# THE LIVED EXPERIENCES OF IMMIGRANT FAMILIES WHO HAVE A CHILD WITH A DISABILITY: A HERMENEUTIC PHENOMENOLOGY

by

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Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

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#### Abstract

The purpose of this phenomenological study was to understand the lived experiences for immigrant families in the United States who have a child with disabilities. The central question guiding this qualitative hermeneutic phenomenological study is: What is the lived experience of immigrant families who have a child with disabilities? The theory guiding this study is Bronfenbrenner's bioecological theory as it provides a lens to examine the influence and impact the ecological systems have on immigrant families' perceptions of raising a child with disabilities. This study included ten participants who immigrated to the United States from around the world. Data was collected through individual interviews, creation of timelines, and through collecting questionnaires to create triangulation. Coding was used to analyze the data in an organizational analysis to look for patterns and themes to emerge from the data. Qualitative data analysis resulted in the development of four main themes: the value of connection, parent perspective and experiences, the advocacy process, and challenges and barriers faced by immigrant parents. The significance of this study was found to be the importance of connection and education in developing a collaborative partnership with schools. Future research is recommended to examine the views and perspectives of both immigrant parents and special education teachers in building a collaborative partnership.

Keywords: immigration, special education, barriers, partnerships

## **Copyright Page**

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## Dedication

To my husband, Jaime, and our children, Lilianna, Miles, Donte', Gracyn, Rosa Marie, Sakoya, Lorenzo, and my granddaughter Josephine.

#### Acknowledgments

Reflecting on my educational journey, I feel overwhelmed by the support I have felt from my family, friends, teachers, mentors, and colleagues. Thank you for cheering, encouraging, supporting, and praying for me. I am grateful to my Heavenly Father for this opportunity to pursue my education.

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I am grateful for my in-laws, who immigrated from Mexico. They have taught me what determination looks like and have always shown me unconditional love. My parents are my biggest cheerleader and have an unwavering belief in me. My mom taught me the importance of confidence and hard work; she believes in me.

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pursued my education, thank you. You have all shown me unwavering support, and I love you all so much.

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#### List of Abbreviations

Autism Spectrum Disorder (ASD)

Central Research Question (CQ)

Education for All Handicapped Children Act (EAHCA)

Free and Appropriate Public Education (FAPE)

Individualized Education Program (IEP)

Individuals with Disabilities Education Act (IDEA)

Least Restrictive Environment (LRE)

Sustainment Development Goals (SDG)

United Nations (UN)

World Health Organization (WHO)

#### **CHAPTER ONE: INTRODUCTION**

#### **Overview**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. One of the primary goals of educational research is the concern for social justice and bringing public awareness to the struggles and hardships of individuals in the educational setting (Freebody, 2003). The problem is that many immigrant families face barriers in establishing a relationship with school leaders and teachers (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020). Chapter One concentrates on this study's historical, social, and theoretical background. It also addresses the purpose and problem statements and my motivation for conducting this research.

#### Background

Parents and teachers have struggled to collaborate to address the needs of children with special needs (Camard et al., 2022; Francis et al., 2017; Guerrero & Sobotka, 2022; Rivard et al., 2020; S'lungile et al., 2015). While collaborative relationships between families and schools help families feel more empowered to advocate for their children and participate in decision-making (Collier et al., 2017), families often feel communication is lacking and are dissatisfied with their involvement in their child's education (Kurth et al., 2020). The following sections examine historical, social, and theoretical background information pertinent to this study.

#### **Historical Context**

Prior to the mid-twentieth century, individuals with disabilities were often denied the right to public education and were kept in their homes or sent away to institutions. World War II challenged stigma surrounding individuals with disabilities by shining a light on the physical and

psychological disabilities as soldiers returned home from war (Elkind, 1998). In 1959, the Declaration of the Rights of the Child was adopted by the United Nations (UN) General Assembly; the declaration stated that a child has a right to education. The constituent countries adopted the Sustainment Development Goals (SDG) in 2015, creating UN goal number four, "Ensure inclusively and quality education for all and promote lifelong learning," (p. 891) which stated that all individuals should be ensured that they will receive an inclusive and quality education (Moschen et al., 2019). It is estimated that more than a billion individuals globally live with a disability, and 80% of those live outside the United States (World Health Organization, 2011), where very few receive educational services or any form of rehabilitation (Eleweke & Rodda, 2010), which would result in immigrant families who have family members with disabilities who have not received educational services or rehabilitation interventions for their disability. Recently, the United Nations International Children's Emergency Fund (UNICEF) published a report that analyzed the well-being of children with disabilities and found that 49% of children with disabilities had never attended school, 47% more likely to be out of primary school, 33% more likely to be out of lower-secondary school, and 27% more likely to be out of upper-secondary school compared to children without disabilities (United Nations Children's Fund, 2021). Consequently, students with disabilities may enter the school system without Early Intervention (EI) or schooling.

As late as the 1970s, students with disabilities were often discriminated against by the public-school systems and not admitted into schools in the United States (Chinn, 2004). If they were, they were segregated into schools for individuals with disabilities, institutionalized, or at the very best, placed in a self-contained classroom with little to no interaction with the other students. Schools and teachers often had the power to decide on admitting or not admitting a

student based on the severity of the individual's disability. One way schools could discriminate against children with disabilities was through an IQ assessment. Over a hundred years ago, the Stanford-Binet Intelligence Scale (SBIS) was developed in the United States and produced an intelligence quotient (IQ). The score determined whether a person was below average, average, or superior in general cognitive ability (Zaboski et al., 2018), with a way of quickly identifying which students would excel academically and which ones would struggle (Houts, 1976). The test had many flaws and could not fully measure an individual's intelligence, and interestingly, the developer of the SBIS recognized the weakness in the test as it would not be able to account for emotional intelligence and creativity in the testers (Houts, 1976). The popularity of the IQ test spread, and soon the military was using it to place soldiers in jobs based on the results from the test, and the educational system also began to use it as a way of sorting gifted students and students who would require special educational services (Houts, 1976). IQ tests became too powerful of a tool, and in the 1930s, a policy in the United States allowed for involuntary sterilization of women who were deemed to have a mild intellectual disability from the results of an IQ test, fearing they would not be able to care for their children (Reilly, 1987). While IQ tests have had a troubled history, they have evolved and are used as a key assessment method in education today, but are still accompanied by controversy.

Present intelligence tests have been developed to be interchangeable using a variety of approaches to measure general cognitive abilities. IQ testing for children gives providers a baseline for future comparisons, is used as a tool for school placement, and can even be used to develop a treatment plan if needed (Grondhuis et al., 2018). Utilizing the Kaufman Battery Assessment for Children that included 109 refugee children aged 3–7 years testing learning performance and language, the results showed that refugee children were more than one standard

deviation lower than the mean of the German norm population (Hahnefeld et al., 2021). If the diagnostic criteria for intellectual disability had been applied to this group of children, 24% would have qualified with a disability. However, Hahnefeld et al. (2021) excluded participants with significant impairments, neurological conditions, or apparent developmental delays. Hahnefeld et al. (2021) hypothesize that high trauma and stressed family environments correlated with the children's test results; the results from this study highlight the need to see the whole child and not rely solely on assessment methods. Grondhuis et al. (2018) suggest that clinicians and researchers should be aware that IQ tests for children with ASD are not interchangeable, and the language demands of the testing can impact results and clinician interpretation, therefore impacting possible placement and treatment plans in the educational environment. The IQ test, similar to state assessment testing, can be used as a tool to create a baseline and for comparison growth, but becomes problematic when all individual decisions are based on an IQ test's results.

#### **Social Context**

Education is a human right, and when a global goal is created to educate all children, all means all. Most children in developing countries with disabilities are not being provided an education (Hayes & Bulat, 2017), which turns into adults in developing countries who have not received an education. The lack of education puts these individuals at an even more significant disadvantage and limits their future potential for employment and independence. The United States Congress passed a law in 1982 stating that undocumented children and young adults in primary and secondary schools have the same right to public education as all citizens in the United States. The foreign-born population in the United States has reached nearly 48 million (Camoarota & Zeigler, 2022), with 26.3% of children living with one foreign-born parent (U.S.

Census Bureau, 2019). Cultural understanding of disabilities has impacted the ability of families to pursue educational and rehabilitation services that can be beneficial to individuals with disabilities (Mokaleng & Möwes, 2020; Sharma et al., 2018; Srivastava et al., 2013). The lack of systems and professional development for schools and teachers have also limited inclusive academic growth in many communities. Engagement between families and schools plays a critical role in young children with disabilities succeeding in the school environment (Xu, 2018). Family engagement is a framework suggested by Kelty and Wakabayashi (2020) that was developed on the concept of developing effective relationships and partnerships between schools instead of a mindset of fixing parents and families. Inclusive programming is the partnership process between schools, families, and communities as they become a collaborative team using various resources to meet the needs of children and families with disabilities. Building connections and valuing parents' voices is vital to creating an inclusive program that engages families. A qualitative study found that parents need to be contacted in non-threatening ways, creating events for which all would be included, and regular communication between school and home (Kelty & Wakabayashi, 2020). Cultural and belief differences, barriers to technical knowledge, and teacher/parent perceptions and expectations are some barriers faced in teacherparent communication (Gisewhite et al., 2019).

In addition, a lack of collaboration can be detrimental to a child's development as the child may not reach their full potential. When a child does not meet their full potential due to a lack of health, educational, and developmental services, the child, family, and society pay significantly for it (Clark et al., 2020). The experiences of immigrant families with a child with special needs deserve more attention as it concerns and influences schools, communities, and educational environments. The makeup of the U.S. K-12 public school student population has

changed dramatically over the last 50 years. Students today are more diverse across many categories, including linguistics, culture, geography, and socioeconomics. More than 49 million students were enrolled in public elementary and secondary schools in the United States in the fall of 2020; of those students, 22.6 million were White, 13.8 million were Hispanic, 7.4 million were Black, 2.7 million were Asian, 2.2 million had two or more races, 0.5 million were American Indian/Alaska Native, and 180,000 were Pacific Islander (National Center for Education Statistics, 2022). Immigrant students make up 26% of students enrolled in primary and secondary public schools (U.S. Census Bureau, 2019). Diversity among immigrants to the United States has evolved over recent years as there has been a decline in Mexican migration and an increase in families migrating from Africa and Asia (Van Hook & Glick, 2020). Trends and perceptions of immigrant families can be felt in classrooms nationwide, as immigration has always been a controversial topic for Americans. However, the candidacy and presidency of Donald Trump brought the topic to the forefront as a significant point in his campaigning. During the campaign and throughout his time in office, President Trump often portrayed immigrants as a significant source of depleting the economy and a disgrace to American values (Eshbaugh-Soha & Barnes, 2021) and as potentially dangerous criminals (Kulig et al., 2020). Data collected in surveys have shown that most Americans do not believe immigrants are more criminal-minded than native-born citizens (Kulig et al., 2020).

#### **Theoretical Context**

Researchers have examined immigrants and special education through a variety of lenses. Researchers have used ecological theories to examine how factors related to immigrant families who have a child with disabilities affect the child's mental well-being, their family's mental health, and their school relationships with teachers and peers, and how they connect and impact a child's development and well-being (Diab et al., 2018). Other researchers use the advocacy theoretical model to examine immigrant families' experiences within the social structure of their status as an immigrant and experiences trying to receive services for their child's disability (Balcazar et al., 2011; Camard et al., 2022). Due to limited access to healthcare, health screenings, or EI, parents may have limited knowledge regarding their child's disability. With an overrepresentation of low-income students of color in special education, DeMatthews and colleagues (2020) used the disability critical race theory to examine principal perceptions of students of color and special education qualifications and services. However, other qualitative studies looked at the social support of immigrant mothers of children with disabilities (Khanlou et al., 2014) and the barriers faced by parents of children with disabilities through a grounded theoretical approach (Fellin et al., 2013). At this point, few studies have given a voice to the experiences of immigrant parents who have a child with disabilities. Prior research does not adequately represent or provide a voice to the experiences of immigrant parents in the United States who have a child with disabilities. Examining the experiences of immigrant parents who have a child with a disability through the lens of a bioecological theory can shed light on how the microsystem at the proximal ecological level, to include the home environment and a school setting, directly impacts a child and therefore, the family.

#### **Problem Statement**

The problem was that many immigrant families in the United States face barriers in establishing a relationship with school leaders and teachers (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020). American values tend to permeate the educational system, yet the focus on individualism and independence may not align with other cultures that embrace collectivism (Adams & Santos, 2021b; Sharma et al., 2018). Family perceptions of their roles and the role of teachers may be very distinct from those of the immigrant family (Haines et al., 2018). Rivard and colleagues (2020) found that many immigrant families wanted to participate actively in their child's education, but language barriers in addition to cultural differences impacted perceptions and collaboration of services. Failure to recognize how culture influences one's perspective can lead to misunderstandings and failure to move forward in making educational progress for children with disabilities. Parent and school relationships have been studied extensively (Adams & Santos, 2021a; Haines et al., 2018; Rivard et al., 2020), yet there is a lack of research and literature concerning immigrant families who have a child with disabilities (Kubota et al., 2021; Raymond et al., 2022), and this lack of research has neglected the stress, trauma, and mental health of these families (Kubota et al., 2021; Sangalang et al., 2018). When school leadership and teachers emphasize building relationships with parents, they can better overcome obstacles, work collaboratively, and empower parents as active voices and members of their child's educational journey (Flores & Kyere, 2020). This study aimed to explore the experiences and perceptions of immigrant families of children with disabilities as they navigate a new country, culture, and language and the challenges and barriers they face in developing family-professional relationships with their children's teachers.

#### **Purpose Statement**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families in the United States with children with special needs in the public school system. Understanding the lived experience of immigrant families who have a child with disabilities in the public school system was defined as immigrant families who have a child with disabilities that qualify them for special education services. The terms *undocumented*, *non-citizen*, *migrant*, and *refugee* have different meanings to people (Douglas et al., 2019). The

term *immigrant* was used to embody all terms, as it is essential to remember that regardless of the term, every single person has the same universal human rights and fundamental freedoms (Nations, 2017).

The theory that guides this study was the bioecological theory (Feriver et al., 2020; Tudge et al., 2021) which can aid in understanding the impact teachers and schools can have on families of children with special needs who are receiving services for the first time in a U.S. school setting. The home environment and a school setting would be considered a microsystem at the proximal ecological level, as it directly involves the child. Establishing a relationship between families and schools can benefit a child's growth and development by creating a safe and predictable environment (Diab et al., 2018).

#### Significance of the Study

This study contributes to the body of knowledge describing how immigrant families with a child with disabilities develop relationships with school administrators and educators. Bioecological systems theory explains how child development is impacted by their environments, beginning with those nearest the child in the microsystems and expanding to the macrosystems to include laws, policies, and social stereotypes (Kelty & Wakabayashi, 2020). Families, educators, and administrators will benefit from the findings of this study because its findings may bring clarity to miscommunication and highlight ways for families and schools to develop trust and meaningful relationships. The results from this study can benefit families in gaining confidence in their knowledge of their child's disability and empower them to advocate and collaborate as an active part of their child's educational team. This research can also benefit pre-service teacher programs at the university level and professional development in districts and schools. This section highlights this study's theoretical, empirical, and practical context.

#### Theoretical

Theoretically, this study examines the influence of social environments on human experiences. The theoretical significance of this study contributes to Bronfenbrenner's (2005) bioecological theory which focuses on the fact that children do not develop in isolation, but are significantly impacted by their environment, which includes family, school, community, and society (Kreitzer, 2022). While theories examine the influence of social environments on human experience, there is a lack of studies that examine immigrant families' perceptions of raising a child with disabilities in the United States and the impact the ecological systems have on their experiences. Schools must recognize the significance of collaborating and working with parents because of their impact on a child's development (Malchar et al., 2019). The Sunshine Model (Turnbull & Turnbull, 2017) is used by Haines et al. (2017) to view the benefit of a synergized relationship between families and professionals that directly benefits students and indirectly benefits families and professionals and the importance of implementing policy in special education and the need to increase the expectation of partnerships between families and professionals. This framework is assembled on the collective empowerment of parents, family members, and the professionals involved in the care and education of the child. It emphasizes a focus on building upon the expertise of each member (Haines et al., 2017). Additionally, when families and schools work together, it is in the best interest of the child (Francis et al., 2017; Guerrero & Sobotka, 2021; Haines et al., 2018; Rivard et al., 2020). Understanding the impact on the microsystem layer that families and schools have on a child's development can contribute to developing a family-professional partnership.

#### Empirical

The current research has empirical significance in that the perceptions of immigrant families with a child with a disability are not widely known. What is known is that immigrant families face many barriers (VanHook & Glick, 2020), barriers that are magnified when the family includes a child with a disability (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020; Xu et al., 2022). The empirical literature suggests that parents often do not feel like they have a voice in their child's education and are not participating members in the planning and decision-making process (Kelty & Wakabayashi, 2020). Adair and Barraza (2014) conducted a multisite ethnographic qualitative study of more than 100 immigrant parents, and it revealed that parents worried about teachers being patient and kind to their children, especially when their child had communication deficits, which left them relying on the communication from the school regarding how their child was doing in school. Communication challenges between parents and schools are prominent throughout the literature and are a significant barrier to developing meaningful partnerships between families and teachers (Guerrero & Sobotka, 2022; Haines et al., 2021; Rivard et al., 2020).

Other potential barriers to developing a meaningful partnership are the cultural challenges, stigmas, and views around disabilities that many immigrant families face. A study completed by Rivard et al. (2019) using semi-structured questions, interviewed first-generation families about their experience obtaining an ASD diagnosis for their child. The study included 24 first-generation families, and 11 had both parents as participants; therefore, there were 34 participants in the data collection. During the participants' interviews, 76.5% reported insufficient knowledge or understanding of ASD in their native countries. Social exclusion and stigma were also prominent themes, with 32.4% facing rejection due to diagnosis in their country of origin. Cohen and Miguel (2018) found similar themes in their qualitative study, where

parents relayed adverse reactions from family and community members due to their child's behavior related to their disability. This study builds on the empirical literature by giving insight into the perceptions and experiences of immigrant families with a child with a disability to promote partnership between families and schools.

#### Practical

The practical significance of this study was for the findings to contribute in developing stronger relationships and partnerships between families and schools. Educator training can be designed to train pre-service teachers on effective collaboration and communication between families and schools for the best educational outcomes for students with disabilities (Rossetti et al., 2018). Cultural competence is essential for pre-service teachers as they prepare to teach and interact with students and families from various cultures, lifestyles, and beliefs that may differ significantly from their own life experiences (Toms et al., 2019). Principals significantly impact student learning, and legislation requires principals to advocate for all students, yet they are not required to retain a special education license through the education department (Roberts & Guerra, 2017). School administration must be diligent in their professional development in ensuring they are aware of the support and needs of their immigrant families, especially those with disabilities who require special education.

Findings can inform teacher practices, attitudes, and beliefs about immigrant families with children with disabilities. Culturally and linguistically diverse students are at greater risk of being under and over-identified as having disabilities (Cruz et al., 2019). Consequently, special education teachers must be prepared to support and advocate for these children. Cruz et al. (2019) conducted a study measuring culturally responsive teaching self-efficacy (CRTSE) in special education teachers compared to general education teachers and found that CRTSE did not differ based on teacher credentials. Strong self-efficacy in personal relationships and building trust with students and parents can be a foundation for developing culturally responsive techniques and incorporating specific cultural elements into the curriculum. The participants described experiences from this study can help shape training and development within schools and colleges to better meet the needs of students with disabilities (SWD) from immigrant families. Most importantly, the significance of this study was to give a voice to immigrant families concerning their children with disabilities, to highlight their voices and stories and aid in establishing and deepening relationships between families and schools that ultimately benefit a child's growth and development.

#### **Research Questions**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families in the United States with children with special needs in the public school system. A research question clearly depicts the study, so there is no vagueness or confusion regarding the research (Dodgson, 2020). The research questions guided this study to understand the lived experiences of immigrant families with a child with a disability. The central and sub-questions include:

#### **Central Research Question**

What are the lived experiences of immigrant families in the United States who have a child with a disability?

#### **Sub-Question One**

What role do culturally based understandings of disability and special education play in immigrant families' participation in special education?

