere que yo trabaje. Aunque estemos apretados con el dinero. El dijo, "tu no tienes que trabajar, están chiquitos los niños y los tienes que cuidar por que van a sufrir los hijos en casa de otra gente". Entonces yo iba a su escuela, los llevaba, voy a las juntas, siempre al pendiente.* [After I got into a new relationship, I didn't work anymore, I stay at home, I haven't worked and he [husband] doesn't want me to work. Although we are tight with money. He said, "you don't have to work, the children are young, and you have to take care of them because the children will suffer in other people's homes." So, I went their school, I took them, I go to the meetings, I'm always on the lookout.

Marina added that she feared having another child with autism, she debated this with her husband for 12 years until they finally agreed. She described her fear and how she came to assimilate it:

> *Avía un miedo para poder asimilar de que el tiene autismo, y a sido difícil, por ejemplo, el quería mas hijos, y yo no, hasta que vi que Roberto, mi hijo, fue mas independiente, pues ya me animé. Pero tenia miedo que saliera otro bebe como el. Tardamos doce anos en tener otro bebe después de el, y pues para dedicarle mas tiempo a el.* [There was a fear in the process of assimilating that he has autism, and it has been difficult, for example, he [husband] wanted more children, and I did not, until I saw that Roberto, my son, was more independent, then I was more encouraged. But I was afraid to have another baby like him, [with autism] would come out. It took us twelve years to have another baby after him, and so to dedicate more time to him.]

Participant "Vicente" explains his perspective of coping with the stress in supporting his wife's emotional impact:

> *Fue un poco impactante… ¡No! no fue "un poco", fue significantemente impactante, pero me enfoqué más en ser fuerte para darle valor a ella (Ana) de la manera que lo afectó. ¿Si no me hubiera hecho el fuerte, donde hubiera quedado mi esposa?* [It was a little impactful… No…not "a little", it was significantly impactful. But I focused more in being strong to give her (wife) strength, the way she was affected. If I hadn't been strong, where would my wife be?

Participant Victoria said:

> *Todo desde un principio fue muy difícil para que ella saliera adelante. Me embaracé de nuevo, solo por la idea de que yo quería tener un bebe, quería tener un bebe en mi casa, quería como remplazar lo que no (llora), no podía tener en ese momento, sentí un vació que no podía, aunque yo savia que estaba viva, quería acostarme y sentirla en la cama. Las niñas se llevan un ano tres meces. Justo cuando salgo embarazada, salió del hospital de la "baby". Fueron momentos de mucho estrés y experimentar como mucho dolor, angustia*. [Everything from the beginning was very difficult for her to get ahead. I got pregnant again, just because of the idea that I wanted to have a baby, I wanted to have a baby in my house, I wanted to replace what I didn't… (Cries), I couldn't have at that moment, I felt an emptiness that I couldn't… although I knew she was alive, I wanted to lie down and feel her in bed. The girls are a year three months apart. Just when I found out I was pregnant [with my

> second child]; the baby was discharged from the hospital. There were moments of great stress and experiences of a lot of pain and anguish.]

Among the participants interviewed, a few experienced an interpersonal and relational phenomenon of enmeshment in terms of bonding on the more intense sense of bond with their special needs child than with their other fully abled children or compared to their spouses. Additionally, the participants experienced patterns of parentified children, who took roles of supportive figures in the life of the child with disabilities. Participant "Renata" explains that she assumed the role in her son's affairs as her husband refused to participate in anything related to his life. She explains:

> *Pues mi esposo nunca quiso participar en las juntas, tampoco tenia la paciencia y nunca lo acepto (al niño, todavía no lo acepta*. [Well, my husband never wanted to participate in the meetings, nor did he have the patience. He has never accepted him [our son], he still does not accept him.]

She felt alienated from her husband as he refused to participate in their son's affairs and refused to bond with him. Oher participants illustrated how their family's attachments changed between members. "Margarita" for example, discussed her different roles as a mother and wife. She described how she maintained her self-motivation and put her special needs son's interest first before her own needs, while also being more "separated' from her fully abled children. As a wife she concluded that she and her husband worked well together and became less detached with one another to be able to focus on their son's needs and with the whole family under the new and special circumstances. Here's is Margarita's statement:

> *Como madre, me animo y digo, "yo puedo y tengo la habilidad. Como esposa... mi esposo me ayuda y me comprende, y me ayuda. Pero como que eso nos unió mas. Para estar también mas unidos con la familia. Pero tuvimos que…no renunciar, pero estar un poco mas separados por que teníamos que estar con el niño. Como madre, pues era un poco diferente por que le dedicaba mas tiempo a el (niño con necesidades especiales) y los demás no, ellos fueron mas independientes. Entonces yo pienso que, si me separe algo de ellos.* [As a mother, I perk myself up and say to myself, "I can and I have the ability". As a wife... my husband

> helps me and understand me, he helps me. It [the situation] kind of united us more. To be more united with the family also. But we had to... not give up but be a little more separated [from one another] because we had to be with our son. As a mother, it was a little different because I dedicated more time to him [son with special needs] than the others, they were more independent. So, then I think that I separated myself from them somewhat.]

For "Renata" it was similar; she experienced feeling overwhelmed and stressed in not having the support of everyone, including her older children and husband. She felt especially pressured when having to attend child related meetings on her own without the support of her husband because he told her that he did not understand, but to her, it was hurtful that he lacked the effort:

> *Si, ha sido un tanto estresante porque si hay veces si no tienes el apoyo de todos, de todos, de a la pareja, del papa, Es difícil…. El [mi esposo] decía que no quería ir a las juntas, el decía que, "no entendía".* [Yes, it has been a bit stressful because there are times if you do not have the support of everyone, of everyone, and my partner, of the older ones [children]. It is difficult.]

For participant "Victoria," after separating from her emotionally abusive husband, and remining single, she experienced the impact of social isolation and recalled her assessment of her attachment with her special needs daughter. She described that she felt guilty, uncomfortable, and preoccupied and worried whenever she left her daughter in someone else's care. She described that she felt that she was unable to leave the vicinity:

> *Pues, no puedo irme lejos, no me siento bien dejándola, no me siento a gusto, no la puedo subir al avión, por no arriesgarla, ni a juegos fuertes. Eh ido a México solo dos veces, no me siento bien dejándola, pendiente y preocupada, como culpable. Necesito estar detrás de ella y no quiere tomar la medicina, y no ser constante.* [Well, I can't go far, I don't feel good leaving her, I don't feel comfortable, I can't get her in to an airplane, so not to put her health at risk, nor go on strong rides [rollercoasters]. I have gone to Mexico only twice, I do not feel good leaving her behind, I get worried and concerned, like guilty. I need to be looking out for her and she doesn't want to take the medicine, and not be constant.]

In terms of the attachment style between her daughters, she reported that her younger daughter often felt jealous of her attention since she often coddled and cuddled with her disabled daughter but not with her fully abled one. “Victoria” described her bond with her special needs child as more “attached” than her younger, fully abled daughter:

> *Cuando era mas chica mi otra hija [hábil], siempre le tubo celos a su hermana, me decía yo que no le ponía atención. Una ves me dijo que se sentía mal, creo que hasta se había golpeado ella misma, para que yo le tomara atención y para ver si yo hacia lo mismo con ella. Ella no entendía que era muy complicado, y como me apegue mucho a ella. La apapacho, la mimo. Y hasta este día no me puedo ir a trabajar sin preocuparme, no. Aunque este su hermana allí, son cosas con las que todavía batallo.* [When my youngest [fully abled] daughter was younger, she always jealous of her sister, she told me that I didn’t pay attention to her. Once she told me that she felt ill, I think she had injured herself so that I would pay attention to her and to see if I did the same with her. She did not understand that it was very complicated and like I attached more to her (my daughter with disabilities), I cuddle her, I coddle her. And still to this day, I can't go to work without worrying, no. Although her sister is there, those are things that I still struggle with.]

Some siblings became unconsciously parentified. The participant “Marina” described that in earlier years had observed her oldest daughter being overly concerned, watchful, and putting her brother’s needs before her own. Marina described how her daughter would report on her brother’s every move, what he did, what he ate. And to help her daughter gain a more independent childhood she enrolled them in different schools. She described how scared she felt, but at the same time acknowledged that it was the best thing for her daughter to make this decision.

> *Mi hija, desde chica aprendió que Roberto era diferente y que teníamos que cuidarlo, siempre, ella miraba siempre primero por su hermano. Por decir que estuviera el bien, o jugaba lo que ‘el’ quería jugar. Y Roberto siempre la ha visto como segunda mamá, es lo que yo eh notado. El es mas accesible con ella. Pero cuando estaban en la escuela juntos, tuve que separarlos, por que ya hasta en la hora de lonche ella buscaba al hermano, como cuidándolo. Entonces hablé con mi esposo y le dije, “¿sabes que? ¡Que no se me hace justo para ella que este las 24 horas pendiente del hermano, y no tener una niñez!” entonces los mande a diferentes escuelas. Y si tenia miedo que ella ya no me decía lo que hacia,*

> *comía… todo. Pero si pensaba que ella tenia que vivir su vida normal, y ser independiente de el y tener su niñez mas normal, después si se relajo un poco, y no estaba tan al pendiente.* [My daughter, she learned from a young age that Roberto was different and that we had to take care of him, always, she always looked out for her brother first. To put it this way, to make sure that he was doing well, or she would play what he wanted to play. And Roberto has always seen her as a second mom, that is what I have noticed. He is more accessible with her. But when they were in school together, I had to separate them, because even at lunchtime she was looking for the brother, like watching after him. So I spoke to my husband and I said, "you know what?, it's not fair for her, that she is concerned for her brother 24 hours a day, and to not have a childhood!" So I sent them to different schools. And I felt afraid, that she could no longer tell me what he was doing, if he ate...everything. But I thought that she had to live a normal life and be independent of him and have a more normal childhood, she relaxed a little later on, and was not so concerned about him.]