#### **Sub-Question Two**

How do immigrant families describe their experience and relationship with school leaders and teachers?

#### **Sub-Question Three**

What are immigrant families' experiences collaborating with school personnel with respect to the development and implementations of the child's individualized education program?

#### Definitions

- 1. *Hermeneutic* Focuses on the small parts of life experiences that may seem trivial to create meaning and build understanding (Laverty, 2003).
- Immigration Human migration is the movement of people across an international border or in a state away from their habitual residence, regardless of the reason (Douglas et al., 2019; McAuliffe & Ruhs, 2018).
- Immigrant A person settled in a country other than in the one which they were born (Gimeno-Feliu et al., 2019).
- 4. Disability "A child is evaluated and found to have an intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as 'emotional disturbance'), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and requires special education services" (IDEA, Sec. 300.8, 2018).
- 5. *Special Education* Instruction designed to meet individual students' needs at no cost to parents (IDEA, 2018).

- Inclusive Education Opening access to students with and without disabilities learn alongside each other, and the needs of both students are being met (Armstrong et al., 2021).
- Family-School Collaboration A partnership between families and educators involves shared goals and responsibilities to enhance a child's development and educational outcomes (Malchar et al., 2019).

#### Summary

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families in the United States with children with special needs in the public school system. Chapter One includes an introduction and background to the experiences and perceptions of immigrant families. The problem and significance of this study were established, as there was limited research giving a voice to immigrant families of children with disabilities. This study on immigrant families with children with special needs fills a gap in qualitative literature giving voice to immigrant parents of children with disabilities. The importance of this study includes the theoretical, empirical, and practical implications of how this study might significantly address the weaknesses identified in the literature and may substantially help develop training to address the barriers to establishing a relationship with school leaders and teachers (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020).

#### **CHAPTER TWO: LITERATURE REVIEW**

#### **Overview**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. A systematic review of the literature was conducted to explore the lived experiences of immigrant families who have a child with special needs in the public school system. Chapter Two offers a review of the research on this topic. The research has a theoretical framework based on bioecological theory (Bronfenbrenner, 2005). The recent literature on families receiving diagnoses and their experiences with special education services is reviewed. I then discuss literature surrounding the importance of parent and school relationships to have the best outcomes for children in the special education programs. Finally, a gap in the literature is identified, demonstrating that there needs to be more research regarding the barriers immigrant families face having a child with disabilities developing relationships with schools and navigating the special education programs and services.

#### **Theoretical Framework**

One's life experiences, knowledge, and beliefs make up their philosophical assumptions, even when one is unaware of these thoughts (Ponte, 2014), and one's culture is the foundation on which philosophical assumptions are formed. A theoretical framework is a structure that supports researchers in making predictions and developing connections with the results and how they fit in the domains of the theory (Muthukrishna & Henrich, 2019). Developing the theoretical framework in this qualitative study provides a foundation and structure to build all knowledge for this study (Grant & Osanloo, 2014). The theoretical framework guiding this study is Bronfenbrenner's (2005) bioecological theory. A theory is used as a lens to explain and construct

ideas regarding data and analysis. The theory aids in understanding the impact teachers and schools can have on families of children with special needs who receive services for the first time in a school setting and how the environment can be manipulated to create positive interactive opportunities and minimize barriers within the ecological system.

#### **Bioecological Systems Theory**

According to Neuman (2016), an ecological model maintains that when "structural inequalities are minimized, children are given a fighting chance" (p. 114). The ecological system posits that four areas impact a child's development interaction with a person: proximal process, time, and context (Neuman, 2016). In ecological theory, the potential for positive or negative influence is vital in the early years. Young children spend most of their time with their caregivers and may have limited social time with other adults or peers. It can be a flourishing environment for the child to grow and learn or the complete opposite; regardless of the environment, the child does not have a voice in the care they receive.

The microsystem is the most proximal ecological level, including the settings where individuals directly interact with another person (Ettekal & Mahoney, 2017). A child's microsystem significantly impacts growth and development (Hamilton & Moore, 2003). A home environment and a classroom setting would be considered a microsystem at the proximal ecological level, as it directly involves the child. Establishing a relationship between families and schools can benefit a child's growth and development by creating a safe and predictable environment (Diab et al., 2018). A safe and predictable environment that engages young learners can be accomplished by manipulating the environment to support interactions between adults and children (Neuman, 2016) and allow trust and comfort to be built between families and schools. Additionally, Bronfenbrenner's (2005) Bioecological theory focuses on the fact that children do not develop in isolation, but are significantly impacted by their environment, which includes family, school, community, and society (Kreitzer, 2022). As a child grows, their microsystem expands outside of their family and may contain teacher-student and peer relationships (Titzmann & Lee, 2018). In other words, migrating to a new country shapes future generations (Van Hook & Glick, 2020) as a new country, culture, language, and relationships impact and expand immigrant families' microsystems.

The second aspect of bioecological theory is understanding how the macro levels of race and class influence the micro levels (Tudge et al., 2021). Bronfenbrenner (1991) recognized the influence of outside sources, such as disorganization, stress, and poverty, on children's development. These outside sources place stress on families and can impact how they interact, support, and engage with one another, supporting how the environmental systems directly impact a child's development (Tudge et al., 2021). Parents may have limited education and knowledge concerning developmental disabilities and special education services available to them and their children (Adams & Santos, 2021a; Guerrero & Sobotka, 2022). However, research suggests families of children with disabilities benefit from relationships with the teachers and school their child is attending (Camard et al., 2022; Francis et al., 2017; Guerrero & Sobotka, 2021a; Haines et al., 2018; Rivard et al., 2020). The relationship between caregivers and educators has the potential to educate and empower both sides to serve children with disabilities better.

The third aspect of bioecological theory is the evolution it went through as Bronfenbrenner continued to learn and evolve as one of the world's leading scholars in ecology and developmental psychology (Ceci, 2006). Bronfenbrenner (2005) focused on the influence of the environment on the functioning of proximal processes (Rosa & Tudge, 2013). The environment has a direct impact on the development of a child (Rosa & Tudge, 2013), and manipulating the environment to create learning connecting activities for a child can be used to the advantage of parents and teachers (Neuman, 2016). Bronfenbrenner (2005) viewed child development as a complex system of relationships impacted by different levels of proximity. Families and schools have a direct impact on children's social environment. A child is affected first within their microsystem, but the effects on the child expand throughout their whole bioecological system.

Bronfenbrenner's (2005) bioecological theory will shape this study examining the phenomenon of the experiences of immigrant families with their child's special education experiences within the public school system. Bronfenbrenner's (2005) bioecological theory will guide understanding the function that family social ecology plays in the experiences of families with a child with disabilities receiving special educational services. Applying the bioecological systems theory to this study will help bring a better understanding to the collected data from the participants of the interconnectedness of immigrant families as they do not exist in isolation, but are a part of a more extensive social structure that is culturally influenced by other social domains and institutions (Paat, 2013).

#### **Related Literature**

This study examined the barriers and challenges that immigrant families who have a child with a disability face in the public school system in the United States (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020). This review aimed to identify the barriers between immigrant families and the public school and the requisite partnership skills needed for solving the problem to lay the groundwork for future in-depth research. The scholarly journals referenced in the study examine immigration, special education, barriers immigrant families face, and building and strengthening parent-school partnerships. The literature also exposed gaps within the literature regarding the experiences of immigrant families who have a child with a disability in the United States public school system. The first section of this review represents the experiences of immigrants, while the second section examines education and special education in the United States. The third and fourth sections focus on the needs of immigrant families and the barriers they face while navigating the special education services within the school system. Lastly, the final section focuses on building relationships between parents and schools.

#### Immigration

Human migration is the movement of people across an international border or in a state away from their habitual residence, regardless of the reason (Douglas et al., 2019; McAuliffe & Ruhs, 2018). Human migration is not a new phenomenon, but is now at an all-time high, with more than 258 million people moving across borders (Douglas et al., 2019). Most immigrants migrating to new countries search for better economic opportunities, safety from violence, and more opportunities for themselves and their families (Cigrand et al., 2021; Douglas et al., 2019; McAuliffe & Ruhs, 2018; Sangalang et al., 2018).

Research is limited on the stress, trauma, and mental health of individuals' experiences with migration (Sangalang et al., 2018). Using Bronfenbrenner's (2005) bioecological theory model, Cigrand et al. (2021) found that participants relied heavily upon their microsystems as they navigated and assimilated in the mesosystem and advocated for change within the macro system. In other words, even in a global world where most, if not all, countries have experienced migration, the individual and unique stores of immigrants are sparse (Cigrand et al., 2021; Raymond et al., 2022). The outcomes of policies and laws that serve and protect immigrant families directly impacts the development of human capital (Albornoz et al., 2017). The foreignborn population in the United States has reached nearly 48 million (Camoarota & Zeigler, 2022),

and immigrant children in homes with at least one parent being foreign-born has risen to 26% (U.S. Census Bureau, 2019), meaning that approximately one in four children live with at least one immigrant parent. Moreover, their voices must be heard and included in policies and laws to serve better and protect them and their families.

#### Immigrants with families

Pursuing a better life for immigrant families can be daunting and overwhelming as they face many challenges assimilating to a new country, culture, and language. Children who migrate early in their youth have an easier time with acculturation than children who migrate during adolescence (Titzmann & Lee, 2018). Immigrant children's ecological systems put them at risk due to the trauma and stress of migration on families (Arakelyan & Ager, 2020; Hayes, 2021). Immigrant families face a substantial process when they migrate to the United States. It has been measured as one of the most stressful events a family can face (Falicov, 1998) as they leave their home, community, and extended families behind. Immigrant children face challenges as they begin school in their new country and often face academic, social, and psychological challenges (Birman et al., 2007).

Immigrants who come to the United States illegally also have to worry about their legal status and the possibility of deportation. The Department of Homeland Security estimates there are over 11 million undocumented immigrants in the United States (Baker, 2021). Yet, a study conducted by Fazel-Zarandi et al. (2018) found the number of undocumented immigrants to be closer to 22 million. Bucheli et al. (2021) conducted an analysis using the following questions as a guide to examine the impact on Hispanic youth school enrollment affected by immigration arrests at various ages, how U.S.-born and foreign-born status affect Hispanic youths' school enrollment, and how Hispanic youth in mixed-status families school enrollment is affected by

immigration arrests. The quantitative study demonstrated the educational disparities for Hispanic youth in immigrant families and revealed how strategies and policies could affect the educational and human capital development of U.S.-born Hispanic and foreign-born youth (Bucheli et al., 2021). The stress and challenges of documented and undocumented immigration can adversely affect a family's ability and willingness to pursue an education for their children, resulting in generations of children who have not received an academic education that can help individuals break the cycle of poverty.

#### **Immigrant Children with Disabilities**

Resettlement in a new country can be very challenging as families navigate the loss of their country, culture, and language and the challenges with assimilating into a new culture. Having a child with a disability exacerbates an already challenging situation (Raymond et al., 2022). There is a lack of research and literature concerning immigrant families who have a child with disabilities (Kubota et al., 2021; Raymond et al., 2022), and this lack of research has neglected the stress, trauma, and mental health of these families (Kubota et al., 2021; Sangalang et al., 2018). Immigration status and having a child with a disability create barriers for families seeking a quality education for their child (Bešić et al., 2018). The perspective and attitudes toward disabilities are neutral to negative, with more leniency for children with physical disabilities and more negative attitudes toward children with behavioral disabilities (Bešić et al., 2018; Chudzick et al., 2021). Consequently, immigrant families with a child with a disability face the barriers that come from learning a new country, culture, and language, and they also face the barriers of navigating an educational system for their child with exceptional needs.

Different beliefs can also play a role in creating an inclusive educational system. Parent understanding, perspective, and views regarding child development vary across cultures. A quantitative study conducted in China, which included 193 valid questionnaires regarding the importance of inclusive education, found that parents who had a child with disabilities had higher ratings (M = 4.25, SD = .82) than parents of children without disabilities (M = 4.19, SD = .66) on the measurement of 'General beliefs' (Hu et al., 2017). In Zimbabwe, where the inclusion of children in mainstream schools is mandated through policies and legislation, Majoko (2017) conducted a qualitative study and analyzed the data using conductive thematic content analysis and found that parents had positive attitudes regarding inclusive education, but serious concerns regarding teacher knowledge and training (Majoko, 2017). The lack of teacher knowledge and training has also been a problem and worry for parents and policymakers (Sharma et al., 2018) as programs are implemented to meet the needs of students with disabilities. While children worldwide face many barriers to receiving an education, especially those with disabilities, it is essential to remember that every child deserves an education; it is not a privilege, but a human right.

#### **Education for All**

Families immigrating from other countries into the United States may have very different ideas of what education looks like for their children with disabilities. It is estimated that only 5% of students with disabilities complete primary school, and 90% of children in low-income countries with disabilities do not receive any form of education or any form of rehabilitation services (Eleweke & Rodda, 2010; Hayes & Bulat, 2017). A major barrier to implementing an inclusive education that is culturally aware is not being aware and including the values of culture and community of the child and instead depending on the importance of the Western world and expecting those values to transfer into different countries and cultures (Sharma et al., 2018). While the Declaration of the Rights of the Child was adopted by the United Nations (UN) General Assembly and declared that every child has a right to education, Page et al. (2022) argue that global goals do not take into consideration the distinct cultural differences of regions around the world. Many obstacles are faced by teachers in developing countries with large class sizes and limited space, and make it very difficult to meet the needs of individual learners, especially ones with disabilities. Westerners and non-profit organizations have worked over many years to support and implement inclusive education in developing countries, but have faced many barriers over the years. One principle is that Western society fails to understand the meaning of inclusiveness and hierarchy within different cultures, making it challenging to promote and implement a program that varies from culture to culture (Armstrong et al., 2021). Sharma et al. (2018) found that one barrier in creating an inclusive educational system is discriminatory attitudes towards educating individuals with disabilities, often due to the lack of information regarding disabilities and education. One qualitative study reported that teachers struggle to differentiate content for students with special needs and lack knowledge and confidence in implementing special education services (Kurniawato, 2021).

The Pacific Disability Model proposes integrating the Pacific Disability Forum (2018) and the United Nations Sustainable Development Goal to meet the needs of students with and without disabilities throughout the Pacific Countries (Page et al., 2022). Failure to recognize how culture influences one's perspective can lead to misunderstandings and failure to move forward in making educational progress for children with disabilities. Policymakers and stakeholders are vital to the success of educational reform; families, educators, and community members are essential to the success of inclusive education. The paucity of monitoring and implementation has made it difficult to implement policies and practices and ensure that they are adequately implemented throughout the schools in the community of developing countries (Sharma et al., 2018). Educating a child with disabilities and including their families in the process can help them overcome challenges by providing resources, opportunities, and knowledge.

# **Special Education in the United States**

According to Watson and Vehmas (2019), the philosophical and cultural foundation upon the negative sentiments towards individuals with disabilities is ingrained in Western culture, yet a shift began to happen during World War II that significantly impacted society's view of disabilities (Elkind, 1998). The screening process discovered a variety of disabilities among young men wanting to join the military that did not allow them to join the military. Still, they attended schools and lived among community members, where most were oblivious to their disabilities (Elkind, 1998). Disabilities were often viewed as a medical problem or a tragedy that the person or family had to deal with; the screening process assisted in shedding light on how one can have a disability and opened up more educational and vocational opportunities (Elkind, 1998). During the postmodern era, individuals with disabilities were often denied the right to public education and were kept in their homes or sent away to institutions. World War II challenged a stigma surrounding individuals with disabilities by shining a light on the physical and psychological disabilities as soldiers returned home from war, and the treatment of people with disabilities by the Nazi German government also helped soften society's attitudes and views. Societal views shifted, with emphasis on a moral obligation for the soldiers and civilians injured during the war (Watson & Vehmas, 2019).

The Civil Rights movement had a significant impact on inclusive education throughout the United States. The Brown vs. Board of Education in 1954 had far-reaching implications regarding segregation in the school setting. The Board of Education's attorney argued that by integrating African Americans into the public schools, children with disabilities would also want to be a part of public schools (Chinn, 2004). The Brown case laid the foundation for creating schools where all individuals could receive an education. The Civil Rights Movement had a significant impact on the rights of individuals with disabilities. As "separate but equal" was deemed unconstitutional, parents, educators, and individuals with disabilities began fighting for the same rights as individuals without disabilities (Gay, 2004). Mothers started support groups for other parents of children with disabilities and later formed national recognition organizations and influenced federal changes, but parents did not stop there; they took their fight for their children's rights to the courts and won cases that guaranteed that children with disabilities had the right to a free and appropriate education regardless of their disabilities (Ferguson et al., 2014). The dedication and advocacy of parents have brought reform on many levels for individuals with disabilities. Parents have dedicated themselves to advocating and fighting for reform to ensure that all children, despite disabilities, are given the same opportunities as all children.

In August 1966, Christmas in Purgatory: A Photographic Essay on Mental Retardation, was released without charge to families and friends of individuals with intellectual disabilities (Blatt, 1974). This book exposed the suffering of people living in understaffed, ill-staffed, and overcrowded institutions that lacked the love, compassion, and learning environment desperately needed for these individuals. The children and adults were found living in deplorable conditions that were overcrowded, understaffed, and erroneously staffed, and were living in conditions that were unsuited for animals, let alone for human beings. While less than 50 years have passed since the photos from these institutions were released, America has made great strides in protecting the most vulnerable. However, many immigrants leave countries where individuals with disabilities do not have the same rights and protections as those without disabilities.

As late as the 1970s, students with disabilities were often discriminated against by the public-school systems and not admitted into schools. If the schools accepted them, they were placed in a self-contained classroom with little to no interaction with the other students (Chinn, 2004). In 1975, the Education for All Handicapped Children Act (EAHCA) passed and mandated that all students with disabilities would be eligible to receive special education services (Yell et al., 2020) and, more specifically, required schools to be responsible for evaluating individuals with disabilities and developing educational plans that would ensure equal access to a quality educational service (Miller et al., 2019). The law continues to evolve through revisions to meet the educational needs of children with disabilities. The 1990 reauthorization of EAHCA changed the law's name to the Individuals with Disabilities Education Act (IDEA), and one of the focuses of the law is a free and appropriate public education (FAPE) for all children. A legal document called an Individualized Education Program (IEP) is a specially designed document detailing the instructional and related services for each child receiving special education services to ensure that they receive a FAPE. An IEP team meets with parents or legal guardians to collaborate and create annual goals for a child with disabilities that affect their learning and success in the school environment (Kurth et al., 2020).

Americans have progressed in their views of individuals with disabilities and the importance of education for all. There is still much work to bring awareness and equity and reduce discrimination against individuals with disabilities and their families. Federal legislation has been shaped and developed over the past 40 years to improve the education of over six million students with disabilities (Frey, 2019) through the hard work, dedication, and passion of parents, educators, policymakers, and community members who have dedicated themselves to advocating and fighting for reform to ensure that all children receive a free and appropriate education. The fight is still ongoing for students with disabilities as it is required by federal law that all students are educated in the least restrictive environments with the assumption that educational needs can be met in the general education setting (Williamson et al., 2019), yet challenges, controversies, and politics play a prominent role in implementing an inclusive educational environment for all children (Kleinhammer-Tramill et al., 2020).

## **Understanding the Needs of Immigrant Parents**

Parent and school relationships are vital to student success (Adams & Santos, 2021a; Haines et al., 2018; Haines et al., 2021; Rivard et al., 2020). A qualitative study by Haines and colleagues (2021) examined the nuances of family professional partnerships with families new to the U.S. school system. The themes that emerged during the analysis of the study were assumptions teachers and families held about each other, communication challenges, and different perceptions of student achievement and progress (Haines et al., 2021). Cultural differences between parents and teachers may look like parents are not interested or like teachers are the experts and indifferent to the needs of parents (Haines et al., 2021; Rivard et al., 2020). Communication challenges are a common theme in the literature and have been named a significant barrier to developing meaningful partnerships between families and teachers (Guerrero & Sobotka, 2022; Haines et al., 2021; Rivard et al., 2020). However, parents may have limited knowledge of typical development and may be unaware of their child's developmental disability (Guerrero & Sobotka, 2022); additionally, different perceptions of student achievement and progress can confuse parents when the teacher focuses on the abilities, not the disability (Adams & Santos, 2021a). Encouraging communication and healthy relationships between parents and teachers is critical to creating an effective education for students (Zabel et al., 2019). Using a lens of cultural acceptance and accepting that some views and beliefs vary from oneself

can open the lines of connection and communication and remove barriers that threaten the partnership between families and schools.