Participant "Alberto" described that he also felt that he had switched familial roles with his adult daughter. As he became older, and increasingly debilitated, he relied more and more on his daughter's support, who stepped in when her mother passed away six years ago. "Alberto" described the conversation that he had with his daughter "Alma":

> *Estaba hablando con Alma, y le dije, "¡estoy llegando a un grado de que me siento yo más tu hijo, que tu papá!". Cuando no está aquí para ayudarme con* Dieguito, *yo me siento desvalido completamente. El estrés está muy cargado.* [I was talking to Alma, and I said, "I'm getting to the point where I feel more like your son, than your father!" When she is not here to help me with Dieguito, I feel completely helpless. The stress is very charged.

Personal Agency and Coping Mechanisms

A part of this research included the inquiry as to what coping exercises or mechanisms, if any, the participants utilized to mitigate their stress and difficulties. These included personal agency efforts and perspective taking, such as being optimistic and using acceptance to cope. The participants also used a handful of community-based resources for aid with moral support and/or with respite type care for their child. All of these were factored in to understand how participants mitigated or integrated their experiences and difficulties. The heteronormative cultural group shared interwoven spiritual and religious beliefs and theoretical frameworks within the Catholic Church doctrine, and thus many conceptualized and even attributed their circumstances to the “Will of God.” Spirituality and religious coping were among the top factors utilized to manage internal traumatic distress and grief, stress, and illnesses. A range of meanings were identified; each of the coping mechanism listed below will show how their specific religious or spiritual practice helped ameliorate their stress and emotional burden.

As far as personal agency, participants utilized perspective and acceptance to assimilate their experience. For example, “Alberto” simply stated, “¡Pues Dios tiene su plan!” [Well, God has his plan!"] meaning that he had surrendered his internal battle and accepted his fate and his son’s, trusting that God had a plan for him.

Similarly, participant Victoria described that she felt that it was God’s will that her daughter was born with a disability and therefore it was her responsibility to fulfil the role and to meet her child’s needs.

> *Mas que nada, aceptarla, Dios me la dio así, y que yo soy la parte que ella necesita, si yo me dejo caer ella va a caer. Ella a sido mi pilar y mi impulso. También estando a la defensiva, siendo fuerte, sacando a mis hijas adelante. Pienso que Dios me a ayudado por que nunca tome terapia, yo se que la eh necesitado, y la necesito, pero ahora yo eh tratado de manejarlo tomando una perspectiva mas positiva.* [More than anything, accepting that God gave her to me like this, and that I am the piece that she needs, if I let myself fall she will also fall. She has been my pillar and my impulse. Also, being on the defensive, being strong, pushing my daughters forward. I think God has helped me because I have never taken therapy, I know that I've needed it, and I need it, but now I've tried to handle it, taking a more positive perspective.]

Bertha’s experience also resonates as she described feeling used by God, being put to the test because she felt courageous and because of her great faith. She described how she had made an offering to the Virgin of Guadalupe to intercede for her son's health. Bertha stated;

> *Yo decía que Dios me había utilizado por que yo era una mujer fuerte, por que yo estaba bien aferrada en mi fe, yo sola, la escuela de los niños y los deportes. Por eso yo me eh quedado sola y hasta ahora empiezo a salir a ayudar a otros con este problema. También con mi rutina, muy rutinaria. Pero, Dios fue lo que me ayudo mas. Mi fe en Dios, con la certeza de que eh echo todo, todo lo que se necesitaba para sacarlo adelante, por que si es muy difícil (Solloza, pausa), muy difícil. Además, tenia grupos de oración, ofrecía misas, le hice la promesa a la virgen de Guadalupe que se lo iba a llevar a la catedral a la cuidad de México.* [I used to say that God had used me because I was a strong woman, because I was firmly attached toward my faith, I was alone, only the children's school and sports [helped]. That's why I have remained alone until now I've started to go out and help others with this problem. Also, with my routine, very routine oriented. But, God was what helped me the most. My faith in God, with the certainty that I have done everything, everything that she needed to get ahead, because if it is very difficult (Sobs, pauses), very difficult. In addition, I had prayer groups, I offered masses, I made a promise to the Virgin of Guadalupe to intercede and I'd take him to the cathedral in Mexico City.

While Renata declared that she prayed for God's help and for Him to find her help with her son's health and behavioral issues, she declared:

> *Mi estrés me lo quitaba yo… Le pedía mucho a Dios que encontrara a alguien que le ayudara a la criatura*. Y *pues, cuando los niños se iban a misa conmigo, o me los llevaba al parque, me llevaba mi rosario… o en la iglesia. Iba un tiempo a un ministerio, pero, eso solo era solo estudio bíblico, aunque también hacían oraciones por ellos, por el niño. Como que sentía esa tranquilidad y paz conmigo, me sentía a gusto y me relajaba.* [My stress, I reduced it... I asked God a lot to find someone to help the child. And well, when the kids went to mass with me, or I would take them to the park, I'd take my rosary… or in church. I would go to a ministry that was only like bible study, although they also prayed over the kids sometimes. I felt that tranquility, that inner peace, I felt satisfied and I would relax.]