# **Cultural Awareness**

Culture plays a significant role in shaping and developing all facets of behaviors regarding parental beliefs, social expectations, behaviors, and parenting strategies used within families (Esposito & Setoh, 2021). A child with a disability brings new challenges to families and parenting as they navigate delays, possible health challenges, and behaviors they may have never been exposed to within their family. Esposito and Setoh (2021) have found that cultural differences and parents' perception of self-efficacy plays a considerable role in outcomes for a child with disabilities; additionally, it is customary in some cultures to not educate their children with disabilities (Haines et al., 2018; Kurth et al., 2018). Empirical studies, commentary papers, and reviews were gathered by Esposito and Setoh (2021) to analyze the Parental Involvement in Developmental Disabilities among different cultures. Grouping the studies by continent, Esposito and Setoh (2021) examined parents from diverse countries with the desire to bring a global representation of parent involvement for children with developmental disabilities. In the studies examined from Africa, Esposito and Setoh (2021) found that activities related to cognitive development for children with disabilities increased care and decreased neglected by their caretakers. In the Americas, the analysis highlighted the significance of parent-involved interventions that integrated cultural components to support interventions throughout diverse communities (Esposito & Setoh, 2021). Additionally, studies in Asia established the impact and influence culture plays in acceptance, stigma, and support for families of children with disabilities (Esposito & Setoh, 2021). The European studies included in this research by Esposito and Setoh (2021) highlighted the discrimination and stigma felt by families and caregivers of

children with disabilities and the importance of understandable communication to foster social inclusion. Finally, in Oceania, Esposito and Setoh (2021) found a correlation between parenting stress, mental health problems, and the severity of their child's ASD symptoms. Classrooms across the United States have children from various countries worldwide, and teachers often lack knowledge of various cultures. However, this research highlights the importance of learning more about the cultures where families come from better to meet the needs of children inside the classrooms.

Expectations influence how people view those around us and the lens through which they see the world; they impact our behavior and the decisions we make for ourselves and our families (Panitz et al., 2021). Parents' expectations for their children strongly impact a child's outcome; however, expectations can differ across cultures and are adapted to societal norms (Washington-Nortey & Serpell, 2021). Learning by being curious about different cultures is imperative in understanding better the perspective of parents and caregivers with children with disabilities. Ecuadorian mothers of children with and without disabilities found their children with disabilities to be less stressed and felt like they had more control over their children and used more coping strategies compared to those who did not have children with intellectual disabilities (Esposito & Setoh, 2021; Villavicencio & López-Larrosa, 2020). In contrast, mothers in China and Taiwan had increased family-associated stress and poorer health-related quality of life (Esposito & Setoh, 2021; Liang et al., 2021; Wang et al., 2020). When a parent perceives discrimination towards their child with disabilities, it can negatively affect their self-esteem; a sample of parents in Spain was studied to examine the effects of the perceived discrimination, and the results demonstrated the importance of social support for these families (Recio et al., 2020). In New Zealand, a convenience sample of 658 parents of children with ASD completed

an online questionnaire and found that the majority of the parents in the study experienced anxiety at clinical levels of psychiatric distress (Shepherd et al., 2021). The need for social support is imperative in being able to support families and children with disabilities better. Families who have a child with a disability may be navigating the needs of health issues, developmental delays, and behavioral issues that they feel unprepared to meet, yet due to various reasons surrounding being an immigrant in a new country, they may be unaware of the rights and laws in place to assist and protect their child and family.

#### Diagnosis of Disability

Due to lacking health and educational services, immigrant children may not be diagnosed with a disability in their home country. Parents receiving a disability diagnosis for their child may feel various emotions (Duma et al., 2020). They may have many questions they hope clinicians and educators can answer (Novak et al., 2019); as parents gain knowledge on disability awareness on supporting their child best, they increase their capacity to champion their child (O'Connor et al., 2020). Disabilities can be viewed from three different models: the moral mode, the medical model of disability, and the social model of disability. It is suggested that these models shape the way one views understanding disabilities. The moral model of disability is the oldest model of disability and is often regarded as a punishment from God for sins that may have been committed by the person or the parent, or even ancestors' sins committed in the past (Retief & Letšosa, 2018). Consequently, some view individuals with disabilities as blessed and feel like the disability enables individuals to experience life lessons better than those who are not disabled (Retief & Letšosa, 2018). The medical model of disability supposes that neurotypical is what all people desire and view a disability as a negative in a child's life and an impairment that needs fixing (Mackenzie et al., 2016). The focus is on changing the child instead of how pedagogy and

the environment can be altered, changed, or modified to meet the child's needs. Parents who align with the medical model tend to prefer a segregated classroom for their children with special needs (Mackenzie et al., 2016). The social model of disability views disability and impairments as separate and that an impairment is a restriction to one's body through the intellectual, physical, and sensory. The disability is viewed as "something one experiences as the results of society's lack of accommodating behaviours, beliefs and environments..." (Mackenzie et al., 2016, pp.5). Acknowledging the various ways people view a disability, the significance of the impact of beliefs and cultural beliefs are vital in creating personal and systematic change.

There can be a broad spectrum to disability diagnoses, and educators must understand where parents are coming from with a diagnosis to understand better their feelings towards their child's services and educational plan. However, studies are minimal on how different cultures respond to a disability diagnosis (Hamilton et al., 2020). Immigrant families come into the public school system with various backgrounds, and schools and educators must take the time to get to know them, so they can meet them where they are and help build a collaborative relationship instead of barriers. Duma et al. (2021) conducted an exploratory, descriptive qualitative research study to examine parents' views on caring for children with a disability. The study took place with residents of Happy Home in Eastern Cape province, South Africa, in a rural setting with minimal health facilities. It included 37 parents or caregivers of children with a disability. Four themes emerged from the group and individual discussions: health and rehabilitation-related issues, negative attitudes toward health professionals, challenges with the disability diagnosis, and lack of support from the family and community members (Duma et al., 2021).

It is not uncommon for parents or family members to place blame for the disability, which often falls on the shoulders of the mother, giving the father an excuse to abandon the mother (Duma et al., 2021). Abdullahi et al. (2017) conducted a systematic review of the literature from 2002 to 2016 examining the risk of children with a refugee or immigrant background for attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), and intellectual disabilities (ID). The evidence pool used in this study was small; however, it demonstrated that children from a refugee or immigrant background had an increased prevalence of neurodevelopmental disability when their mothers migrated from an at-risk developing country, particularly with ASD with ID, consistent after controlling for different covariates (Abdullahi et al., 2017). The stigmatization and social isolation have made families deny the disability (Duma et al., 2021; Novak et al., 2019). Consequently, the child may miss out on EI that can increase their health and education outcomes. Novak et al. (2019) and O'Connor et al. (2021) agree on the importance of supporting parents as they go through the different stages and emotions to include denial, anger, feat, and sadness upon receiving the disability diagnosis and being ready to coach parents as they accept and take on the role of champion and advocate for their child. Reactions may vary, largely depending on the cultural acceptance regarding disability. While the research is minimal on the experiences of immigrant parents receiving a disability diagnosis, school teams must be prepared to support parents throughout the diagnosis process to move the parents into a champion and advocate for their children.

## **Barriers**

Collaboration between home and school is an ongoing challenge for families and educators. Effective collaboration and communication between special education teachers and immigrant families are essential in providing the best educational outcomes for students with disabilities. Research has clearly shown that immigrant families face many barriers (VanHook & Glick, 2020), and how those barriers are magnified when those families have a child with a disability (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020; Xu et al., 2022). For collaborative, effective relationships, family and professionals must be heard. Unfortunately, parents often feel their voice is not heard regarding their planning and decision-making for their child (Kelty & Wakabayashi, 2020). Differences in language, culture, and views on disabilities do not need to be seen as a negative, but rather a strength; as Steven Covey (1998) advocated, "Strength lies in differences, not similarities" (p. X).

# **Barriers of Partnerships**

The literature on immigrant families' experience with EI services tends to be sparse. Parents and teachers have struggled to collaborate to address the needs of children with special needs (Camard et al., 2022; Francis et al., 2017; Guerrero & S'lungile et al., 2015; Rivard et al., 2020; Sobotka, 2022). Misunderstandings and miscommunications have created barriers between schools and families (Rivard et al., 2020). Families and schools may have different perceptions of each role in a child's education, which can lead to misunderstandings (Adams & Santos, 2021; Haines et al., 2018; Rivard et al., 2020). Many U.S.-born parents of children with disabilities struggle with being active members of their child's educational team and often have limited knowledge of special education services (Adams & Santos, 2021). Schools and educators must be aware of the gap between their experiences and knowledge of the special education program and services compared to parents who may be very new to it. School professionals must take their time to explain the process and services available to the families thoroughly.

The perception of education for a child with a disability may also be very different in other countries. Teachers in Indonesia have made significant progress in providing education as a human right to all students, but the term *inclusion* has not been clearly defined and lacks cohesive implementation (Kurniawato, 2021). Students with disabilities are often viewed for

their deficits, and unconsciously or consciously, expectations are set low for these students. Some cultures do not send or consider sending their child with a disability to school because they believe they will not fit in and are unacceptable for learning academics in a school environment (Haines et al., 2018; Kurth et al., 2018). In contrast, U.S. teachers expect parental involvement and advocacy for their children (Rivard et al., 2020). Consequently, parents may not advocate for their children or feel their roles and the teachers' roles are very separate.

Unfortunately, immigrant families who have a child with a disability not only face barriers to inclusive education, but may also deal with the attitudes of their immigration status (Hansen-Thomas & Chennapragada, 2018; Kast et al., 2021). A quantitative study analyzing parent attitudes toward migration conducted by Kast et al. (2021) found that particular variables influence attitudes, including levels of education, cultural distance, and their experience with migration. The need to enhance knowledge regarding inclusiveness for individuals without migrant backgrounds and who have lower levels of education is highlighted in this study (Kast et al., 2021). The attitudes of parents and educators regarding immigration, migration, and refugees in classrooms emphasize the need for multicultural classrooms. Ideally, they would be a place where all students receive an equitable education that embraces diversity utilizing culturally responsive teaching pedagogy to guide educators in their instruction. Hansen-Thomas and Chennapragada (2018) emphasized teacher education's importance in incorporating a culturally responsive pedagogy in the classroom. College programs must prepare educators for the culturally diverse classrooms for which they teach, for school administration to offer professional development to educators to support them in implementing evidence-based strategies with students, as well as for educators to make the time and effort to seek out their knowledge to best meet the needs of the students in their classrooms.

# **Communication Barriers**

Families and teachers from culturally diverse backgrounds who speak different languages often struggle with communication. Researchers consistently document that language can be a significant barrier for immigrant families (Adams & Santos, 2021; Guerrero & Sobotka, 2022; Norheim & Moser, 2020; Raymond et al., 2022; Willemse et al., 2018). It is critical that the social environment surrounding a child work and collaborate for the child's positive outcome (Bronfenbrenner & Morris, 1998). A language barrier between schools and families adds another layer of difficulty in communication. When communication is limited, it can often be one-way, with more directives and information given from teachers to families without questions and concerns being asked or addressed by teachers, and the lack of communication from parents can look like disinterest on the parent's side (Rivard et al., 2020; Willemse et al., 2018).

Providing information to family members in their native language is not equivalent to equaling the playing field for immigrant families if the information is unfamiliar or inaccessible (Haines et al., 2021). It is necessary for educators who are working with linguistically diverse children and their families to be ready to collaborate with interpreters effectively (Acar & Blasco, 2016). In a multisite ethnographic qualitative study, more than 100 immigrant parents participated in focus groups utilizing video-cued multivocal ethnography method to encourage dialogue on sensitive subjects, making it easier for these parents to voice their concerns for their children (Adair & Barraza, 2014). The study revealed that parents worried about teachers being patient and kind to their children, especially with language barriers. Parents of children with disabilities may have a greater concern and communication barrier as their child may be unable to verbally communicate, leaving parents to depend completely on the communication between them and schools to know how their child is doing in the school environment.

Scholars have repeatedly encouraged teachers to get curious when it comes to getting to know the children that are coming into their classrooms, and thereby begin the process of building relationships with families (Adair & Barraza, 2014; Rivard et al., 2020). Not being able to speak or understand the dominant culture's language can be seen as a deficit in the schools. The education system often fails to understand that one's native language is not just a way to communicate, but is a part of one's culture and identity. However, viewing and respecting the child's home language and culture as an asset can assist in development (Yamauchi et al., 2022). Families and schools have the most proximal impact on a child's microsystem, and when there is a bridge between the two, it greatly increases a child's opportunity for positive development and success.

## **Strengthening Parent School Relationships**

The right to collaborate with educators exists for all parents, but immigrant families may face a barrier in communicating their child's family preferences due to feeling unwelcomed or not being a part of their child's educational team. Teachers may not be asked or willing to meet the expectations of immigrant families (Yamauchi et al., 2022). Nevertheless, it is in a child's best interest for parents and teachers to work together to create a collaborative partnership to best meet their needs. Family-professional partnerships transpire when families and education professionals consider each teammate in a child's education and build positive partnerships based on trust and collaboration (Haines et al., 2018; Rivard et al., 2020). A trusting relationship is a basis for a solid family-professional partnership. An equal relationship between family and professionals empowers parents to use their voices in advocating their hopes and expectations for their children (Camard et al., 2022; Rivard et al., 2020). Asking questions is recommended for teachers to build rapport and a relationship with families (Rossetti et al., 2018). Teachers and

school personnel can ask three guiding questions when building a relationship with families: (a) How culturally responsive am I? (b) Who is this family? (c) Have we developed a collaborative partnership? (Rossetti et al., 2018). Teachers and school personnel must spend time reflecting on their experiences and biases, so they are ready to be a collaborative and open partner. Cultural humility requires professionals to reflect on their perceptions and experiences and how this may impact how they interact and think about the families of the children they serve in their classrooms (Rivard et al., 2020). Humility requires setting aside one's opinions and expertise and being willing to learn from others.

# **Empowering Families**

IDEA (2004) states that parents should be involved in all decisions, including placement, services, present level, goals, and eligibility (Kurth et al., 2020). Family support and input are critical to developing programs that meet the needs of families and students with disabilities (Hess et al., 2006). Delgado-Gaitan (1991) conducted a four-year study in southern California analyzing parent-involvement activities that fostered participation in children's schooling for isolated Spanish-speaking parents. The results showed that nonconventional activities that were socially and culturally geared toward the Spanish-speaking students created feelings of empowerment and inclusiveness for the families that were usually isolated due to their communication barriers. Schools must be willing to think outside the box to facilitate a culture where all families feel welcome to participate and contribute to their child's educational team.

Schools that create opportunities for parents whose primary language is not English create a welcoming educational environment to empower and engage families and foster a collaborative relationship between families and schools. The support offered by a cultural liaison can empower families with cultural support (Adams & Santos, 2022). A cultural liaison is a

bilingual and bicultural advocate who can do more than interpret for families; they can help minimize potential misunderstandings and facilitate communication between families and schools (Adams & Santos, 2022; Haines et al., 2018; Rosetti, 2017). Using research-based strategies, schools can create environments that provide cultural support, minimizing potential barriers while empowering families to best support and advocate for their children with disabilities.

## **Professional Development**

For actual change to come to the educational system with effective implantation of inclusive education, there must be a shift in old ideas, models, theories, and tools that have been utilized (Carew et al., 2018). The need for teacher development in family partnerships must begin in pre-service programs to prepare teachers to develop partnerships with families so they are prepared to meet the needs of their students (Willemse et al., 2018); teachers need to develop skills and strategies in order to deliver a high-quality education to each child in their classroom despite cultural and learning differences (Ahmed et al., 2022). The need for well-trained and developed special education teachers appears to be a global issue. Teacher education plays a vital role in the success of inclusive education in developing countries. "Thus, the achievement of inclusive, equitable, quality education and lifelong learning opportunities for all learners ultimately depends on sustainable training and supply of qualified teachers in developing and underdeveloped countries" (Nketsia et al., 2020, p. 51). Students with disabilities are often viewed through a medical model of disability with the attitude that the student needs to be "fixed" and whether it is unconsciously or consciously, expectations are set low for these students; students with disabilities must be deemed capable learners. Universities often focus on theories and defining disabilities, but pre-service teachers miss the practical knowledge of

effectively teaching children with disabilities (Al-Shammari et al., 2019). The missing piece in implementing inclusive education in classrooms appears to be in the "how-to" to make it work in classrooms already established in school settings. As these shifts happen and new approaches and models are introduced, they are field-tested to ensure that they can be deemed evidence-based practices and applicable (Singamoney, 2018). Suppose the theories and procedures are not easily relevant in the school setting. In that case, they will never use them, and teachers, administrators, and policymakers will fall back on what they know and are familiar with regarding inclusive education (Subban & Mahlo, 2017).

Teachers who received training in inclusive settings felt much more confident in their abilities to meet the needs of students. Teacher self-efficacy is not set in stone and may ebb and flow depending on the child and the disability (Guo et al., 2021). Teachers who received little to no training in inclusive practices had reported low levels of self-efficacy in their knowledge and experience with inclusive practices (Sharma et al., 2008). Moreover, Sharma and colleagues (2008) conducted a qualitative study across four countries regarding teachers feeling ready to teach in an inclusive classroom and found that confidence levels were much higher in teachers and self-efficacy when teachers received training in inclusive practices.

Student behavior is one of the most significant influences on teacher burnout (Brunzell et al., 2019; McCullough et al., 2021), and student behavior due to disability also affects teachers' self-efficacy (Ahmed et al., 2022). However, professional development focused on behavioral strategies in creating positive classroom behavior support, improved classroom behaviors, teacher attitudes, and self-efficacy (Cummings & Swindell, 2019), primarily when the behavioral strategies taught are for students with disabilities. One can anticipate that immigrant families experience some form of cultural shock as they adjust and assimilate into a new country. When

teachers recognize the impact and potential trauma experienced by immigrant children, they can better utilize strategies to support the student. Stronach et al. (2019) emphasized the need for special educator training to improve engagement and communication with families with a focus on resources that were developed to facilitate the communication needs and barriers between immigrant families and schools.

An environment has the potential to support and constrain behaviors (Neuman, 2016). Teachers can foster a classroom environment that is safe and predictable to help the student develop trust and a feeling of safety within the classroom. Once these have been established, the teacher will have built a rapport with the child and be better prepared to build upon learning and developmental skills (Cummings & Swindell, 2019). Classrooms can be arranged in the environment to minimize behaviors by using the five senses as a guide when setting up the classroom (Cummings & Swindell, 2019), and minimizing student behaviors helps to alleviate teacher stress (Zeng et al., 2021).

# **Inclusive Education**

Inclusive education seems like a simple concept to implement in an educational system but has proven to be anything but simple and has been enveloped in controversy since introduced during the 20th century (Anderson et al., 2019). The definition of inclusive education may vary by whom is asked; UNICEF (2017) defined inclusive education as all students being educated in the same classrooms and schools. They argued that an inclusive educational environment is the most effective way to combat the barriers to education across the globe that rob millions of children of access to education and, therefore, the opportunity to participate in social, economic, and political life (Dignath et al., 2022). As a Sustainment Developmental Goal created by the United Nations, the lack of inclusive educational services is recognized as a global problem. However, inclusive education in South Africa has shown a significant value of social justice when inclusive education is implemented (Manicka, 2018), and ensures that all children receive an education despite learning differences. It has been widely recognized that inclusive education is beneficial for children with disabilities in helping them to have positive outcomes (Al-Shammari et al., 2019; Armstrong et al., 2021; DeMatthews et al., 2020). Nevertheless, the educational system still needs to prepare educators to meet the needs of diverse students.