Initially, Margarita stated that she was angry and argued with God. She asked him "why it had happened to her." She negotiated it and stopped going to mass and thought that God had forsaken her. But after some time, she started praying from home when everyone went to church. She describes that her experience of leaving the home to go to mass was related to her son's apprehension to be left behind. Yet, she regained the religious prayer practices:

> *Espiritualmente …yo renegué, pregunte, "¿por que a mi?", lo negocie… (llora, toma una pausa). Yo tengo un tiempo que no voy a la iglesia, y me dice mi esposo, "¿por que no vas?". Y es que no siento el deseo de ir, dure un tiempo que peleada [con Dios], por que según yo le pedía ayuda, "¡ayúdame, ayúdame!", y yo creía que Dios no me hacia caso. Y cuando si iba y era peor, el se ponía nervioso, vigilante. Y entonces, pues no voy, mi esposo si va. Yo le pido [a Dios] aquí en casa, no quiero ir y que mi hijo este preguntando por mi y se ponga vigilante, haber que hago, haber que digo, no… si no me pregunta nada.* [Spiritually…I argued, I asked "why me", I negotiated it (cries, takes a pause). It's been awhile that I haven't gone to church, and my husband asks me, "why don't you go?". I don't feel the desire to go, for some time now, I have fought [with God], because according to me I asked Him for help, "help me, help me!", but I believed that God didn't help me. And when I went, it was worse, my son would get nervous, vigilant. So then, well, I don't go, my husband does. I pray [to God] here at home, I don't want to go and have my son asking about me and being vigilant, watching what I do, what I say, no... if I don't do, he won't ask me anything.]

While Marina also incorporates her religious beliefs and practices, she meditates and takes a temporal perspective. She acknowledges that her trials are temporary and tries to process her struggle to overcome it by remaining calm.

> *También, yo creo mucho en Dios, entonces me pongo a orar, o me pondo a pensar que la etapa que estamos viviendo es temporal, entonces va a pasar. Ósea, trato de analizar lo de adelante y decir, ¡bueno, esto que esta pasando ahorita, no es para toda la vida, va a pasar, y lo podemos procesar y superar".* [I also believe a lot in God, so I start to pray, or I start to think that the phase we are experiencing is temporary, so it will pass. That is, I try to analyze the future and say, well, this is happening right now and it's not for life, it will pass, and we can process and overcome it.]

Felicia asked for God's guidance, but declared that she did not attend mass, but rather prayed at home. Felicia prayed for her children's well-being, as well as for her own healing:

> *Lo único que me a ayudado es… y le pido a Dios es que me mejore de mi cara, (parálisis parcial). Solo le pido mas vida y salud, es lo único. Yo siempre le eh pedido a Dios que me ayude, que proteja a mis hijos, no hay como el, como Dios.* [The only thing that has helped me…and I ask God is to improve my face (partial paralysis). I only ask for more life and health, that is the only thing. I

> have always asked God to help me, to protect my children, there is no one like him, like God.]

Victoria described she had a teacher who became concerned about her and recommended that she write in a journal as a means to cope and vent her emotions. Victoria related;

> "*No, nunca e tenido ayuda de nadie, ningún servicio*. *La ayuda de un maestro fue lo único, me enseno a escribir y sacarlo, y repetirlo y procesarlo, aunque hay muchas cosas que son imposible olvidar. Pero cambiando la perspectiva, una y otra ves.* [No, I have never had help from anyone. No services. The help of a teacher was the only thing he taught me to write and how to get it out, and repeat it and process it, although there are many things that are impossible to forget. But changing the perspective, over and over again.]

Supportive Services and Interventions

Supportive services are a means to assist parents of a child with a disability to compensate for those aspects which affect their ability to care for and nurture their child. The term includes specialized adaptive training, evaluations, or assistance with effective use of adaptive equipment and accommodations that allow a parent to benefit from other services such as American Sign Language and braille interpreters (Brassart et al., 2017). This may also empower parents with information and emotional support and alleviate parental responsibilities.

The participants ranged in feeling supported by community agencies, with specific interventions aimed to support parents of special needs children, to feeling isolated and unsupported. For the parents that felt supported, service-related interventions such as respite were the most mentioned: The Regional Centers provided these services. Participants related how they had found encouragement and respite through the agency. Participant Marina related;

> *Tenemos la ayuda de "Respiro" por medio del Centro Regional, y pues le pagan a mi mamá 16 horas para que se quede con el, para mi esposo y yo podamos tener una cita de pareja, una o dos veces al mes" Eso nos ayuda a descansar y conectar como pareja.* [We have help from "Respite" through the Regional Center, and they pay my mother 16 hours to stay with him, so that my husband and I to be able to have a date night once or twice a month. This helps us to rest and connect as a couple.]