Teacher attitude and belief system is a vital piece in the success of inclusive education as educators implement practices into their teaching. There is a connection to preservice teachers' attitudes toward the successful implementation of an inclusion classroom (Edivanto et al., 2020). It is recommended that teacher attitudes be evaluated as part of the whole school approach to ensure a sustainable, inclusive culture in the school (Anderson et al., 2019; Dignath et al., 2022). Immigrant families assimilating to a new country with cultural differences may be perceived as not wanting to be involved (Rivard et al., 2020) when in fact, they are facing the same challenges as U.S. parents with learning the educational system for their child with disabilities with the additional stresses of learning a new country. Rivard and colleagues (2020) found that many immigrant families wanted to participate actively in their child's education, but cultural differences impacted perceptions and collaboration of services. Autonomy tends to permeate the educational system, yet the focus on individualism and independence may not align with other cultures (Adams & Santos, 2021b). Family perceptions of their roles and the role of teachers may be very distinct from them (Haines et al., 2018). Educators in Pacific Island Countries often do not feel they have a voice in creating policies, curricula, and professional development to implement inclusive practices in their classrooms successfully (Armstrong et al., 2021).

Different views and perspectives regarding instruction and practices have led to many misunderstandings and disagreements regarding planning and collaborating with fellow educators. One way to combat this obstacle is to create procedures and routines supported and modeled by school and district leadership, preventing fragmented relationships between special and general education teachers (Nelson, 2020). Administrators must create procedures and routines that create a structured environment that fosters learning, communication, and collaboration between educators and families. Communication is vital, and conversations during planning and implementation should be focused on goal setting and follow-through (Da Fonte & Barton-Arwood, 2017). Literature supports the feelings and comments of preservice teacher candidates in recognizing the integral part communication and collaboration play in developing strong, positive, effective relationships with co-teachers' communication (Da Fonte & Barton-Arwood, 2017), yet there has been minimal research on successful and effective training of teachers with a high-quality education in low-middle income countries (Carew et al., 2018).

As policymakers, universities, schools, and teachers move towards the goal of inclusive education and partnerships with families, the critical skill of problem-solving will be at the forefront of the planning and implementation process. One crucial factor that must be remembered is when implementing inclusive education in a school, the values and the culture need to transfer into the implementation. As teachers move towards inclusive education, they must expand and address their "concept learning, problem-solving, critical thinking and creativity, cognition and technology, and instructional applications" (Schunk, 2019, p. 253). One barrier many teachers have faced is needing help identifying the problems preventing the implementation of a thriving, inclusive educational learning environment. When solving problems, it is common to use heuristics to identify the issues and find solutions (Schunk, 2019). Using creative problem-solving strategies and enhancing communication skills can help address some problems with establishing trusting collaborating partnerships between teachers and families (Haines et al., 2018; Rivard et al., 2020).

# **Parent Participation in the Special Education Process**

The literature establishes the importance of home-school collaboration and how vital it is to include families in the education of their children (Collier et al., 2017). There are many benefits to home-school collaboration, especially for students with disabilities. Collier and colleagues (2017) found that school-home collaboration improves the quality of life for students with disabilities, increases their academic achievement, students have higher grades and graduation rates, and students have better attitudes for school and higher educational aspirations. Collaboration benefits all students and is a vital part of student success.

Unfortunately, schools and parents often have conflicts over educational decisions for students with disabilities. Rossetti and colleagues (2018) found three main barriers families face: (a) lack of accommodation for language needs, (b) lack of accountability from school, and (c) lack of opportunities to collaborate with school personnel. Kurth and colleagues (2020) reported schools often do not seek out parental input, are resistant to alternative outside recommendations for services and plans, and often do not respond to parental input. Parents often feel rushed during the IEP meetings and do not understand the jargon used in special education, which harms their ability to advocate for their children (Rossetti et al., 2020).

According to IDEA, parents are an essential part of the IEP team and process. They should be a part of all decisions made, including placement, services, present level, goals, and eligibility (Kurth et al., 2020). When parents are viewed as valued contributors in the decision-making process, the result is an effective program where all participants can work and

collaborate to create a most beneficial plan for the student. When communication is open between home and school, it creates a positive foundation for the IEP team to work together to build an IEP that is satisfactory to all members (Slade et al., 2018). It is vital to remember that communication must be made outside of the IEP process and consistently happen. Collaborative relationships between parents, teachers, and school administrators help families feel more empowered to advocate for their children and participate in the decision-making process. Working with parents, schools, and teachers to create a partnership where all participants have a voice and come together to create a learning plan that is beneficial to the child is one way to help address the problem. Support must be given to families, teachers, and schools to provide support while recognizing and respecting the culture of the people in developing countries.

#### Summary

This literature review explored the experiences of immigrant families with a child with disabilities. Bronfenbrenner's (2005) bioecological theory focuses on the impact of the microsystem, and families and schools are the most proximal systems in a child's life. The barriers faced by immigrant families in navigating a new country, culture, and language have also created barriers in family-professional relationships. Research continually establishes the positive impact these relationships can have on a child's development (Francis et al., 2017; Guerrero & Sobotka, 2021; Haines et al., 2018; Rivard et al., 2020). In order to build a trusting, collaborative relationship, educators must embrace a growth mindset and feel comfortable in asking families questions to know more about their child, their concerns, and the expectations they have as parents. When self-reflection and cultural humility is practiced, educators are better able to learn from the families of the children they work with in their classroom settings (Rivard et al., 2020). Immigrant parents are not apathetic regarding their child's education, but want to be

proactive participants; however, they may be hesitant or uncertain about how to begin to build a relationship with educators (Haines et al., 2018). It is crucial that as the relationship and collaboration begin, educators take the time to truly listen to the questions and concerns of families and remember it is a federal law that, according to IDEA (2004), parents are an essential part of the IEP team and process. Schools that create opportunities for parents and offer cultural support create opportunities for parents to be empowered as a parent of a child with a disability and are more prepared to be collaborative members of their child's educational team.

#### **CHAPTER THREE: METHODS**

#### **Overview**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. Chapter Three describes the research design, research questions guiding the study, setting, and participants. A description will be provided of how data was collected and analyzed. Chapter Three will conclude with trustworthiness and ethical considerations to demonstrate transparency regarding the research.

#### **Research Design**

I selected a qualitative research method for this study to understand the participants' personal experiences in a natural setting by answering my research questions that capture an indepth, thick, and rich description of the experiences of participants allowing for themes to emerge from the collected data (Creswell & Poth, 2018). One of the primary goals of educational research is the concern for social justice and bringing public awareness to the struggles and hardships of individuals in the educational setting (Freebody, 2003). Immigrant families with children with disabilities face challenges navigating a new country's healthcare, education, and special education systems while also trying to learn about available special education services.

A qualitative researcher interviews the participants and analyzes the data to generate new knowledge. Moustakas (1994) said, "Phenomena are the building blocks of human science and the basis for all knowledge" (p. 26). A qualitative study is appropriate for exploring the experiences of immigrant families who have a child with special needs as it addresses a social and human problem (Creswell & Poth, 2018). Qualitative research allows researchers to understand the meaning of people's lived experiences through a study that explores the

experiences and stories of individuals experiencing a phenomenon (Crist & Tanner, 2003). In using a qualitative method in this study, I will use interviews to collect first-hand accounts of the lived experiences of immigrant families. In a phenomenological study, it is important to find individuals who have experienced the phenomenon (Creswell & Poth, 2018). For this study, I will refer to refugees, asylum-seekers, and documented and undocumented persons as immigrants, and children with special needs will be children who are eligible for an Individualized Education Program (IEP) in a United States public school system.

This study utilized a hermeneutic phenomenological research design. Hermeneutic phenomenologists recognize that individuals are unique, and their stories over a shared phenomenon help researchers understand their lived experiences (Creswell & Poth, 2018). A hermeneutic method is a complex approach to understanding the lived experiences of individuals. Instead, the hermeneutic circle assists researchers in understanding the meaning of the whole by looking at the interrelation connections between the parts to embrace a more indepth holistic understanding of lived experience (Lengyel, 2018) and being able to achieve new understanding through interpretive experience instead of basing ideas on biased beliefs (George, 2020).

Martin Heidegger was a philosopher who developed hermeneutic phenomenology, which focuses on the diminutive parts of life experiences that may seem trivial to create meaning and build understanding (Laverty, 2003). Unlike with transcendental phenomenology (Moustakas, 1994), the researcher does not bracket out personal experiences in a hermeneutic phenomenological study. Still, they must be open to their thoughts, assumptions, and biases as they collect and analyze the data. The biases and assumptions of the researcher are essential to the interpretive process and require the researcher to engage in self-reflection throughout the process (Laverty, 2003).

Phenomenology is more than the description of the interviews collected by the researcher; it is the interpretive process by the researcher to interpret the meaning of the participants' lived experiences in the study (Creswell & Poth, 2018). This study concentrated on the experiences of immigrant families in the United States who have a child with special needs in the public school system.

## **Research Questions**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. The following questions will guide this study:

# **Central Research Question**

What is the lived experience of immigrant families in the United States who have a child with a disability?

# **Sub-Question One**

What role do culturally based understandings of disability and special education play in immigrant families' participation in special education?

# **Sub-Question Two**

How do immigrant families describe their experience and relationship with school leaders and teachers?

# **Sub-Question Three**

What are immigrant families' experiences collaborating with school personnel with respect to the development and implementations of the child's individualized education program?

It is essential to recognize that the participants in this study have experienced the phenomenon in various ways. Social constructivism requires the researcher to look for the complexity of the participants' experiences and perceptions of a situation instead of narrowing it to a few ideas (Creswell & Poth, 2018).

#### **Setting and Participants**

This hermeneutic phenomenological study was conducted in Hawaii. Pseudonyms were used for schools, school districts, and participants in order to protect the confidentiality of participants. Lewis County is the pseudonym for the school district. The school district has many immigrant families, as immigrant children comprise a quarter of elementary families within the school district. It was also essential to ensure that researchers utilize purposive or deliberate sampling when making choices of individuals who fit the characteristics they will study, as it is an integral part of producing evidence from a study. The participants in this study were immigrants to the United States, including naturalized citizens, non-U.S. citizens, refugees, asylum-seekers, and migrant families with children with disabilities who qualified and received special education services in public schools for a minimum of one year.

# Site

According to Hawaii school reports, there are 295 schools (258 public, 37 charter) all belonging to one statewide school district, Hawaii Department of Education. This district serves students from preschool through twelfth grade; students in the age range of 3 to 21 are eligible for special education in the state of Hawaii. The student population is diverse, with nearly half of the population being Native Hawaiians and Filipino and the rest being White, Pacific Islanders, Asians, and Black (Partnership for a New American Economy Research Fund, 2021). Children from immigrant families comprise 26% of the LCSD population (Hofstetter & Mchugh, 2021), with students and families coming from various countries worldwide.

This research planned to take place with families who have children enrolled in one of these three elementary schools, with pseudonyms given to each school. The first school is Makua Elementary with 91% of the student population being minority and 66% of enrolled students being economically disadvantaged. The second elementary is Makai Elementary with 80% of the student population being minority, and 52% of enrolled students being economically disadvantaged. The third elementary is 'Ula Elementary with 91% of the student population being minority, and 65% of enrolled students being economically disadvantaged. The third elementary is 'Ula Elementary with 91% of the student population being minority, and 65% of enrolled students being economically disadvantaged. These statistics are just a few indicators that reflect the diversity within the schools, making them an ideal setting for the focus of this study. Four families participated remotely during the study and lived in Texas, Maryland, and South Carolina. The families who lived in Hawaii had children who attended Makai Elementary and children who received EI services and were zoned to attend 'Ula Elementary.

# **Participants**

The participants in this study were immigrants to the United States, including refugees, asylum-seekers, and migrant families who have children with disabilities who qualify for special education services with an IEP in the United States. Criteria for participants included being an immigrant family, and having a child with a disability who receives special education services in the United States. All families shared this phenomenon. Creswell and Poth (2018) instruct that ten or more participants must be used to reach saturation in a purposeful study sampling. The participants were purposively selected because of their experience of being an immigrant family with a child with a disability as a shared phenomenon. Saturation, the point where new data

stopped revealing fresh insights, was reached with ten participants in the study (Creswell & Poth, 2018). Pseudonyms were used for all participants during the study to ensure confidentiality.

# **Table 1**Parent Participants

Parent	Age Moved to United			Child's
Participants	States	Citizenship Status	Country of Origin	Disability
Sarah	21	U.S. Citizen	Philippines	ASD
Rachel	27	U.S. Citizen	Philippines	Speech and Communication
Anna	16	U.S. Citizen	Congo of Africa	Speech and Communication
Kyle	19	U.S. Citizen	Philippines	ASD
Adam	20	U.S. Citizen	Morocco	ASD
Sylvia	29	U.S. Citizen	Puerto Rico	Spinal Muscular Atrophy
Jose	30	U.S. Citizen	Mexico	ASD
Tahina	09	U.S. Citizen	American Samoa	Speech and Communication
Ava	20	U.S. Citizen	Virgin Islands	Intellectual Disability
Tara	06	Permanent Resident	Philippines	ASD

## **Researcher Positionally**

This qualitative study was motivated by my experiences working with immigrant children with special needs and their families. Navigating the educational system and the services available to children with disabilities can be very complex and daunting, and for families in a new country, this can be overwhelming. Sitting in a classroom in Hawaii, listening to a classmate on a student visa from Tonga describe his eight-year-old daughter's physical challenges she faced, he told us she had never been in a school before moving to Hawaii. This was shocking to me. I had no idea that more than 90% of children with disabilities in the Pacific Islands do not attend school (Sharma et al., 2018). My husband is a child of immigrant parents, and their experience with the school system was very standoffish, and they had very little involvement in their children's educational experience. As a special education teacher for children with disabilities, I have found myself drawn to helping and collaborating with parents from outside the United States to help create an environment where they feel like they are part of a collaborative partnership regarding their child's education.

# **Interpretive Framework**

The lens shaping this study was social constructivism, intending to rely on the participants' views of the situation (Creswell & Poth, 2018). Social constructivist researchers seek to understand their world, while a transformative framework provides a voice and an action plan for improving situations (Creswell, 2016). Social constructivism requires the researcher to look for the complexity of the participants' experiences and perceptions of a situation instead of narrowing it to a few ideas (Creswell & Poth, 2018). It was essential to recognize that the participants in this study had experienced the phenomenon in various ways. The right kind of questioning can be a catalyst for initiating movement and sustainable positive change (Sharma,

2020). Researchers use the meanings and experiences of the participants in studies to deepen their understanding of the phenomenon (Creswell & Poth, 2018).

# **Philosophical Assumptions**

Researchers bring a particular set of values, beliefs, and philosophical assumptions to their research. Philosophical assumptions shape research and it is difficult yet essential to be aware of assumptions and beliefs and cognitively decide whether to incorporate them into research or bracket them out (Creswell & Poth, 2018). The three fundamental philosophical assumptions addressed in this phenomenological study are ontological, epistemological, and axiological.

# **Ontological** Assumption

Our life experiences, knowledge, and beliefs make up part of our philosophical assumptions, even when one is unaware of these thoughts (Ponte, 2014). Ontology is how the researcher views reality and the assumptions one has influenced our interpretive frameworks (Creswell & Poth, 2016). My belief that every human is a child of God and created in His image influences how I view the world. Nevertheless, I believe an individual's perception of reality is impacted by their experiences and beliefs. I had prepared myself as a qualitative researcher to be receptive to participants' perspectives and views by collecting multiple forms of data to find themes and patterns in my research questions.

# **Epistemological** Assumption

Epistemological assumptions are based on knowledge and how claims are justified (Creswell &Poth, 2016). I am a person who wants knowledge to be justified, especially when information is given to me by an individual in a position of authority. During qualitative research, it is essential to conduct studies in the "field" to understand better what the participants in a study are conveying (Creswell & Poth, 2016). It is vital as a researcher to not jump to conclusions or let biases get in one's way when researching to understand people's experiences better.

# **Axiological** Assumption

Axiological assumptions address the values researchers bring to their research (Creswell & Poth, 2016). Qualitative researchers make their values and biases in order for others to know what may influence their research (Creswell & Poth, 2016). While researchers will try to see through a clear lens when conducting research, it is nearly impossible to remove our experiences, knowledge, and beliefs that make up our philosophical assumptions. I hope that my belief that we are all children of God helped me see people in a nonjudgmental way and view them with the more transparent lens built on the commandment of loving one another.

## **Researcher's Role**

In a phenomenological study, the researcher is the human instrument (Creswell & Poth, 2018), a term first introduced by Lincoln and Guba (1985) as a way to address the qualitative researcher's part of the scientific process. As a wife, student, and teacher, I have a very soft spot in my heart for immigrant families, especially those who have a child with disabilities. I am a wife to a first-generation son of Mexican immigrant parents; I have first-hand knowledge of the barriers my in-laws faced with their legal status in the United States. This made them hesitant to attend large gatherings at their children's schools, whether academic or extracurricular. During my undergraduate program, a classmate from the Pacific Islands shared that his eight-year-old daughter had never been enrolled in school because of her physical and cognitive disability. I have since learned that this phenomenon is very common in developing countries.

A belief I brought to this study was that every child deserves to attend school and receive an education. As the researcher, I know that my beliefs play a role in my research, and in order to neutralize my beliefs and biases, I wrote memos throughout the process as a way to reflect on my thoughts and ensure that my assumptions aligned in developing an ethical research study. I also employed member-checking with participants to increase validity by having participants validate the correctness of statements, intent, and accuracy of analysis of the interviews (Lincoln & Guba, 1985).

## Procedures

This hermeneutic phenomenology study was conducted in four stages. The first stage was obtaining permission from Liberty University's IRB to conduct the study. Second, after receiving approval from Liberty University IRB, the recruitment began by using a purposefully selected convenience sample of participants I know who meet the criteria (Creswell & Poth, 2018) and employing the snowball method to gain participation in the study by asking participants to identify family or friends willing to participate (Creswell & Poth, 2018). The third stage was the data collection through semi-structured individual interviews that began with constructing a timeline. The interviews used two recording devices, transcribed by the recording program and then edited by me. During the fourth research stage, the data analysis and synthesis occured, where the researcher reads and reread the transcripts, completely immersing themselves in the data (Kawulich, 2005).

# Permissions

Approval from Liberty Institutional Review Board (IRB) was obtained before beginning data collection (Appendix A). No participants under 18 were asked to participate in this study, so

parental or guardian consent was not needed in this study. Upon receiving the necessary IRB approval, participants were provided a consent form to participate in the study (Appendix D).

# **Recruitment Plan**

After receiving approval from Liberty University IRB, the recruitment used a convenience sample of a purposefully selected sample of participants I knew to meet the criteria (Appendix B) (Creswell & Poth, 2018). Purposeful sampling requires interaction between the researcher and participants to determine their appropriateness for data collection (Lincoln & Guba, 1985) and provide a participant pool that adds knowledge to the phenomenon through the interview process (Creswell & Poth, 2018). I then employed the snowball method to gain participation in the study by asking participants to identify family or friends willing to participate (Appendix C) (Creswell & Poth, 2018). In order to have a study with validity, ten or more participants must be used to reach saturation in a phenomenological study (Creswell & Poth, 2018). The study planned to have a minimum of ten participants and add more participants until thematic saturation was met when the data no longer adds new knowledge (Creswell & Poth, 2018).

Participants who volunteered to participate in the study were made aware that their participation is voluntary before they agreed to participate. An informed consent form was provided outlining the requirements, rights, and risks of the participants in the study. Each participant was given a pseudonym to protect their privacy, and legal names were not used in the study to protect confidentiality.

## **Data Collection Plan**

The goal of hermeneutic research was to generate meaning and understanding by asking participants questions that allowed their stories to unfold by illuminating and clarifying their

experience with the phenomenon (Dibley et al., 2020). According to Creswell and Poth (2018), data collection is more than determining which types of data to collect; it also involves obtaining permissions, anticipating ethical issues, planning for recording interviews, a solid sampling plan, storing data securely, and anticipating and responding to issues as they arise in the field. When conducting qualitative research according to Creswell (2013), the researcher must be sensitive to conducting interviews and collecting data in a natural setting to the people and places involved in the study. The focus of this phenomenological study was to bring awareness of the shared experiences of immigrant families who have a child with disabilities in the United States public school system. The researcher utilized a questionnaire for each participant, created timelines with each participant at the beginning of each interview, and 1:1 interviews with each participant. Based on the findings of van Manen (2016), phenomenological research is always focused on the meaning of the lived experience. The point is to "borrow" the experiences and contemplations of others in order to comprehend better the "significance of an aspect of human experience, in the context of the whole of human experience" (van Manen, 2016, p.62).

# **Questionnaire Data**

The first form of data I utilized was a questionnaire (see Appendix E), that also served as a screening for participation. The questionnaire was gathered at the beginning of each interview. The questionnaires were used to obtain information from participants about demographic information. The demographic questionnaire was designed to collect data on participants' demographic characteristics: age, gender, marital status, number of children, length of time in the United States, U.S. citizenship status, language fluency, disability of the child, and life before and after moving to the United States. Questions one through three of the questionnaires are related to age, gender, and marital status. Questions four through ten acquire about the participants' country of origin, language, length of time in the United States, and citizenship status. Questions 11-13 ask the participant about the number of children they have, if their child has a disability, and the diagnosis of their child. The concluding questions 14-15 are short answers and ask participants to describe life before and after moving to the United States.

# Questionnaire Data Analysis Plan

Questionnaires are used to corroborate data in qualitative research to improve the triangulation and validity of data and to enhance the scope and range of the research to ensure that a thick, rich description of the lived experience is available from each participant. To begin the analysis of the questionnaire data, the researcher must first read responses from the openended questions to examine the raw and authentic responses from participants and initiate the preliminary data coding process by employing a combination of deductive and inductive codes which are generated from the research questions and data (Rouder et al., 2021). Constructing meaning from the questionnaire data is a way to solicit authentic and diverse participant feedback and then categorize and code the emerging themes and patterns. Using a descriptive label is an ideal coding for documents by using a noun or short phrase to assist in classifying emerging themes and patterns from the questionnaires (Saldaña, 2021) and assigning codes to each answer in the questionnaire line by line from the participants (Bowen, 2009) followed by a data analysis using Saldaña's (2021) first and second-order coding procedures. The themes that emerged from the questionnaires assisted in understanding the meaning behind participants' lived experiences.

# Timelines

Timelines were the second data collection method for this study. Timelines are a visual representation of particular or selected events in a participant's life that can be created

collaboratively with the researcher and contribute to qualitative inquiry (Marshall, 2019). According to Marshall (2019), the most used timeline method is the classic timeline marked with key events from the participants' life and can be created in 10-15 minutes, yet it generates a large amount of data for exploration and reflection and can be found in Appendix F. Utilizing the timeline method provides a visual representation of a person's life, allowing for a clearer perspective of the individual perception of the events and a more comprehensive view of their life experiences (Adriansen, 2012). Researchers who employ the timeline method have found that their data is more thorough and contains detailed descriptions of life events while also improving participation, increasing engagement, enhancing rapport, mitigating language limitations, as well as a more collaborative interview as participants are more at ease and more likely to be actively engaged in the interview process (Marshall, 2019). The tool for this method is a large piece of paper and colored pens. The timeline is typically drawn vertically or horizontally on the paper, and the interview questions can guide the timeline (Adriansen, 2012). The researcher can garner rich and in-depth information through the creation of a timeline with the participants.

## Timeline Data Analysis Plan

Using phenomenological reflection as a guide to analyze the timelines of participants aids in understanding the phenomenon and experiences of individuals in the study. Reading through the timeline with a wholistic approach; with the question of understanding the fundamental meaning of the events and recording meaningful words and phrases (van Manen, 1997). After reading through the timeline multiple times, searching for and recording phrases and events that support the emerging themes, analyze these events to see what they reveal about the phenomenon (van Manen, 1997).

## **Individual Interviews**

Philosophical hermeneutics was a way to deepen understanding of individuals' intricate social-relational, cultural, and historical human experiences within a research study (Hovey et al., 2022). Interviews allow for detailed qualitative data that helps better understand the participants' lived experiences, their perspectives, and the impact the phenomenon has had on their lives (Rubin & Rubin, 2004). Individual interviews are a common form of data collection within qualitative studies as it allows researchers to gain knowledge through the experiences of the participants (Creswell & Poth, 2018). In all interviews and interactions with the participants, it was vital to create rapport to have rich, meaningful dialogue; this is especially essential in individual interviews (Creswell & Poth, 2018). The interview questions found in Appendix G have prior approval from Liberty University IRB and the dissertation committee. During each interview, there were two recording devices to ensure accuracy and to mitigate technical issues.

Qualitative research often uses semi-structured interviews to ensure that interviews prompt similar information from the participants in the study (Adeoye-Olatunde & Olenik, 2021). Semi-structured interviews allow for flexibility and probing questions that can lead the participants to share their experiences more deeply and with the details that make their stories distinctive. Belotto (2018) found that using a semi-structured interview allowed her to follow the participants' lead in the study instead of leading them through the interview process, resulting in more relevant and rich descriptions of their experiences. Immigrant families face many barriers, and it is incredibly essential to building a rapport of trust and empathy for them to feel comfortable and collect rich quality data (Creswell & Poth, 2018). Pseudonyms were used to protect the confidentiality of participants and locations and the data collected during the interviews was locked in filing cabinets and electronic files were password protected.

## Individual Interview Questions

- 1. Tell me a few things about yourself. CRQ
- Please tell me about your family. CRQ (Prompt Do you do things together or separately?
- Please tell me about your transition to the United States. CRQ (Prompt- Comparing life before to their life here.)
- 4. What motivated you to immigrate to the United States? CRQ
- 5. Please tell me about your children CRQ (Prompt- specifically ask about child with disability.)
- 6. When and how did you receive the news about your child's diagnosis? CRQ (Prompt-Was the diagnosis received through the health care system (medical diagnosis) or through the school system (educational diagnosis)?)
- 7. What was your experience with receiving the diagnosis? CRQ
- 8. How did your family members respond to the diagnosis? CRQ
- 9. How has your child's disability impacted your life? CRQ

10. Describe your experience interacting with the administration and teachers at your child's school. CRQ

- 11. How would you describe your treatment as a parent of child with a disability? CRQ
- 12. How is your child's disability viewed in your culture? SQ 1
- 13. Describe your role as a participant in your child's education. SQ 1
- 14. Please describe your relationship with the school administration. SQ 2
- 15. Please describe your relationship with your child's teacher. SQ 2
- 16. What type of collaboration have you done with your child's school concerning their

education? SQ3

17. How do you feel like collaboration can be beneficial to your experience with your child's school? SQ 3

18. Please describe your experience attending your child's IEP meeting. (Prompts – how, if at all, were you prepared for the meeting? Was there a translator present or offered? What input was requested from you? How did you feel going into the meeting, during the meeting, and after the meeting? SQ 4

19. What opportunities have you had to contribute to your child's IEP? SQ 4

20. Had assessment results and other materials been translated in time for IEP and

have skilled interpretive services been provided for the IEP meeting? SQ 4

Final Question: Is there anything else you would like to share with me on this topic? Or any questions you thought I might ask about but didn't?

Questions one through nine focus primarily on building rapport and understanding the central research question of the lived experience of immigrant families with a child with disabilities. Creswell and Poth (2018) state that establishing rapport is essential to creating an environment of candor and non-judgment. Questions 10, 11, 14 and 15 are specific to the relationships between parents, the administration, and their child's teacher. These questions lead into 13 through 19 on the collaboration between the families and school regarding their child's education.

# Individual Interview Data Analysis Plan

Hermeneutic phenomenology researchers must reflect on the participants' lived experiences in their study to reflectively analyze the thematic elements of the experience. According to van Manen (1997), the sole intent of phenomenological reflection, which he believes is both easy and challenging, is to understand the fundamental meaning of something. Furthermore, van Manen (1997) explained that to understand a phenomenon, the text must be approached to find meaning through themes by reflectively analyzing thematic or structural elements of the experience. For this study, my plan consisted of utilizing the phenomenological reflection process. Each interview transcript was analyzed with the wholistic approach, employing a highlighting approach, detailing each sentence with a word or short phrase (Van Manen, 1990).

The first step in the reflective method is to read the text in its entirety with the question of understanding the fundamental meaning of the text and documenting meaningful words and phrases (van Manen, 1997). Next, is rereading the text several times, looking for revealing statements or phrases regarding the phenomenon to understand the emerging themes better (Van Manen, 1997).

Another technique that will be used throughout the qualitative analysis is the process of coding, which is recording the phrases with code words from each interview into a list and then looking for connections and themes within the list and compiling them into similar categories. Coding is a way to analyze the data in an organizational analysis that allows patterns and themes to emerge from the data; it is a way to arrange things in a systematic order and to make it a part of the classification system in order to categorize the data (Saldaña, 2021). The first coding session assigns a code to each interview sentence, and then in the second coding cycle, there is more coding refinement and clustering of codes as the themes emerge (Saldaña, 2021). I plan to use Saldaña's (2021) first and second coding for my interview analysis to discover emerging themes and meanings from the qualitative data. The final step in the phenomenological

reflections is to analyze each phrase theme and ask what it reveals about the phenomenon or the individual's experience (van Maren, 1997). The thematic analysis in a phenomenological reflection process strives to understand the patterns of meaning from the data gathered from participants' lived experiences.

## **Data Synthesis**

Data were triangulated across participants and data collection methods to explore the stories of immigrant families with a child with disabilities. Triangulation across multiple data sources increases credibility and the opportunity to arrive at a definitive conclusion (Shenton, 2004). Triangulation of sources allowed for an increased understanding of the study taking place. Additionally, triangulation is accomplished in this study by collecting and analyzing three data types: questionnaires, timelines, and individual interviews (Shenton, 2004). The hermeneutic analysis interprets life experiences, including the "ordinary and extraordinary" (Rackley, 2020, p.2). According to Van Manen (1997), researchers should begin the analysis process with the assumption that the participants had already meaningfully interpreted the descriptions they gave during the data collection. During the analysis, researchers must read and reread the transcripts, completely immersing themselves in the data (Kawulich, 2005). Managing and organizing the data can be challenging by the sheer amount collected through the timelines, questionnaires, and interviews. The thematic analysis in a phenomenological reflection process strives to understand the patterns of meaning from the data gathered from participants' lived experiences (Sundler et al., 2019). First, it is essential to prioritize memoing throughout the analyzing process to develop new ideas and better understand the studied topic (Maxwell, 2013). The next step following reading and memoing the data is coding (Appendix I) to find common themes throughout the data. Interpretation transpires through reflection, and Van Manen (2014) advocates for the

reflective tradition in approaching a thematic analysis and believes that to understand lived experiences, researchers must use writing as a tool for reflecting and profound understanding. Van Manen (2014) argues that phenomenological writing is a necessary mediating aspect to truly immerse in the research process. During analysis, identifying and writing themes requires the researcher to write and rewrite using detailed descriptions that usually require more than one to two words to sufficiently identify the patterns and themes (Sundler et al., 2019). The themes will then be categorized as patterns and connections within the text to interpret what the findings mean in connection with the phenomenon (Taylor-Powell, 2003). It is an integral part of analyzing data by symbolically assigning an interpretation of large segments of texts into smaller portions while identifying links and themes among the data (Creswell & Poth, 2018). The analyzed themes are categorized as "structures of experience," and collectively, participants' experiences emerge (Van Manen, 1990, p. 79). Therefore, the data analysis sheds light on immigrant families who have a child with disability and their experiences within the public schools in the United States.

## Trustworthiness

Lincoln and Guba (1985) established the foundational criteria for trustworthiness in a qualitative study through credibility, transferability, dependability, and confirmability. Positivist researchers have questioned the reliability and validity of qualitative research because qualitative researchers cannot address the reliability and validity in the same way as naturalistic work (Shenton, 2004). I will be employing Lincoln and Guba's (1985) foundational criteria of trustworthiness to explain the transferability and relevance to various contexts.

# Credibility

Credibility in a study requires researchers to employ the foundational criteria of trustworthiness to validate honest findings and to the extent that the results are authentic and accurate in representing truth (Lincoln & Guba, 1985). Triangulation and member checking will be used in this study to attain credibility (Lincoln & Guba, 1985). This study will collect three data types: individual interviews, timelines, and questionnaires to accomplish data triangulation (Shenton, 2004). Member checks are essential to developing credibility in a study to ensure data accuracy (Lincoln & Guba, 1985; Shenton, 2004). Member checking is used to increase validity by having participants validate the correctness of statements, intent, and accuracy of analysis and final representation of the interviews, and increases the study's credibility as it encourages feedback on the findings and serves as a check for possible misinterpretation (Creswell & Poth, 2018; Lincoln & Guba, 1985). Member check was used to have participants validate the accuracy of transcripts, significant statements, and themes. Six of the ten participants responded to the member checking via email and verified accuracy.

#### Transferability

Transferability implies that the findings of this study can apply to a future study within a different context and setting or within the same context at another time (Lincoln & Guba, 1985). Transferability is created through detailed, thick, substantial descriptions throughout the study (Lincoln & Guba, 1985). As a researcher, I must interpret how the participants in the study add insight into the phenomenon and how this interpretation of the participants' experiences can be generalized to other studies (Creswell & Poth, 2018). In order to obtain a maximization of variation among participants, my study includes participants from various countries of origin, different disabilities among the participants' children, and varied lengths of time living in the United States, as well as children born in the United States. The researcher can do their best to

create conditions for transferability, but the judgment of transferability belongs to the prospective future researcher.

## Dependability

Dependability is a foundational criterion for establishing trustworthiness in qualitative research. Dependability shows that the findings in the study are consistent and capable of repeatability (Lincoln & Guba, 1985). The dissertation committee ensures that the dependability criteria are met prior to approval, and this is achieved through detailed descriptions of the methods used; detailed, thick descriptions of themes; member-checks of the findings and interpretations; a reflexive journal kept by the researcher; and by an inquiry audit done by a third party of the research processes used throughout the study.

### Confirmability

Confirmability conveys neutrality in a study to ensure the findings are shaped by the participants in the study and not a reflection of the researcher's bias, motivation, or interest (Lincoln & Guba, 1985). Confirmability will be achieved through triangulation by collecting data in various ways, memo-writing, and an audit trail (Lincoln & Guba, 1985; Creswell & Poth, 2018). Qualitative research requires that researchers take a reflexive stance during their research and data studies, and memoing lends itself to this reflexive stance (Birks et al., 2008). Memoing is a tool that should be saved for only the analytic portions of a study, but is a way to document and reflect from the beginning of conceptualizing a study (Birks et al., 2008). I plan to memo weekly and reflect on it as I compile new ideas throughout the researchers (Creswell & Poth, 2018). An audit trail allows the findings to be retraced by other researchers (Creswell & Poth, 2018). An audit trail also ensures document accuracy and that proper record-keeping reflects the study's findings (Lincoln & Guba, 1985). Feedback can be given during early interpretations

concerning the audit trail and procedures to help the researcher clarify and articulate their thinking as patterns emerge in the data (Creswell & Poth, 2018).

## **Ethical Considerations**

When conducting a qualitative study, researchers must ensure that the participants in their research are suitable representatives of the population the study is looking at, the participants are fairly represented in the findings, and confidentiality of participants is guaranteed (McDuffie & Scruggs, 2008). The quality indicators ensure that participants are suitably treated and represented in the qualitative study to ensure reliability and validity (Creswell & Poth, 2018). In conducting a hermeneutic phenomenology study, the researcher must be aware of their assumptions and biases, as Heidegger (1962) believed that a person could not set aside their pre-understanding of the world. In a phenomenological study, it is essential to follow the organization, presentation, and data analysis and ensure that the researcher summarizes the study in its wholeness (Moustakas, 1994). The study was used to understand the phenomenon of immigrant families with a child with a disability in public schools. When conducting a study, Creswell and Poth (2018) outline a timeline for ethical issues to consider at the beginning of the study, during data collection, and while analyzing the data.

In order to successfully work with participants in a study, the researcher must establish trust and respect and ensure that participants understand the voluntary nature of the study (Creswell & Poth, 2018). Prior to beginning the study, IRB approval must be granted from Liberty University. At the beginning of the study, the purpose of the study must be disclosed to the participants as they will be given an informed consent form with a written statement as to the general purpose of the study and how the data will be used and reviewed with participants during the interview process. Data can only be collected once IRB approval and participants' informed consent forms have been collected. It is essential to discuss the purpose and use of the data collected during the study with each participant (Creswell & Poth, 2018).

Pseudonyms were used for all participants' names and identifying information to ensure participants' privacy and confidentiality (Creswell & Poth, 2018). Security software and password protection was utilized to protect all data collection and documentation collected from participants during the study. Ethical considerations are essential to the data analysis as researchers have spent time collecting personal stories and experiences from individual lives; participants must be protected from harm by ensuring that all personal identifying information is avoided (Creswell & Poth, 2018). Researchers must report on multiple perspectives and contrary findings to conduct an ethical study (Creswell & Poth, 2018).

#### **Summary**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. This chapter summarizes the selected methodology and explains why the phenomenological approach was an appropriate research methodology for this study. I used a qualitative design to explain this study's procedures, research design, and analysis. Triangulation will be established through individual interviews, timelines, and questionnaires. I completed a data analysis through coding and the development of themes. This chapter included sections on trustworthiness to ensure the study is credible, dependable, confirmable, transferable, and ethical. This chapter also discussed my role as the researcher and my positionality.

#### **CHAPTER FOUR: FINDINGS**

#### **Overview**

The purpose of this hermeneutic phenomenological study was to describe the lived experiences of immigrant families with children with special needs in the United States public school system. A total of 10 participants participated in the study. This chapter provides a narrative description of each participant, presents the study's findings, including themes and subthemes, and answers the research questions and sub-questions. A summary is provided at the end of the chapter.

#### **Participants**

This study included immigrant parents who have a child with a disability receiving special educational services in the United States. This study consisted of 14 participants who met the research study criteria and were willing to participate. The participants all satisfied this study's eligibility requirements: over 18 years old, immigrated to the United States, and have a child with a disability receiving special educational services. Participants included seven female and three male participants aged 26 to 60. The participants immigrated to the United States at various ages, ranging from ages six to 30 years old. All of the participants spoke a minimum of two languages; one participant spoke three languages, and another one spoke eight languages. Four participants immigrated from the Philippines, one from the Congo of Africa, one from Samoa, one from Mexico, one from Morrocco, one from the Virgin Islands, and one from Puerto Rico. Blackwell and colleagues (2021) discuss in their research that Puerto Rican migration to the United States is considered transnational; while the people of Puerto Rico are U.S. citizens, they are still crossing geopolitical, cultural, and racial boundaries, which are the exact boundaries crossed by immigrants moving to the United States. The languages spoken by participants in this

study are English, Berder, Darija, Portuguese, German, Arabic, French, Lingola, Tagalog, Creole, and Samoan. The children of the participants had various disabilities. Five of the children had ASD, three were diagnosed with speech and communication, one with intellectual disability, and one with spinal muscular atrophy. Participants were randomly assigned pseudonyms according to their gender and cultural background to protect their identity. Participants shared their experiences in the structure of individual interviews, questionnaires, and timelines. Six of the ten participants responded to the member check, all of whom confirmed the accuracy and completeness of the transcripts. Direct quotes were taken from the participants' 1:1 interviews. **Anna** 

Anna is a military spouse, mother of two children, and a refugee who fled her war-torn country. As a sixteen-year-old girl, Anna moved to the U.S. alone, leaving everything she knew behind in Africa. It was not a choice if she should go or stay, as a war was happening, and both of her parents had passed on. She boarded her first plane, took a long trip to America, and ended up at an international boarding school in Texas. Learning the English language was challenging, besides learning the school's academic content and playing basketball. She felt uncertain of her future when she was kicked out or dismissed from her school due to her age, as the school did not feel like she would be able to graduate on time due to her age and language barrier.

Anna believes that God is aware of his children and sent her a godfather who took her and eventually her sister in when she moved to the U.S. and helped to set them up with a new school that provided 1:1 services to prepare her to transfer to the local high school. The influence of her godfather reminded her to smile and that she was still in her youth, to have fun, and to make memories doing typical things such as going to the mall. Through his insistence and guidance, she slowly felt her smile come back and a return to her youthful age. The pain of losing her godfather to cancer was excruciating, but he reminded her that God had a plan for all of them and she would be okay; she thinks of him often. Anna felt a tremendous growth in her mindset and self-awareness as she realized that she could learn a new language and stay on top of her academics, which helped set her up for success in college.