Margarita responded that she had not sought help elsewhere for herself, but that she had indeed received supportive services from the Regional Centers. Participant Margarita asserted that her oldest daughter was paid to help with the care of her special needs son so that she could take time for herself, "to recharge batteries." Margarita's help through respite proved to be helpful;

> *La verdad, no eh buscado, solo del centro regional se lo llevan a hacer actividades, pero para mi, no. Y "Respiro", le pagan a mi hija, me salgo un rato, me despejo un rato, pienso en otras cosas, es como un momento para recargas las baterías. Me ayudan mas que nada por el Centro Regional. Se lo llevan y un rato estoy bien, tres veces por semana, yo me pongo a ver mi trabajo, mis tareas domesticas. Siempre tengo la preocupación de que le pueda pasar algo en la calle y mas si llegan tarde.* [The truth, I have not searched, only from the Regional Center they take him to do activities, but not for me. And "Respite", they pay my oldest daughter, I go out for a while, I clear up for a while, I think about other things, it's like a moment to recharge my batteries. They help me more than anything through the regional center. They take him and for a while I'm fine, three times a week, I see the work I need to do, my housework. I always have the concern that something might happen to him on the street, especially if they are late.]

The couple Victor and Ana described participating in a support group through Regional Centers. Victor related;

> *También tenemos el Centro Regional que anualmente nos reunimos en las reuniones de "Orientación y Consejos" son un grupo de apoyo si nos han ayudado significantemente. Apenas tenemos dos años que nos integramos.* [We also have the Regional Center where we meet annually at the "Orientación y Consejos" [orientation and advice] meetings. They are a support group and they have helped us significantly. We've only just been participating for two years, .

Similarly, participant Alberto said: “Pues solo el Centro Regional, con “Respiro”, le pagan a mi hija para que me ayude, y así, eso es todo.” [Well, only the Regional Center, with “Respite”, they pay my daughter to help me, and so, that's all.]

Other supportive factors were school staff support, such as for transportation and reading and translating documents. Felicia expressed that she had found instructional aides to be instrumental with her ability to get to school related meetings and to interpret documents;

> *Si, las tutoras me ayudan con el transporte, y a leer, por que no se. Ellas me ayudan en la escuela a ir a las citas. A Lucero, le ensenaron a leer, y todo, ella sabe leer con braille, ayudándola a ser independiente y en su programa, me ayudan con los papeles, y cuando necesito que me lleven a algún lugar. Aparte de eso, nada mas.* [Yes, the tutors help me with transportation, and to read, because I don't know how [to read]. They help me get to appointments at school. Lucero was taught to read, and everything, she knows how to read with braille, helping her to be independent and in her program, they help me with [reading and filling out] papers, and when I need to be taken somewhere. Other than that, nothing else.]

Likewise, Renata reported that school related staff, or more specifically, “wrap-around” had been helpful, which helped her to become more engaged and proactive to participate in her son’s school related meetings. She expressed that her school had been accommodating to find a “parent-partner” as a liaison. Additionally, her child’s psychologist incorporated collateral sessions for her and her son.

> *Lo que me ayuda mas es el “wrap-around”, y mi…participo, también me dan, me dan “parent-partner”, o con la doctora “Dr. C” la psicóloga, cuando voy a la terapia y también a mi me decía, me gustaba como me hablaba, me también “paciencia, paciencia, por que nunca va a ser igual que otros niños”.* [What has helped me most is the Wrap-Around program, and my… I participate, I also receive, I’ve received a “parent-partner”, or with “Dr. C”, the psychologist, when I go to therapy and she also tells me, I like how she said to me, “patience, patience, because he will never be like other children”.]

Vicente and Ana said:

> *Pues, en las clases [en la escuela de la niña], preguntando con las trabajadoras sobre como debemos responder, que decir, que hacer. Hemos aprendido a normalizar la situación. Y el grupo de apoyo, nos a ayudado a todos.* [Well, in the classes [at our daughter's school], asking the workers about how we should respond, what we should say, what to do. We have learned to normalize the situation. And the support group has helped us all.]

Parent-led support groups in the community also came up as a means to engage parents and their entire families to be less isolated and to feel integrated into an environment where they felt like not a minority but as part of an inclusive group of parents with children with disabilities. Bertha expressed that through her support group, she had learned to process her grief, as well as how to respond to negative and stigmatized comments. Bertha expressed that her support group was more like family:

> *Pues en el grupo de apoyo, te haces otra familia porque te entienden lo que su estas sintiendo, no es como si te lo platican a ti… es decir, hay hermandad, por que esas personas ya han pasado por esa tristeza. En el grupo te ensenan que decir, como contestar, que es la enfermedad no es como algo que tu quisiste… "se llama así y es por esto", y pues educar a la gente…. y como hay gente muy, muy cruel, te ensenan como preparar al niño…cuando le dicen groserías, como contestar*. [Well, in the support group, you gain another family, because they understand what you are feeling, it is not as if someone is telling you about it, there is a brotherhood, because these people have gone through that sadness. In the group they teach you what to say, how to answer, that you didn't wish for the disorder to happen to your child….it's called "this and that and it happened this way" and we educate people, and since there are very, very cruel people, they teach you how to prepare your child... when they bully him, how to answer.]