The stark difference in how a disability is viewed and how individuals are treated was vastly different in her home country than in the U.S. At her public high school in Texas, Anna recalled watching how kindly the teaching staff interacted with students with disabilities. She did not remember ever seeing individuals with disabilities in her African school. The shame, feelings of unsafety, and lack of financial resources seem to penetrate families in Africa and the way they care for their children with disabilities. It is uncommon to see pictures or videos of individuals with disabilities on social media from her home country, and she thought the families sharing their children in the U.S. were courageous. Her daughter's speech and communication delay would be looked at with judgment where she is from, but she doesn't feel shame because she believes that her daughter is a little delayed, but will be fine as she learns to talk.

# Tara

Tara immigrated to the United States from the Philippines in her later elementary years. She spent her teenage years on the West Coast. Her mother lives in the Philippines. She is a military spouse and a mother to twins, one developing typically and the other recently receiving an ASD diagnosis. While Tara suspected in her heart that her child may be autistic, having the words said aloud by the pediatrician changed her whole world. She described this during the interview, "Like our whole world just stopped, like, you know, in the movie, like you can hear it, and then they say, 'Oh, what's that? I'm sorry.' Like it took a minute for me to understand them." The diagnosis brought mixed emotions – relief, and fear about how others would treat him. When Tara called her parents to let them know about her son's diagnosis, they both said to be grateful that he has his health. Throughout the interview, Tara kept returning to being thankful for the diagnosis. Tara's focus on being grateful for the diagnosis is that it has helped her better understand her son and has given her more patience to handle the different challenges that can come from raising a child with ASD who is non-verbal. Tara's cousin, who lives in the Philippines and has a child with a disability, told Tara,

No, it's okay now that you guys are in the States. You guys get all the benefits. So yeah, we're very lucky because I told him, like, don't get out of the army. Stay there for a while; it's really needed.

Tara relied upon her support system and commented how lucky she was to have such a sound support system. Her support system in Hawaii included a close family friend from the Philippines, Philippine families from past duty stations, and a close friend she met in the neighborhood who has a child with delays who is also from the Philippines.

# Rachel

Rachel moved to the United States in her late 20s from the Philippines with her husband, where they both joined the United States military. She described her life in the Philippines as a comfortable lifestyle, but heavily dependent upon her parents. Since moving to the United States, Rachel feels that life is comfortable and happy, but with many more opportunities. While Rachel learned what she describes as "proper English" in school, she experienced culture shock when she moved to the United States and struggled with how fast those around her spoke in English. She had to rely on lip reading and, even then, could only pick up a few words in each sentence. It took her months to feel confident to speak to others in her military unit, I get to meet different people, and that's when I started learning who knows what it's like learning deeper English. I get to work with different people from different backgrounds. So, non-English speakers like myself, so it made me boost by a little bit of my confidence a little bit.

Before meeting other people who were non-native English speakers, Rachel would not speak in work settings. She recalled that whatever she was told to do, she would complete the task, but said, "I just do and don't talk too much because I'm afraid to speak." She went on to say that while she disagrees with this, in the Philippines, intellect is judged upon the way you speak, and therefore, she was afraid to speak English and make a mistake and have her intellect judged by those she worked with in the military.

Rachel's daughter has speech and communication delays, and she feels guilt over being away from her daughter so much with work that she decided to leave the military to stay home and be more available to her daughter. After a trip to the Philippines, where Rachel hired a speech pathologist and occupational therapist to come into her mother's home in the Philippines to work with her daughter, they saw leaps of growth happen within a short time. Rachel said, "It kind of hit me that maybe the reason why she has delays is because of me because I don't get to spend time with her." Transitioning out of the military was a tough choice for Rachel as she loved serving in the military and enjoyed her profession within the service, but a sacrifice she was willing to make to focus more on her daughter to be able to meet the needs of her daughter. **Sarah** 

Sarah immigrated to the United States from the Philippines in her early 20s after marrying an American man. It was a difficult adjustment for Sarah, who grew up surrounded by friends and family and then found herself in a new country, and the only person she knew was her husband. They lived in a metropolitan area on the East Coast, and Sarah recalls that her husband did not want her to leave the house alone, so she stayed inside all day alone. Sarah added, "But I don't know why I just stayed in the house when I didn't have the kids yet." Sarah's husband passed away seven years after they were married, leaving her a widowed mother of two young children. A month after his passing, she received the diagnosis that her youngest child had ASD. Sarah struggled with depression after the death of her husband and her daughter's diagnosis of ASD and returned to the Philippines for a short time to be with her family.

After returning to the United States, Sarah enrolled her daughter in a preschool program and had her first Individualized Education Program (IEP) meeting. Sarah recalls that her first meeting was less than 15 minutes because everything had been predetermined, and she was just there to say, "yes" or "no." During COVID, the school closure and virtual learning really opened Sarah's eyes to her daughter's experience in the school setting. Sarah's daughter ran around the house while her classmates participated in the virtual class. Sarah began to Google and learned about free and appropriate public education (FAPE) and determined that her daughter was not receiving an appropriate education.

So, I started gaining knowledge about what you can do and things like that. But I can't do it on my own because, you know, my English is a limited language. So, I hired me a lawyer and an advocate.

After a considerable amount of time, money, and countless meetings with the school, they agreed to create a setting outside of the general education classroom to meet the educational needs of Sarah's daughter. Sarah describes the experience with the school as a "long battle" that took a toll on her emotional and mental health. After the school agreed to the IEP changes and with three weeks left in the school year, she left for a year-long vacation in the Philippines with her family. Her goal was to pursue her education. Sarah recently moved to Hawaii with her two children to start fresh and chose the location due to her family on the island and the proximity to the Philippines. While her daughter's IEP has now expired, she is not worried about the upcoming meeting or feels like she will need the support of an advocate because "I'm not new with all that vocabulary."

## Kyle

Kyle moved to the United States from the Philippines when he was 19 years old after waiting two years for petitions filed by his family, who moved to the United States two years before he was approved to move with them. Kyle joined the United States Army, gained his citizenship, and petitioned his wife and child to join him at his duty station in the US after getting married. There are a lot of hurdles and paperwork for immigrant families to be together. While stationed in Japan, Kyle's wife experienced complications while giving birth to their son; it was a difficult and trying time for their family. Kyle described the close friends from the Philippines they made while stationed in Japan who supported their family during that time, "Good thing we have friends over there; our friends are the ones that helped us out." Kyle and his family depend on the friends they make at their different duty stations for support as they are far away from their family, and the friends they have found have been from the Philippines.

Kyle's son received services through EI for delays in communication, social, and cognitive development. He was under the care of a pediatrician and had an appointment scheduled with the developmental pediatrician for suspicion of ASD. Before the interview began, Kyle's wife shed tears talking over her concern of an ASD diagnosis and what it would mean for their son. During the interview, when asked about the upcoming developmental pediatrician appointment, Kyle responded, "I don't know, like, for me, it is what it is, but hopefully, he doesn't have ASD. Hopefully, we can still fix... I don't know. It's like, there's no cure for that. But hopefully, some miracle happens, though." Kyle expressed that he had mixed emotions about his son's delays, but worked hard to find the positive and felt that a diagnosis would bring answers about his son's behaviors and delays. Still, it was also very overwhelming to think about his son's future with an ASD diagnosis. Kyle worried that raising his son away from his family has negatively affected his development. He is concerned that his son has missed out on language development because he does not have examples of older cousins living close by like his older child had when they lived in the Philippines.

#### Jose

Jose is a school educator teaching Spanish for over 30 years. He and his wife moved to the United States from Mexico when their first three children were young and added three more children to their family while living in Texas. They had never heard of ASD until they moved to the United States, and Jose remembers hearing the word autism for the first time when he heard that Sylvester Stalone's son was diagnosed with ASD. When their youngest son was diagnosed with ASD, it was a very overwhelming time for Jose and his family, but they were very proactive in trying to find the best way to help their son, "Okay, we cannot sit down and cry. We have to do something. Then we start looking for therapies for health and everything else. We moved from Austin to New York because they had the best treatments in the nation." Jose and his wife moved across the country seeking out the best treatment for their son and feel that if they had stayed in Mexico, their son's quality of life would have been very poor because of the lack of services available to children with ASD. The strong desire to provide their son with the best possible services was a very challenging time for Jose and his family; Jose recalls, "We had to do whatever we could, and with the information that we had, so it was challenging. To be honest with you. It was challenging." ASD has impacted the whole family, according to Jose, but his older children love their younger brother and feel a responsibility to help support him. They have felt this since they were young and moved across the United States. Jose said, "My kids were very, very cooperative, and they understood that everything was for their brother; everybody pitched in to try to help." Jose has faced challenges when working with the school regarding his son's IEP. He often felt like the schools needed to be more honest with his progress as they didn't see any evidence of this progress in the home. Jose was confident in his knowledge and expressed that he did not struggle with speaking up with questions and concerns. "I am an educated person. So, I know what I'm doing."

# Adam

Adam came to the United States as a 20-year-old on a student visa from Morocco. He grew up in a culturally diverse home, and when asked about his culture, he responded,

When you say culture, I don't think it's just isn't an adequate thing to think it's just based on family. Because I do not like to generalize things to a person, and two, I don't belong to one culture because I grew up in a multi-dimensional family, and everywhere I go, I just fit just perfectly.

Language is integral to Adam's identity, as he grew up immersed in five languages and learned three more languages during college and military training. After leaving college to care for his ill dad, he returned to the United States and joined the military, where he continued to immerse himself in different languages and cultures.

Adam and his wife have one son who is autistic. While they face challenges in finding schools and therapies to meet his needs, Adam focuses on the positives of his son's diagnosis. He

speaks fondly of how gifted his son is regarding technology. Adam is a deeply religious man and spoke of the blessing his son is and expressed,

We're blessed. And we're going to turn that blessing into a way of thanking God for having you, so we're gonna give you our time. So, our best way to thank God for you is to give you time because we were blessed with it.

While Adam travels extensively with the military and is often separated from his family, he tries to stay connected through Facetime. He tries to attend all meetings via Zoom. When he is home, he also makes a point of dropping off and picking up his son from school and therapy appointments to build a connection with those who work so closely with his son.

## Ava

Ava grew up in St. Croix in the U.S. Virgin Islands and immigrated to the United States at 19 when she enlisted in the United States Army. She recalled how she only had one white classmate growing up and the culture shock Ava felt when she arrived at boot camp and was surrounded by so many white recruits. She remembers thinking, "I was like, they aren't as scary or mean as I thought." Ava's mom worked in the resort hotels and as a housekeeper for transplants whose company housed them and provided cleaning services, and her experiences were "not great." Ava reflected that as she got to know the other soldiers, she could tell her mom about her positive interactions. Still, she said during training, she met four girls from the Caribbean and how much that cultural connection helped them throughout that time, "We just kind of stuck together and clung to each other. So, it was nice to have that safety net of like, you know, the cultural understanding with you."

Ava's daughter has an intellectual disability and is now in high school. Ava reflected that at the beginning of her journey, when her daughter entered school, there was a resource teacher who advocated for her and her daughter and would have conversations about her daughter's rights; she said that it helped to propel her on her journey of advocating for her child. It can be scary for Ava to speak up, especially in the beginning. Still, she relies heavily on her faith and relationship with God, and she utters a prayer before meetings, saying,

Okay, Lord, you trusted me with her. You have to give me what I need to be a good mom to her and make sure that you know she is where she needs to be and what I need to say to people and, like, give me the courage because sometimes it's scary even when you're saying it.

Ava is now a special education teacher and is helping other parents educate their children and ensure that all parents are aware of their rights.

## **Sylvia**

Sylvia is a mother of three who moved to the United States with her husband and three small children when she was 29. They didn't speak English and had no work lined up, but they knew they wanted to give their family more opportunities than were available in Puerto Rico. Sylvia's youngest son was diagnosed in Texas shortly after his first birthday with spinal muscular atrophy (SMA). When talking about her son's diagnosis, Sylvia shed tears and recounted, "We've been through a lot because it's not just his diagnosis. It's the rest that comes with it." Sylvia was her son's primary caregiver, with a reprieve only from her husband until he turned six years old and began to receive overnight respite care. When Sylvia's son began preschool, she accompanied him every day by volunteering in the classroom because "it's hard to take your baby to school with his disabilities." She eventually was hired as a special education teacher's aide at his school and accompanied him to school every day during his elementary years. The SMA causes many respiratory issues, and Sylvia's son is not immune. He has spent countless days and weeks in the hospital under the care of a physician; Sylvia has been there every day and night with him, occasionally switching out with her husband. Reflecting on their time in the hospital, Sylvia commented, "You know, I don't know. I really don't remember how I did it." While Sylvia is a very devout and dedicated mother, she expressed that it has been difficult for her at times, especially in the beginning, to speak up and ask doctors and teachers questions. When asked if she was offered an interpreter and used one, she replied,

First, yes. But then I am the kind of person that likes to learn, and I will be independent. I don't like to wait for anybody to do my stuff. And I learned, I learned, and I think I'm okay, not perfect, but I think I'm okay.

Sylvia acknowledged she compensates for her language barrier by saying, "Because I have my accent, I try to use some words that make me look smart."

## Tahina

Tahina, born in Samoa, is the youngest of eight children, and her mom was widowed when she was two years old. Tahina's grandparents lived in Hawaii, and after her grandfather passed away, Tahina's mother moved their family to Hawaii to take care of their grandmother; Tahina was seven years old at the time. She indicated that her mom always planned on moving back to Samoa, but ended up staying in Hawaii so Tahina could have a better education, but they still returned for extended amounts of time during her childhood. In Tahina's culture, family and duty are integral parts of their society, and when Tahina was in college, her mom's health deteriorated, and she became her full-time caregiver until she passed ten years later. Tahina shared that the village where she is from has a weekly meeting where they discuss family matters, and she added, "Sometimes I feel like even that it's more about the big extended family rather than your little family." Tahina lives in a rural area in Hawaii where her daughter attends school, and one of the teachers is a close relative. She said that when her daughter was evaluated, and the educational team recommended she attend a self-contained preschool, she didn't have any objections because she felt comfortable with the education team. She went on to say, "I was just really not like, 'I don't care,' but I'm just like, 'Okay, I mean, as long as you guys know what you're doing, you're the one working with her.'"

#### Results

This study was guided by the central question: What are the lived experiences of immigrant families in the United States who have a child with a disability? Purposeful sampling provides enriched insight into each participant in the homogeneous sample's specific experience with the phenomenon being investigated and adds knowledge to the phenomenon through the interview process (Creswell & Poth, 2018). The results of this study are presented through reflective analysis an interpretive processes recommended by van Manen (1997). Four themes were identified in the data that align with the theoretical foundations of the influence of social environments after analyzing and triangulating individual interviews, timelines, and online questionnaires.

## **Theme Development**

Hermeneutic phenomenology is the interpretive process by the researcher to interpret the meaning of the participants' lived experiences in the study (Creswell & Poth, 2018). The biases and assumptions of the researcher are essential to the interpretive process and require the researcher to engage in self-reflection throughout the process (Laverty, 2003). To accomplish this, I read and reread as I transcribed the in-depth individual interviews (Appendix H) to capture the essence of significant statements, key concepts, and ideas in the data (Creswell & Poth,

2018). I wrote exploratory notes (Appendix K) on each participant's experiences, selected significant experiential statements, and clustered them into the logical structure of emergent theme (Appendix L) (Smith & Nizza, 2022). This process was repeated for each participant. The emergent themes were clustered one by one into similar groupings (Appendix I), and from there, as broader themes emerged, I went back into the data to select experiential statements to support the broader themes (Appendix J). I color-coded experiential statements by participants to ensure that the broader theme represented multiple participants. I repeatedly went back to the central question and sub-questions to ensure that as I engaged in the interpretive process of analyzing the data, I did so with the central question as my guide.

Each of the ten participants was actively engaged throughout the interview process, completed a questionnaire before meeting for the interview, and created a timeline at the beginning. Six individual interviews were conducted in person, three interviews were conducted via Google Hangouts, and one interview was conducted via telephone. All interviewees were recorded and interviews lasted between 40 and 90 minutes. The interviews were semi-structured, utilizing pre-written interview questions (Appendix G) with follow-up and prompting questions. The six participants who had in-person individual interviews created timelines (Appendix F) at the beginning of the interview, and the participants dictated the remaining four. I wrote them out for the participants and then showed and reviewed them with the three participants over Google Hangouts and reviewed them over the phone with the final participant. All ten questionnaires were completed independently via Google forms before the individual interviews (Appendix E).

Themes	Sub-Themes
The Value of Connection	Personal Connection
	Social Connection
	Professional Connection
Parent Perspective and Experiences	Relying on God to Guide Parenting
	Acceptance of Disability Diagnosis
	Guilt
The Advocacy Process	Examples in Advocating
	Developing your Voice
	Building Courage to Speak Up
	Empowered to Collaborate
Challenges and Barriers Faced by Families	Recognizing and Valuing the Importance of
	Language
	Impact of Strained Family-Professional
	Relationships
	Mental Toll

The interview questions for the individual interviews were developed to encourage participants to share their motivation to immigrate to the United States and transition to life there. As participants described their experiences, a core value of connection was identified from analysis of the data. Moving to a new country and leaving everything you know behind can be a very challenging and uncertain time. Eight participants left their country and immigrated to the United States for better opportunities for their families. Sylvia pointed out, "You know, we came here like everybody else we know with no work, no, nothing, you know. We come here to give my kids a better life." The opportunities in the United States allowed Jose to grow his family and be able to provide for them as a high school teacher, which was not possible in Mexico. He emphasized,

And I am so glad that we moved because I told my kids if we didn't move here, half of you wouldn't be born because it's next to impossible to have six kids in Mexico. With three, it was a challenge. Three more, no, we couldn't have done it, and so that was a huge, huge, huge change, but I love it.

Two participants had different motivations for moving to the United States. Tahina described her culture's importance and responsibility for caring for the elderly, and her mom moved their family to Hawaii from American Samoa to take care of their elderly grandmother. Tahina recounted,

We moved here when I was like nine because my mom came to take care of her mom. Okay, my grandma, her mom, is living with her brother here, and he needs help. So we moved here so my mom could take care of her, and like not too long after we moved here, she passed away. I think, my mom always intended to move back to American Samoa, but I think she stayed here for me. Anna was the only participant to leave her country under dire and dangerous circumstances,

My parents passed on that, and then we had to leave like people have to leave the country because of, you know, the war that was on. So that is why I left and my, you know, my dad's friend, who helped me like to leave, you know, trying to help a lot of people to leave, that is how I came to America, so that's why I left at 16. It wasn't easy.

Despite the different reasons for leaving their home countries, the need for connection among familiarity from their culture was a common thread throughout the interview process. Throughout the interview process, the value of connection was prominent, with the superordinate themes emerging: personal, social, and professional.

### **Personal Connection**

Participants generally left their home countries surrounded by extended family and friends. They moved to the United States, where they were all alone like Anna or only had their small immediate family with them, and it was a lonely time for many of them. Anna recalled, "I remember I couldn't even smile during that time. I wasn't smiling. I wasn't a smiling person. I would just stare. I don't have anybody." Rachel reflected, "When I moved here, it's different. You feel like alienated. It was hard. I was being supported by my mom back in the Philippines. But when I moved here, I didn't have any support." Being in a new country and away from family, language, and culture can be a very lonely experience. Ava described the experience,

I was young. And I was just used to my experiences, you know, my culture, how we viewed things because, you know, it's islanders against everybody else, or it will be like islanders against, like, what you deem the white people who are taking over or come to, like, take away your culture or, you know, instill themselves in it. So it's like, now I have this child. I'm already intimidated because they're already seen as kind of like better, you know, more educated. You know, they have the expertise. I didn't have much education at that time. So it was a very lonely time.