Bertha said:

> *El grupo de apoyo, pero como fue solo corto tiempo, dos años, siento que si fuera mas tiempo ayudarían mas a los padres a procesar todo. No hay muchos grupos, y eso es de mucha ayuda. Después de todo somos los mismos padres que nos ayudamos. Estoy tratando de hacer un grupo de mujeres solas, aquí en la casa, para hacer un grupo y hacer actividades.* [The support group, but since it was only a short time, two years, I feel that if it were longer they would help parents to process everything. There are not many groups, and that is very helpful. After all, we the parents are the ones who help each other out. I am trying to make a group for single women, here at home, to make a group and do activities.]

Vicente and Ana said:

> *El grupo de "Sueños y Esperanza", con el grupo de Karaoke, a ella le dan servido de terapia…socializarse. El Karaoke la han conllevado a esforzarse por hacer ejercicios con la boca y su coordinación con el folclórico. Alli tienen un grupo de baile folclórico, un partido de béisbol y dos certámenes al año también. Y también para al día de las madres los miman a ellos y a las mamás. Eso nos ha servido mucho porque nos juntamos con otros papás que también tienen hijos con necesidades especiales.* [The support group of "Sueños y Esperanza" [dreams and hope], along with the Karaoke group, that has served her therapeutically, being socialized... Karaoke has led her to do exercises with her mouth and her coordination with the folkloric [dance]. There they have a folkloric dance group, a baseball game and also two contests a year. Also, for Mother's Day, the moms and kids are pampered. This has helped us a lot because we get-together with other parents who also have children with special needs.]

Barriers to Services and Support

These participants shared that they had not been provided or informed about possible services in the community early on. They also had concerns with lack of childcare. As previously mentioned, the majority of these parents faced difficulties with enmeshment and alienation from their partners; therefore, this made it increasingly difficult to leave their child behind and opted to not go. Others had difficulties with illiteracy and transportation, while others simply did not know of services available to them, and many assumed that there would be associated costs and fees, which they could not pay due to limited means.

Few participants shared that they had participated in therapy, as in Renata's case mentioned previously, with her child's school psychologist who did collateral work with her. However, this was only related to the child's academic achievement and behavioral issues, which does not always provide the school psychologist the ability to provide social justice advocacy and/or personal therapy.

Ana found a therapeutic group but, not being connected or informed about Respite through the Regional Center as well as being isolated and emotionally enmeshed with her daughter, found it challenging to attend any gatherings since the group did not provide childcare. Ana reported;

> *También me invitaron a un grupo en el hospital Memorial, pero no me sentí a gusto allí, por que no tenían guardería para la niña, y pues se me complico mucho y tuve que dejar de ir, no la puedo dejar, estamos demasiado apegadas, tanto ella conmigo, como yo hacia ella.* [They also invited me to attend a support group at Memorial hospital, but I did not feel comfortable there, because they did not have childcare for my daughter, and it was very complicated for me and I had to stop going, I cannot leave her, we are too attached, both of us, her toward me and I toward her.]

Finally, parents recommended practicing mindfulness, patience, and grace. Margarita stated;

> *Pues solo tener mucha calma, gracia y paciencia, mucha fuerza para seguir adelante. Pensar en ellos. Es lo único, pura fuerza y pues pensar que uno tiene que ayudarlo a el.* [Well, just being calm, being gracious and with patience, a lot of strength to keep going. Think about him. That is the only thing, pure strength and therefore thinking that I have to help them.]

Participants provided some personal insight and gave advice to professionals in the field of special education and community-based organizations. They suggested to help children to gain as much independence as possible.

CHAPTER V: CONCLUSIONS

Results from the present study on the lived experiences of Mexican-immigrant parents of children with an identified disability bore relevant findings that have implications for clinical and special educational practices as well as for community-based agencies and for future research. This chapter will identify how participant results in this research align with existing literature on the topic and synthesize the information into brief sections.

Immigrant parent's conceptualization of their child's disability were identified primarily with a feeling of loss toward the ideal nonhandicapped child they never had. Participants shared the feeling of being unprepared and being grief stricken, and of helplessness. Similarly, a host of other experiences such as guilt, denial, powerlessness, anger, negotiation, and sadness endured. Some participants showed signs of affective and interpersonal impairment such as depression, anxiety, and isolation only aggravating their circumstance.

Elements identified with regards to mental health and stress related health problems were those whose initial distress persisted and had difficult partner relationships. The persistence in distress may have possibly led to physical health issues, such as muscle spasms, pain not otherwise associated with a known diagnosis, facial paralysis, total body paralysis, and diabetes.

As for those who did receive adaptive functioning skills or any form of support, their conditions improved and resulted in less isolation and more advocacy and participation in the education of their children. Consistent with the literature, social isolation is a significant factor to stress and mental health problems for the immigrant parents with children with an identified disability (Banks, 2006; Singh & Lin, 2013; Ijalba, 2016; Khanlou et al., 2017). Participant responses underscored how undersupplied support is and how it contributed to their isolation.