Jose echoed similar feelings when he moved his family to the Midwest, "It was challenging in Kansas. I think we met two people who spoke Spanish. That was it. I don't remember like having a community. We were more than looking for the Latino community; it was most challenging." While the transition to a new country is a trying and challenging time, adding a child who has a disability adds a whole new level of feelings of alienation and being alone. Tara described the feelings of being a mother to a toddler with ASD as "I feel like now it's becoming more normal to have a child with autism, but a lot of people still don't understand until it happens to them. They don't feel what we feel and experience." Sarah, whose daughter is now in upper elementary and having been diagnosed with ASD right before her third birthday, has been dealing with the struggles that come with having a child with behaviors that are not often accepted by others, such as "I feel, you know, the judgment, and though I don't feel uncomfortable with the things that are going on with my daughter. I don't take her to parties. I haven't since she was diagnosed." While all participants expressed gratitude and appreciation for their life in the United States and its opportunities, it does not remove the struggles and pain of leaving their homes to start over in a new country.

## Social Connection

Multiple participants discussed their meaningful connections with others from their home countries. Rachel is from a military family, and at their first duty station, they sought out others from the Philippines. "So, there we have a big Filipino community there. That's where I got my

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support." Anna credits a man she met in Texas, whom she calls her godfather, for helping her transition to the United States:

He really liked to teach me like, 'Hey, this is what you have to do. You have to work hard

in America. If you want to make it. You know, coming from Africa. You don't know anything, and finding someone who helps you and pushes you is like it's a blessing.' He also pushed her to remember her roots and to stay connected to her culture. Anna elaborated, "So he's the one who found me people from my country. He said you have to keep up with your culture. It's very important. Yeah, he finds me Congolese people, and they're like one of my Congolese family people." When asked about connections with other families who have a child with a disability, Tara and Kyle, who are friends, got together as families and talked about the connection they had with each other due to their sons being autistic. "Good thing we have friends over there, our friends are the ones that helped us out."

The participants spoke in depth about the connections they sought out with those from their culture, but other than online support groups, they did not feel the same pull to connect with other families who have a child with a disability. Sylvia commented,

In this area, I don't know anybody with the same condition as him, and I work with special needs kids, and I've never met one. I just have a Facebook group, you know, with some information, or if you need help with something, you can ask them, but I don't really have a support group.

When you have a child with extensive medical needs such as Sylvia, the social connections are often minimal, and she relies on her husband and older sons as her support system and acquaintances she meets at church, but working full-time and taking care of her son has limited her opportunities to make and develop social connections. Working and caring for a child who has extra needs and, therefore, extra appointments and therapy sessions can make it hard for parents to make connections with others. Rachel shared, "I don't have time to, like, go, you know, spend time with friends, and that's when I had like started not going out with my friends, and I don't even have close friends anymore." Parents sacrifice a lot of their own time and energy to care for their families, and a child with a disability requires a lot of sacrifice from parents.

# **Professional Connection**

The connection and relationship between parents and schools/professionals can create a safe and comfortable feeling for parents or become a very stressful experience for both parties, especially parents. A trusting relationship between parents and professionals is beneficial for the child. When there is trust, it can be an empowering experience for the parents and assist them in working and helping their child's development. Anna's experience was positive when working with the EI service providers who came into her home.

You guys come to help. Not you coming to harm the kid. No, you're coming to give help like as much as you can. So this kid can get better on whatever concern the parents have. So the parent has to open up and be like, hey, this and that, you know, and hey, we noticed this. They're helping me but so they're not telling me what to do. But they're helping me realize that what are the things that I can work with my daughter.

Adam, who often travels for work, has made it a priority to get to know the teachers and therapists who work with his son and tries to connect with them whenever he is home by dropping off and picking up his son from school, attending teacher conferences, open houses, and IEP meetings. He described his connection as, "I have a great relationship with his therapist, and his school teachers and staff. And every time I get a chance to see them, talk to them. I always do." Tahina also interacted positively with their child's teacher and felt like they made time to connect school and home, "The teacher was good. The teacher was very helpful. They just get you, you know, they make time to explain how things go." Unfortunately, this is not the case for all the participants, and many had their trust broken and did not feel like there was a strong relationship between home and school, which caused a lot of turmoil and stress in their personal lives.

During IEP meetings, Ava did not feel like she had a safe and secure connection with the school and concluded,

I think they see parents as like the enemy and they're not interested in like, you know, building good relationships because I guess they feel like maybe they're giving you

ammunition to sue later. And you know, so I don't feel that support, especially now.

She is not alone in feeling like the school saw parents as the "enemy," and Sarah described going "to battle" and having "a lot of stress from fighting the school." Her relationship with the principal at her daughter's school was very strained. When asked about her relationship with the school, she replied,

I don't care if she doesn't like me because, you know, they have to give compensatory services for, like, almost a year of instruction that my daughter missed. And they really don't like me, and I get that, and you know, I can't help that. I'm just advocating for my daughter.

While she felt vindicated in her advocacy, the strained relationship between home and school did have an adverse effect on her health, "I got into depression. I got more depressed because of fighting and stress and a lot of stress from fighting the school." The school-home connection can have a positive effect where parents feel like they are being heard and a part of their child's education, or they feel like they are seen as the enemy and have to "fight and battle" against the school who, as Anna commented, are "there to help."

### **Parent Perspective and Experiences**

A common thread that was woven through the participants is the feelings of being overwhelmed by the challenges that accompany their child's disability, whether this be the behaviors, frustrations over communication, doctor and therapy appointments, or the sacrifice of their well-being in order to care for their child. In eight of the ten interviews, participants mentioned that in their country of origin, family members or others would say their child or other children with similar delays were "just late." It needs to be clarified if concerns regarding delays in a child are dismissed or if there remains the belief that children grow and develop at their own rate or if parents lack understanding regarding development. Kyle described his experience,

So, in our culture, like they're not aware of a lot of disabilities and delays. They say hey, he's a male, and he's late in his progress. They don't care about autism. Probably, there is like less information about autism, so they don't know; it's not a big deal back in the Philippines.

When Rachel's daughter was not hitting the milestones for her age, the pediatrician expressed concern and recommended that she seek EI services. Rachel added that up to that point, she had not been concerned over her daughter's lack of language development and thought, "Oh, she's just not talking, but she's gonna be fine. Yeah, like she's gonna talk so that I wasn't too worried, I guess." It was not until a later evaluation by a speech pathologist that they told Rachel that her two-year-old was at the speech level of a nine-month-old infant that she became concerned, "So it's a more reality for me like okay, that's a huge difference. So that was my wake up. That's when I realized, okay, there's really something wrong."

Parents are known to worry and feel guilty and overwhelmed, but throughout the interviews, these feelings penetrated through many of the different experiences shared by the participants. Kyle talked about how he and his wife worry about their son's development because their older child can speak in phrases at this age. Now, living in the United States, their son is having completely different experiences as he is not surrounded by family, and they feel like their son has missed out on all the language and experiences their daughter had from living with cousins when she was younger. Several participants in the study reported experiencing anxiety and guilt while raising a child with a disability. However, some expressed the importance of relying on their faith in God to navigate these challenging situations. All participants expressed an abundance of gratitude and love for their children.

## **Relying on God to Guide Parenting**

During the interview process, six of the ten participants spoke about their faith and reliance on God to help guide them as a parent of a child with a disability. Anna, Sylvia, Adam, and Ava spoke extensively about how they relied on God to navigate life. They leaned on Him as they went through challenges and trials and made decisions regarding how they lived and supported their child. Ava emphasized how her faith has helped her to be a better mother,

I really factored into my faith and like I'm like, really my biggest prayers just like, Okay, Lord, You trusted me with her. You have to give me what I need in order to be a good mom to her and make sure that you know she is where she needs to be and what I need to say to people and, like, give me the courage because sometimes it's scary even when you're saying it.

Adam, from Morocco, believes each child, regardless of disability, is a gift, and expressed his view on raising a son with ASD, "We're blessed. And we're going to turn that blessing into a way of thanking God for having you, so we're gonna give you the time. Our best way to thank God for you is to give you time." Relying on God and having faith that He is aware of you grows gratitude. As Sylvia put it, "I'm pretty sure God moved me over here because over there, I don't know if he would still be alive. But I thank God he moved me over here because over here, you have more opportunities and more resources." Anna conveyed the same sentiment with her move to the United States and meeting others who helped her through transition as she reflected, "When you are by yourself, and God bless you with people who can help you. You have to take the opportunity. So I took the opportunity." While raising a child is full of challenges, raising a child who has a disability presents a whole other level of challenges for parents and the child. Gratitude and a willingness to see that there is a bigger picture helped parents navigate the challenges they faced as parents who had a child with additional needs. Anna's faith came through in our conversation as she mentioned relying on God, trusting in God's plan, and getting through the hurt and pain of loss by believing in God. Her face lit up when she talked about going to church. Anna continued, "It's still hard, but I look at the stuff from the right angle. I always say that God knows why he allowed that to happen. "Like God gave you these kids to you. Thank Him instead of hiding them."

## Acceptance of Disability Diagnosis

Suspecting a diagnosis compared to receiving an official diagnosis from the doctor can be a very overwhelming experience. It is a difficult journey to get a diagnosis and understand the condition. All the participants spoke of growing up in school and having little to no interaction with individuals with disabilities, so they were charting new territory with their child's diagnosis. Each participant shared their unique experience with disabilities before becoming a parent of a child with a disability. Anna's interaction in Africa was minimal with individuals with disabilities, and she talked about the maltreatment and neglect they often endure. Still, her experiences in the United States gave her hope, watching school teachers compassionately feeding and caring for students and parents on social media sharing their child's disabilities and therapies. When talking about her child's communication delays, Anna discussed that while her family would respond understandingly and encouragingly regarding her daughter's communication delays and reassure her that she would eventually talk, others would not and would look at her like there is something wrong with her, and "the pain" that would accompany having your child looked at with judgment.

Tahina's first child was a micro preemie, and after that experience, they embraced the attitude of, "nothing is gonna surprise us now. Like with the rest of our kids. It's just like, yeah, let's just go with, just go with it." Tara's son, who is a twin, had been diagnosed with ASD the week before our interview and spoke of the surreal feelings she felt when the doctor told her that her son was autistic. She described those feelings as,

Our whole world just stopped, you know in the movies they can hear, but not understand. And then they say, 'Oh, what's that? I'm sorry.' It took a minute for me to understand the doctor giving us my son's diagnosis.

Tara discussed the grieving process and fear she felt for her son's future and how the diagnosis brought clarity and answered questions, yet it was not the life she envisioned for her son or her family. Tara summarized as,

It's really different knowing what he gots now, but it feels good. Also, that he got diagnosed. We know now. We know how to communicate with him now. Regarding my patience with him because before I didn't know what to do anymore, but now, like, it's okay, more patience. Kyle described how, at times, his son would interact and play with him, and other times, it was like he was in his own world, completely oblivious to those around him. He questioned the interactions as, "Sometimes he confuses me because he will look at me and play and then not even notice me. That's what I like stay confused and I think does he have autism or not." Kyle hung his head and paused before adding, "I don't know." When Sylvia's son received his diagnosis, the extended family accepted the diagnosis with varying levels of support and understanding, with some members being more emotionally supportive than others. When I asked Sylvia how she felt when the doctor told her the diagnosis, she shared, "Yeah, I cried the whole time. But then you realize that you have to go on."

The diagnosis is the beginning of the story. Slyvia told it well, "I said we've been through a lot because it's not just his diagnosis it's the rest that comes with it." Jose's family, who moved from Mexico to the United States, had never heard of ASD until their younger son was diagnosed,

Well, we had no idea what was going on. So it was very new for us. And then we have a lot of recommendations, and you have to do this, and you have to do that we're just following what the doctors and everybody was saying. But it's been, it's been a journey. It's been tough. It's been very, very difficult.

After processing the diagnosis, he described that he and his wife pointed out to each other, "Okay, we cannot sit down and cry. We have to do something." They packed up their family and moved from Austin to New York to receive therapy for their young son at the Autism Center of America. Jose recounted that they knew they were going to do anything needed to help their son: "We had to do whatever we could with the information that we had, so it was challenging. To be honest with you. It was it was challenging." Jose's immediate family sacrificed for the benefit of their son and brother. While it was a very challenging time for their family, Jose reiterated that it was a sacrifice he would make again for the benefit of his son's prognosis and quality of life: "Not wrong, just different." It was intriguing as Tara worked on rephrasing words when describing her son's behaviors, such as licking the floor and "humping the ball," from "odd" behavior to "different one." The parents spoke respectfully of their child and the unique behaviors they demonstrated and often shifted their wording to "not wrong, just different" and "different, but still okay." The respect and love each parent had for their child was evident in the way they spoke of them, their disability, and the challenges they face.

### Parents' Experiences of Feeling Guilt and Stress

The stress and worry that comes from a child with a disability were felt by 80% (n = 8) of the participants in this study. Sarah worried about her daughter's future, and Tara worried about how society would treat her son. Parents also felt guilt surrounding their child's delays and placed much blame on themselves for the delays, believing that they were to blame for the delays, which placed many burdens on them and often left them feeling alone and hopeless over the diagnosis. The shock and fear that came with the diagnosis often left them feeling hopeless, overwhelmed, and depressed. The participants' understanding of the models of disability seemed to shape the way they viewed and understood disabilities and also correlated with some of their feelings regarding disabilities. The participants who seemed to view disabilities through a medical model expressed more impact on mental health than the participants who seemed to view disabilities through a social model. Tara and Kyle both hoped that their children would be able to outgrow the diagnosis and live a "normal life." Anna spoke of the judgment and vulnerability that accompanied disability in her country of origin, and many of the participants

spoke of the stress that came with trying to ensure their child was receiving the services needed to support them.

While many participants spoke about guilt concerning the extra attention required by their child with a disability, Jose did not mention guilt; he expressed challenges, struggles, barriers, trying their best as parents, and providing opportunities to their kids, but he did not express guilt. He gave himself grace as a parent, saying,

It's been hard because you keep your attention on the kid that needs the most. And you assume that the rest are going to be okay because they are normal. So, we probably make the mistake of not giving enough attention to others, but nobody teaches us how to do that. So yeah, you have to learn the on-the-go.

In contrast, Sarah struggled to feel she was doing enough for her older son. When asked how her daughter's disability impacted her son, she replied,

I try to treat them the same, but sometimes it is hard. So, I put my son in soccer. I make him busy so he will not notice my lack of affection. I'm tired. Tired of the catering to my daughter and yeah, and sometimes I don't give attention to my son. What I do is put him in soccer, put him in karate class, put in, you know, put him in this...

Feelings of inadequacy and guilt for the attention that is spent on the child with the disability and not on the other children are leaving parents feeling depleted. Ava, a working mother of three, described the feeling as,

It is draining; you're tired. And you are then feeling the guilt of, like, you have to give all this extra attention to this child and like hoping that your other children are not like, oh, why did she get that or why? You know how come you're always taking off to go with her or why you always, so just a lot of that like drain of like, Am I doing enough? Am I good enough? Have I done enough?

During the interview with Sylvia, when asked about the impact of her son's disability on her other children, she replied, "It's hard for me to explain to my other kids that they need me so much. But if they needed me, I would do the same thing for them." She went on to tell how she has to miss some of her other children's activities because of appointments and how her son had a routine check-up at the children's hospital three hours away, and he ended up hospitalized for two weeks; she did not have as much as a toothbrush with her and had other stories of unexpected hospitalization and the stress it placed on their family.

Rachel struggled to know how to connect and interact with her daughter who has a disability. Connecting with her older son was not an issue for her, but with her daughter, she explained, "I just cannot relate to my daughter. I didn't know how to relate to her in that in a way that she'll understand, or I can teach her." When asked about her experience with EI, Rachel stated that she did not see progress in her daughter's development and went on to say,

I guess that it was me who was the problem, like, why EI didn't work. We would never follow through with what we received in the services. It did not help her. And so we kind of blamed ourselves why she's falling behind is because of us; yeah, we'll buy her toys, but we don't play with her.

### **The Advocacy Process**

The study participants came from countries with strong cultural values in the family. Kyle described the importance of family in his culture, "In our culture, family is important. If, your family is eating, everyone should be eating. Everyone should be at the table. That's what we do." Tahina talked about the importance of the extended family and how the village she is from has a weekly meeting to discuss family members. Moreover, she expressed the responsibility to the family to help each other out and that the focus is more on the extended family unit than the smaller unit. She said, "Sometimes I feel like even that it's more about the big extended family rather than your little family." In cultures where the immediate and extended family are invested in each other, it can be challenging to use your voice to advocate for your child and their educational rights. It is a process that can be challenging to many, but it is a skill that can be learned. Education plays a role in a participant's level in the advocacy process. An authority bias is the tendency to attribute greater accuracy to the opinion of an authority figure and be more influenced by that opinion (Howard, 2018). Authority bias was more significant in participants who did not discuss education compared to the participants who talked about their education or educating themselves on their child's disability and rights.

### **Building Advocacy Skills Through Role Models**

A question guiding this study was: How do immigrant families describe their experience and relationship with school leaders and teachers? As participants reflected and spoke on their experiences with EI providers, teachers, and school leaders, they often spoke of individuals in their lives who assisted them in the process of speaking up and asking questions through conversations with the individual or having them present in formal meetings with school leaders and teachers. Ava wasn't familiar with the word *advocate* when her daughter started school and spoke fondly of her daughter's resource teacher, who would pause and take the time to clarify things for her during meetings and talk with her outside of the meetings to help educate and inform her of their rights and her daughter's rights. Ava stated,

Her resource teacher was the first teacher that ever mentioned the word advocate to me. And that was the first time I heard advocate and the first time I heard about like, you can deny this, and you can say no to this, and like what she has in her IEP. So, she would stop and pause and say, 'Mom, did you really understand what they just said?' You know, and I know they would give her dagger eyes, but she would stop and ask, and that was the start of my journey of like, okay, I need to look and see and more of what it looks like to advocate for my daughter.

Sylvia described a similar experience with her son's homebound teacher and how she would advocate to ensure he had what he needed to be successful. Sylvia related that the language barrier made it difficult at times, but because they both had the same goal of ensuring her son had the best educational experience possible, they were able to work through the challenges of language. Sylvia elaborated, "Yeah, his awesome homebound teacher he's had since he was five; she was the one that was fighting for everything. I asked her to come to every IEP meeting, she's been a blessing and loves my boy."

While teaching professionals served as examples in advocating for Slyvia and Ava, social media provided examples for Tara, Anna, Kyle, and Rachel. Anna mentioned that it is not common in her country for parents to show their child on social media if they have a disability,

I like in America you will see people who has like a kid with disability they will put them on TikTok talking about like if you notice this or you notice that in your children you know, by the fact of having the courage to post their kid to put them there to encourage other parents it's a big thing for me. When I look at those parents, I was like they're strong, and they really love their children.

Expounding on the influence of social media, Tara mentioned that in the Philippines, celebrities were using their social media to share their experiences as parent advocates for children with ASD. Tara remarked, "It also kind of like gives me hope." Sarah discussed with a friend her

frustrations over her child's placement in a general education class where her needs were not being met and how she did not know how to get her daughter the services that she needed when the mom exchanged her own story of hiring an advocate to fight for her son's educational needs,

I got to know the mother of my son's friend, and I shared that my daughter has autism, and she shared that her son had autism too, and they had to fight the school too. And that they won, and she recommended that I get an advocate, so I hired an advocate.

Mothers help mothers, or even more, mothers who have a child with disabilities, help and support each other by sharing their experiences and resources.

## **Developing your Voice**

The participants described their experiences collaborating with school personnel concerning the development and implementation of the child's Individualized Education Program as a process of growing their knowledge and exercising their voices by asking questions of the school personnel regarding their child. Sarah felt frustration and confusion during COVID when her daughter participated in online learning, and she witnessed her daughter's lack of participation in the class. She observed the students engaging with the teacher in the live Zoom classes. At the same time, Sarah's daughter paced in circles in the living room, completely unaware of the class happening on the computer, and Sarah began to question what was happening in the classroom when her daughter was in school and stated,

So finally, I said, I'm going to find out what's going on and what's good. You know, you're a mom you have to learn and me if I don't know something I Google and I selftaught myself. All my knowledge was like from the internet. I just self-taught myself if you have the money, you can hire an advocate and a lawyer, so I did that. Lucky me, I have the resources to fight for my daughter's right to her public education. Sylvia also spent time educating herself about her son's medical condition and reported that before and after every appointment, she spent much time searching and reading on the internet not only about his condition, but also the procedures and recommendations from the doctor; this mindset transferred as he went through his schooling and his physical needs were not being met in the classroom setting. Slyvia explained, "That's the thing that you, as a mother, have to choose to look, search, and learn about all of the things for your kids." It can be an intimidating experience to speak up about your child with professionals during a meeting or appointment, especially if you need more knowledge about the topic.