In terms of health care accessibility, these experiences posed an added strain on the demands required for an already difficult adaptation of having to care for a special needs child in accessing high-quality medical care. This is due to lack of awareness and knowledge, eligibility criteria for health care programs and insurance, immigration status of the parent or child, English language fluency, an unfamiliarity with the health care systems, biased cultural assumptions, and stigmatization impeding access to health care and other supportive programs (Lequerica, 1993; Langdon, 2009; Magaña et al., 2016; Povenmire-Kirk et al.. 2010).

As the literature suggests parenting aggravation to be attributed to factors such as family structure instability and relationship quality, lack of social support, faith and religiosity, lack of knowledge and poor understanding of the special education system, difficulty accessing services for their children, lack of fluency with the English language, financial stress, occupational unemployment, transportation difficulties, dispersed services, presence of mental health problems, limited knowledge of social services, excessive paperwork, long waiting times, isolation, biased cultural assumptions, stigmatization, emotional strain, lacking care coordination, which can all hinder parental involvement in the child's education and/or the impede timely placement for the child (Moes and Frea, 2000; Zakirova-Engstrand & Granlund, 2009; McHatton et al., 2010; Povenmire-Kirk et al., 2010; Jung, 2011; Hibel & Jasper, 2012; Lindsay et al., 2012; Singh & Lin, 2013; Fellin et al., 2015; King et al., 2015; Kan et al., 2016; Rivera et al., 2016; Björquist et al., 2017; Kim & Kim, 2017; Roberts & Guerra, 2017; Su et al., 2018).

Similarly, in terms of acculturation, both the literature and these stories demonstrate that immigrant parents of children with disabilities face especially high levels of disruption with their adjustment process in the new culture. Furthermore, being afraid, lost, and confused, as well as struggling with financial strain, all factor in the additive stress of adaption to a new country while rearing a child with special needs. For the participants in this research, the mothers gave up their employment to become the full-time caregivers of their special needs child, straining them further financially with one income. Finally, supported by the literature, the relationship between acculturation and level of parenting stress also depends on degree to which individuals are isolated and how much family support they receive (Lequerica, 1993; Singh & Lin, 2013; Ijalba, 2016; Khanlou et al., 2017; Luu & Neece, 2019). The families in this group reported feeling less isolated and more supported by their participation in support groups in their community, which motivated them to get out of their fear and connect with others like them to become more acculturated and even assimilated.

Participants emphasized their shared cultural values with regard to familial roles, attachment patterns, and other family interpersonal phenomena. Generally, the women held the role of full-time care giver and contact with medical and educational issues. The only exception was the experience of the death of the mother, where the father assumed the role, but even then, he involved his grown daughters and not sons in the caretaking role of the special needs' child. Moreover, parental alienation also appeared to be a factor in many of the individuals involved. The participants discussed instances in which they felt alone in their parental responsibility with the rearing of the special needs child, and/or also emotionally estranged due factors such as cultural values based on patriarchy, where the man is not seen as emotionally attentive, as well as the practical time required to care for a child with a significant physical, cognitive, or behavioral disability.

Lastly, perhaps similarly, due to all the aforementioned factors associated with culture, the older able-bodied children in these families became parentified and were entrusted to help in one way or another with caretaking of child with a disability in the family as well as with the rest of the able-bodied children's needs. The last of the familial interpersonal interactions discovered through the interviews was enmeshment. A few of the parents discussed the patterns of more intense attachment or familial bond with their special need's child than their typical children as well as their spouses. These are areas that require further research to understand the underpinnings as well grasp as the impact on the entire family unit as well as each of the members.

The coping mechanisms participants employed to diminish their stress and ameliorate their difficulties included personal agency efforts such as perspective taking, being optimistic, and using acceptance to cope. But more significant is the themes of religion and or spiritual sources being perceived as both causative and curative. Participants mitigated and integrated their experiences and difficulties through religious and spiritual practices. The homogeneous group, in terms of culture and religious beliefs, conceptualized the reasons for their child's disability as the "will of God" and accepted their fate as a means of purpose and sacrifice. Coping mechanisms utilized among participants were spiritual practices and religious beliefs. Participants employed these practices to manage their traumatic distress, loss, stress, and physical maladies.

Community-based agencies such as the Regional Centers provided service-related interventions such as respite that were supportive to the participants in caretaking for their special needs child as well as providing them with specialized adaptive training. Other agencies offered evaluations and gave assistance with effective use of adaptive equipment, or they offered classes on American Sign Language as well as providing braille interpreters. Other services included support groups and activity-based groups that empowered them with information about their rights with regards to educational matters as well as providing them with knowledge about their child's disability and offering them other general information. These groups served the purpose of offering information and providing emotional encouragement to reduce stress and prevent aggravation.

Participants discussed barriers to services and support. For example, many had not known or been told about services available in the community early on or expressed that some services did not offer childcare. As previously discussed, most of these parents faced challenges with enmeshment, and having a greater difficulty in leaving their child behind, they opted for not going. Others had difficulties with illiteracy and transportation, while others felt alienated and unsupported by their partners, so they found it especially difficult leaving the home. Others discussed barriers with qualification criteria for government-based services such as Medi-Cal, while others reported encountering difficulties with obtaining financial benefits through Social Security due to their illegal status.

Clinical Implications

I recommend that mental health practitioners, educators, and service providers challenge themselves to learn about the experiences of Mexican-immigrant parents of children with an identified disability.

Practitioners working with young children and parents play a critical role in helping family members reframe their caregiving experience in positive ways as well as assisting family members in feeling like they have the knowledge, skills, and ability to successfully advocate for what their children need. Practitioners, educators, and service providers alike assist parents by providing knowledge and reassurance about how support groups may be helpful as well as providing them contact information of possible community-based organizations who organize such groups. Practitioners, educators, and service providers alike who work with young children and parents hold a responsibility to understand the needs of the family and encouraging advocacy for their children's need as well as their own needs, or they become part of the oppressive system.

This research and the literature underscores that healthy family functioning is a critical aspect to the well-being of all members involved and that practitioners, educators, and service providers need to support the needs of the entire family and not just the needs of the child with a disability. Education is important in this area of study because it may open opportunities to reduce social stigmatization of people with disabilities and encourage a perspective of acceptance.

Further research is needed to fully understand the scope of the problem and how best to intervene. Also, future research with this population would provide a deeper understanding and provide valuable insight to provide culturally informed and competent interventions.

I recommend that longitudinal case studies be conducted because they can also serve as instrumental pieces allowing a greater view and understanding of the lived experiences of Mexican-immigrant parents of children with special needs, opening the door to grassroots movements, social justice organization, and advocacy.

Limitations, Assumptions, and Risk Factors

During the recruitment process, I encountered many difficulties obtaining participants for the study, as many school districts did not consider posting fliers for me, despite the interview being with the adult parents. I posted recruitment fliers multiple times indicating the need for participants for this study. Snowball sampling proved to be instrumental as community-based organizations finally agreed to post the flier in their lobbies as well as encouraged participants to speak to me. Likewise, I found that I needed to explain my journey and the purpose of the research as parents inquired about the process details and doubted whether they themselves qualified. Because this qualitative research is based on self-report, there were no reliability or validity data pertaining to the accuracy of the information obtained.

Lastly, the limited research that exists inadequately explains the suffrage this population experiences in an intimate and evocative manner. Therefore, it is my hope that this body of work evokes emotion, empathy, relatedness, and connection to as well as better understanding of the phenomenon experienced by Mexican-Immigrant parents with children with an identified disability in a meaningful way. These participants emphasizes that insufficient supportive programs augment their difficulties and ultimately it translates into poor parental support and advocacy towards the child.

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APPENDIX A

Demographics

PSEUDONYMS	AGE	CHILD'S AGE	MARITAL STATUS	YEAR MIGRATED	OCCUPATION	CHILD'S DISSABILITY
Alberto & Alma	67	24	Widowed	1997	Retired Plumber/ Regional Center Specialist	Cognitive and Developmental delay (Meningitis Infection/Encephalitis)
Bertha	54	16	Widowed	1996	Residential Housekeeper	Deaf/Hearing Impairment
Victoria	31	15	Separated	2000	Hospitality Housekeeper	Cognitive and Developmental delay (Congenital Heart disease)
Felicia	52	15	Divorced	2004	Retired Agricultural worker	Blind/Visual Impairment
Margarita	43	16	Married	1998	Homemaker	Down Syndrome
Marina	36	10	Married	2002	Homemaker	Cognitive and Developmental delay (Autism)
Renata	46	13	Married	2004	Homemaker	Emotional Disturbance/ Cognitive and Developmental Delay (Child Abuse/Neglect)
Vicente and Ana	38	13	Married	2003	Uber driver/ Homemaker	Cognitive and Developmental delay (Hydrocephalus and Hypoxia)

APPENDIX B

Questionnaire

1. Please describe your experiences prior to having a child with disabilities.
2. Please describe your response and/or reaction to learning about your child’s diagnosis or condition.
3. Can you describe the stressors you have experienced, both currently and in the past?
4. In what ways do these stressors impact your ability to parent your child?
5. In what ways do these stressors impact you on an emotional, physical or psychological level?
6. In what ways do these stressors impact your family’s emotional, physical or psychological well-being?
7. How might these stressors influence your relationships, personally and in your community?
8. Can you describe other things that have impacted your parenting?
9. What are the ways you manage stress?
10. In what ways does your personal agency or your community help mitigate your stress levels?
11. What are some community resources/interventions/special education/tactics that have been helpful in reducing your stress/supporting your child’s needs?
12. What are some ways these community agencies can improve or be more effective in helping children with identified special needs and thus reducing your parental stress, and how might these services/interventions be accomplished?