The ability to speak up can be challenging for some parents. However, Ava acknowledged these challenges and added,

In the beginning, you are nervous to ask questions, or you just don't know what questions to ask. Yeah, I didn't know what questions to ask. Because sometimes they say a lot of acronyms. And I hate that because I don't know all that stuff. And they are still doing it. But now I know more, or I can ask what that means. But before, I don't know what to ask; I don't know what he needs. First, I didn't know about accommodations or, you know, all that stuff that he was meeting.

Education is a powerful tool for developing participants' voices to speak up to meet their child's needs and rights. Rachel expressed during the interview that she did not feel like EI was beneficial to her daughter, but never spoke up during her sessions when she needed more clarity regarding the service, "I stay quiet, whatever. Whatever is told, whatever it is, they tell me to do. I just do and don't talk too much." Rachel went on to express that she did tell the care coordinator that she did not need EI services any longer, but the care coordinator talked her into keeping them. Rachel agreed to continue services even though she does not feel they benefit her daughter.

# Building Courage to Speak Up

The more participants educated themselves and spoke up, the more empowered they felt in being able to do so in their interactions with professionals regarding their children. During the data analysis, the influence of education and advocating for their child emerged, and so did a tendency for authority bias, which refers to the tendency to follow and accept the opinions and instructions of authority figures without questioning them (Howard, 2018). Three of the participants did not indicate they had pursued education or self-educating regarding their child's disability and diagnosis; instead, they relied on the information provided by authoritative sources. On the other hand, three different participants expressed feelings of timidness at the start of the journey as parents of a child with a disability. However, as they educated themselves, created connections with others, asked questions, and grew their confidence, they were better equipped to advocate, ask questions, and position themselves to participate actively in their child's schooling and IEP process. Sarah highlighted her journey to gaining her voice and speaking up for her daughter, who she believed her needs were not met in the classroom setting,

All my knowledge was like from the internet. I just self-taught myself that if you have the money, you can hire an advocate and a lawyer, so I did that. Lucky m*e* that I have the resources to fight for my daughter's right to her public education.

Ava went on to say, "I hope I don't make a fool of myself by asking this, but I have to because she can't, you know, so it's still scary." Sylvia expressed the importance of taking ownership and not relying on others to tell you "what is best for your child;" she went on to say, "I think you

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have to learn you have to search for yourself about a lot of stuff. If you want your son to be successful, you know what they mean."

Four participants spoke of the formal education they earned before having their children. None of these four participants talked of authority bias, and all demonstrated an attitude of being comfortable advocating for their child. Jose confidently declared he had no problem speaking up during IEP meetings because he is an "educated man," and he had expectations for his son and the school. Anna also expressed the importance of speaking up and asking questions regarding the concerns you have as a parent to ensure that you can receive the assistance and help required for your child to be successful and reiterated the importance of speaking up by saying, "Parents have to open up and say their concerns. If I do not express my concerns, they cannot help me with them." Tahina had to learn that using her voice and speaking up or saying "no" is not associated with being unkind or mean. She feels comfortable expressing her thoughts and concerns regarding her child because "It doesn't hurt anybody's feelings. Like, I mean, everybody understands, like, if you say no to something, you know, you don't always have to say yes. Or, like, stay quiet about things." Preparing for the meetings beforehand also helped parents feel more comfortable speaking up. Ava described a strategy she uses to prepare for her daughter's IEP meetings, "I write out what I expect to see since her last IEP and I ask a lot of questions. I'm not as afraid to challenge when a teacher says something I disagree with, I will question them." When problems or conflicts did arise during the meeting, Ava was prepared to address them right there in the meeting,

I'm like, no, they, you know, they work for us, you know, basically, or you know, they're here for our daughter, and but, yeah, so, because of that experience and how upset I was about that. That pushed me a little bit more to like, learn more, and do more. And then once that other thing happened, I was more prepared to say, hey, you know, you can't just say these things and show me where it says so and have it in writing.

# Table 3

Participants	Authority	Authority	Authority	Discussed	Discussed	Education
	Bias	Bias	Bias Not	Formal	Self-	not
	Reflected	Reflected	Reflected	Education	Educated	discussed/
	Now	Beginning				mentioned
Rachel	Х					Х
Anna			Х	Х		
Tara	Х					Х
Sarah		Х			Х	
Kyle	Х					Х
Tahina			Х	Х		
Ava		Х			Х	
Jose			Х	Х		
Sylvia		Х			Х	
Adam			Х	Х		

# Authority Bias and Education

# **Empowered to Collaborate**

When teachers and administrators engage with parents and are intentional to communicate and collaborate with families, it helps cultivate collaborative home-school relationships, which often motivates parents to take an active role in their child's education. Strong collaboration serves students, parents, and the child's educational team. For parents and the educational team to collaborate, trust must be established to create open and constructive lines of communication (Sears et al., 2021). The relationship suffers when there are no constructive interactions between parents and the educational team. Jose prefaced that he went into meetings with high expectations and wanted it to be known that he would not be walked all over. He declared, "Day one, I expressed what I wanted and what I was expecting, and they knew that okay, this is not an easy family." Sarah, who advocated because she felt her daughter was not receiving FAPE, won the dispute, and when I asked about her relationship with the principal, she replied,

My relationship with the principal is not really good. I don't care if she likes me or doesn't like me because I'm just advocating for my daughter. So I fought the school, and I was the mean guy because I fought the school. And it's not for me, it's for my daughter. They know what my daughter needs, but then they don't give it right away. You have to fight for it, or you have to ask for it. I think the word is not asking. I think you really have to dig into what your child needs and then prove to them that your child needs it.

Sarah went on to say that while her relationship with the principal was not healthy, she had a good relationship with her daughter's teacher, and they had constructive communication and felt like they had a trusting relationship. She said, "I am not only advocating for my daughter, but also for the teachers because they cannot teach and watch my daughter like they are there to teach, not to take care or not to babysit."

Meeting with teachers and doctors can be a stressful experience for families, and they may leave a meeting feeling like they were not heard or did not share their thoughts and concerns. Ava noted that preparing for the meetings helps her to be more confident in using her voice to advocate for her child when something comes up during the meeting that she disagrees with or wants more clarification before making a decision. She said,

I write out what I expect to see, like what I'm hoping to see for her based on the last IEP. And I do ask a lot of questions. And I'm not as afraid to challenge like when a teacher says something I don't agree with, I say, 'why are you doing this?'

Advocating for your child does not only happen in school settings. Parents of children with disabilities often find they have to advocate for their children in various situations. Tara told how a friend criticized her for seeking an ASD diagnosis for her two-year-old son, telling her that he was too little to be diagnosed with ASD and that if she gave him time, he would grow out of it. Tara emphasized,

You know, as a mom, we know, if there's something wrong, and I want to offer, my child, the best thing we could like offer him, which is, you know, whatever he needs, like the therapies and stuff like that.

Tara added that she hopes to help educate others about ASD so that more parents can get the resources they need for their children, and those who do not have a child with ASD can learn more about ASD through her and her son.

# **Challenges and Barriers Faced by Families**

All the participants in the study faced challenges and barriers related to being immigrant parents who have a child with a disability. At the same time, the challenges and obstacles varied by participants. Three common ones displayed in multiple interviews are the challenges of learning English while trying to maintain their native language and teach their children their native language. Learning the language spoken by the educational teams and doctors is another barrier faced by immigrant families, as educational professionals often use acronyms when speaking about special education disabilities and services. Another common challenge participants face is the impact on families when there is a strained relationship with the school education team. The third challenge that many families face is the mental toll that having a child with a disability takes on parents and families. The stress of health and behavior issues can be very challenging and leave parents often feeling overwhelmed and alone in their struggles.

# **Recognizing and Valuing the Importance of Language**

Several participants spoke multiple languages and dialects and grew up in homes where language was a big part of their identities and family. Anna lit up as she talked about the three languages she spoke growing up in Africa. The joy that her language brings to her and the way it creates part of her identity was apparent as she smiled and laughed, talking about how she would converse with someone who also spoke all three languages. Jose teaches Spanish at the local high school and, in his 30 years of teaching, has met many students whose parents did not teach them their native language, and he felt like this was a disservice to these students. He explained that when his kids walked in his family's front door, they were only to speak Spanish. Jose felt they had enough exposure to English in school and on television, so he felt comfortable making Spanish mandatory in their home. None of the participants requested or accepted interpreters when meeting with their child's educational team, but being unable to speak in their native tongue also limited their ability to collaborate during their meetings.

Rachel acquiesced,

I wish I did request for Tagolog because it's more personal for me, and then I could ask a lot more questions. I feel it's more personal, and you get comfortable easier because most of the time, I forget words that I wanted to say, and then sometimes they end up filling in the words that you're missing because you can't think of the right term and you just settle for yes, just because you can't of think of them.

Sylvia addressed the language challenges she faced and admitted that she became aware that her children were also aware of these challenges when they questioned, "Why do you say 'yes,' Mommy, if you don't know? Well, because it's easier to not let them know that you don't know." Slyvia elaborated on the challenges of speaking a different language. She often felt dismissed by medical providers and educators because they assumed her accent indicated she was "not smart" and did not understand what was being said. However, she assured me that although she may struggle to express herself, she is intelligent and does understand what is being told to her. Sylvia explained how she prepared for appointments and meetings for her son by reading and researching the upcoming topics so that they would take her seriously when she had something to say, "Because I have my accent, I tried to use some words that make me look smart." Rachel shared that she hesitated to speak up and ask questions because she felt selfconscious of her limited English. She said, "But a lot of people test your intellect on how good you speak in English. So, I'm afraid to not be able to speak good English and be judged, and that's why I stay quiet."

During IEP meetings, many participants felt left out of the educational conversation. They struggled to understand the acronyms and professional language used by the education team. Sylvia expressed, "Yeah, I didn't know what questions to ask. Because sometimes they say a lot of acronyms. And I hate that because I don't know all that stuff. And they are still doing it." Sarah's experience corroborated the language challenge, "It was really hard because I'm not familiar to any of those languages that they use. I don't understand what they're talking about. I can't do it on my own because, you know, my English is a limited language."

## Impact of Strained Family-Professional Relationships

The family-school relationship is beneficial for all involved. A strain in the relationship due to a lack of trust and a communication breakdown can hurt the families. Jose described his experience with the different schools his son attended and his lack of trust and communication with them.

I was always fighting with the school, and all the goals that they had for him were just unreal. It's unreal because they tried to justify it, and I am not sure of this, but I'm sure they didn't do what they're supposed to because I cannot see their results. If you don't do it, there's no way you can see results. So I am very sure that they did not do what they were saying. So yeah, that was very frustrating for me. It was not just one school; it was several schools that he attended. I wasn't very happy because the therapists and the teachers, they say, for example, they say that my son said something that I know it is not true. So they were trying to lie to us to try to make us believe that he is making great progress, and that really, really made me mad because instead of saying, Oh, he's not making progress, they would make things up but have no proof. That was one of the things that really made it very frustrating to me.

Jose and Ava described experiences in an IEP meeting where they felt like the color of their skin was a barrier for them. Jose said,

So, you know I learned the hard way, of course, that if you don't scream or you don't raise your voice, people don't listen to you, especially if you are brown or black. They think that or they assume that you're stupid or ignorant.

Ava recalled about the speech therapist who dismissed her concerns because they were black and expounded,

It just came across as we're not going to work on teaching these sounds because she's black, and there's no need to work on this with a black person. So, I was offended by that because it was like you have yet to get to know us, to know how well or not well we speak. I was just saying, like, it's not fair for you to say 100% of black people do these things with sounds. Show me in writing where it says you can't.

Sarah also indicated that she felt dismissed during meetings when she brought up concerns regarding her child and went on to tell her frustrations,

They don't like if you ask questions. They expect you to be tame and not talk that you just keep nodding what they want. You're not really part of the team because they already made their decision that this and that, and you are just there. They were just informing you what decisions they have made already. Because they don't care. How can my daughter like, learn in school? If they don't, nobody is there to help her. Eat, drink, or go to the bathroom? My daughter will come home with a dirty diaper. Number two in there, and it's hard to know when it was there when she did, and it was hard. There came a time when I said I was not going to put my daughter to school because of this. She rather not learn anything then go to school if she is neglected like this.

Sylvia recalled that during an IEP meeting, they discussed her son's physical needs and the type of desk he would need with his wheelchair to be able to participate in class with his classmates in middle school and how the trust was broken the first day of middle school,

When he went to middle school, we had to have an IEP meeting because they had to rearrange things for him at school and told us what they were going to do. They didn't do it. The first day, they didn't have anything; he didn't have a desk and had to write on his lap. They didn't have anything, you know, and he feels so bad that he didn't want to go back.

The lack of follow-through was a breach of Sylvia and her son's trust in the school that resulted in him feeling like it was not a place where he could be successful and part of the general population, so he made up his mind to do homebound study and finished the rest of middle school from his home.

#### Toll on Mental Health

Parents of children who have a disability deal with much stress, and a strained relationship between parents and schools adds to the stress of parents, resulting in anxiety and depression. Sarah, who fought with the school and district regarding her daughter's placement, dealt with depression afterward and ended up taking her children out of school early for a vacation to the Philippines. Sarah described this stressful time, "I got more depressed because of fighting and stress and a lot of stress from fighting the school. I decided I had to get away, or I would lose my sanity." They didn't finish the school year and extended their time in the Philippines, hoping that time with family and away from school would help with her depression.

When asked how the behaviors impacted the family's daily life, Tara said, "Sometimes I get frustrated like my husband knows, like (imitating wanting to scream)." ASD is complex, and the behaviors can invoke feelings of frustration. Another participant corroborated the frustration she feels with her child, especially during the middle of the night when her child can be up for hours at a time, "I just don't know how to respond because sometimes, you know, especially during the night, and I am trying to get my sleep, and I don't, I can't control myself all the time." Tahina talked about how frustrated she feels when she isn't able to understand her daughter due to her communication delay and how this can also cause her daughter to become upset and frustrated when her needs are not being met due to a lack of understanding. Ava described how she often felt inadequate as a mother and worried about who would be there for her daughter when she was gone:

I'm always doing my best. So, sometimes I felt like less than a mom or just like, man, no matter what I do, it's not enough. I feel worried because I know, even now, that she'll always have to have someone in her corner. And I know I'm not always going to be there. And no matter how many things I teach her, she's still going always to need that and the worry and the fear as a mom, like, I'm not doing enough. I'm not doing enough to get her where she needs to be so that the day comes when I'm no longer here. You know, how's she going to do without me, so there's a lot of fear and worry in the emotional piece of, like seeing the same thing over and over in different ways and knowing that she hasn't gotten it she's not gonna get it until she's ready to get it. It's draining, I'm tired.

The participants throughout their interviews expressed love and appreciation for their child, but the mental toll was still evident throughout the interviews.

### **Research Question Responses**

The ten participants completed an online questionnaire, created a timeline of their lives, and participated in one-on-one interviews. Data triangulation revealed the importance of connection, perspective, advocacy, and challenges. The following is a synthesis of the overarching themes as they answer the central and supporting research questions.

## **Central Research Question**

The central research question guiding this study asked: What is the lived experience of immigrant families in the United States who have a child with a disability? The findings identified four central themes: the value of connection, the perspective and experiences of parents, advocacy, and challenges and barriers. Participants' data consistently demonstrated a strong association regarding the need and value of connecting personally, socially, and with professionals. Participants described a common perspective of the importance of their culture in their lives, how they raised their family, and how they viewed and interacted socially. Perhaps the most prevalent feeling among the participants was the connection they felt toward others from their country of origin. The familiarity of someone from their country created an instant connection. In an interview with Ava, she described how she sought out connections from her

culture without realizing that was what she was doing, "When I joined the military, I gravitated toward people closer to my culture. I was used to interacting and dealing with my own race and culture type." Moving to a new country and raising a child with a disability without the surrounding support of family, friends, and the familiarity of your language and country has shown to be challenging for the participants. However, the nature of this study shows parents who grounded themselves in faith in God, courage, and love for their children.

## **Sub-Question One**

The first support question inquired: What role do culturally based understandings of disability and special education play in immigrant families' participation in special education? Several participants described their limited interactions with individuals with disabilities and had minimal to no memory of attending school with students who had disabilities. Anna, who is from Africa, recalled eating lunch in her high school in Texas as a 16-year-old and seeing students with disabilities for the first time in a public school setting. She went on to say,

In our town growing up I never saw a school just for special needs. And I was even surprised when I was going in high school. I will see special kids in high school. They always have like a seat for them there. And I will see like, teacher taking care of them was like, wow, this is so different. In my country, there will be you know, they create and then nobody approached them and when I see the way they take care of them, I will say yeah, this country just beautiful. Oh, it was so neat. It touched me.

Recognizing and valuing the importance of language was an intricate part of the findings, and not only the languages spoken, but also the language used by professionals created gaps and confusion for participants as they interacted and participated with their child's educational team. The essence of the findings is the parents' ability not only to accept their child's diagnosis, but also to shift their mindset to be proactive in finding the best way to help their child. Tara summarizes it well, "Yeah, I cried the whole time. But then you realize that you have to go on."

## **Sub-Question Two**

The second support question addressed: How do immigrant families describe their experience and relationship with school leaders and teachers? Findings from the data revealed that participants' experiences and relationships with school leaders and teachers varied; these findings are less surprising when we consider the ages and severity of the disabilities. Participants who had older children reported a more complex relationship with their child's educational team that evolved from year to year, while the participants who had younger children reported positive experiences and interactions overall with their experiences and relationships. Sarah is a parent of a daughter in upper elementary with ASD and had to "fight the school." She described her relationship with a school leader,

My relationship with the principal is not really good. I don't care if she likes me or doesn't like me because I'm just advocating for my daughter. So I fought the school, and I was the mean guy because I fought the school. And it's not for me, it's for my daughter. They know what my daughter needs, but then they don't give it right away. You have to fight for it, or you have to ask for it. I think the word is not asking. I think you really have to dig into what your child needs and then prove to them that your child needs it. Parents of children with less demanding needs tended to feel like the service providers and teachers efficiently met their child's needs.

## **Sub-Question Three**

The final support question examined: What are immigrant families' experiences collaborating with school personnel with respect to the development and implementations of the

child's Individualized Education Program? The federal law (i.e., IDEA, 2004) mandates that parents have a right to participate in their child's identification, evaluation, and placement. Yet, some participants felt passive, and their voices regarding their children were not heard during the meetings. As parents learned more about their child's disability and rights under the federal IDEA law, they became more confident in speaking up, asking questions, and advocating for their child's academic needs. A few participants described a very amicable and collaborative relationship with their child's educational team, while others had very different experiences working with their child's educational team. Four participants noted their English fluency, accent, and skin color as barriers to how school professionals treated them. Jose explained,

So that you know I learned the hard way, of course, that if you don't scream or you don't raise your voice, people don't listen to you, especially if you are brown or black. They assume that you're stupid or ignorant.

The participants who had faced challenges in collaboration had taken steps to educate and prepare themselves to be active members of their child's educational team.

#### **Summary**

This chapter described the experiences of 10 immigrant parents who have a child with a disability. Four themes emerged from the research, along with supporting subthemes. The data provided convincing evidence demonstrating the power and value of connection within one's culture and the importance of language. The findings provide insight into the barriers and challenges faced by immigrant families who have a child with a disability and how the language of special education may position parents in less agentive ways as their child's educational advocate. While parents faced many challenges raising their children in a new country, they demonstrated a determination to provide their children with the best education and opportunities

they could, and this is often done through sacrifice by the parents, which can take a mental toll on their health and well-being. However, the love they have for their child keeps them determined.

#### **CHAPTER FIVE: CONCLUSION**

#### **Overview**

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant families with children with special needs in the United States public school system. This chapter begins with a summary of the findings relevant to the participants' experiences as immigrant parents who have a child with a disability, followed by an interpretation of the results and discussion of implications for policy and practice as well as the theoretical and empirical implications. Delimitations and limitations are then discussed and recommendations for future research are proposed. The chapter concludes with a summary of the most significant implications of this study.

#### Discussion

IDEA (2004) clearly states that parents should be involved in all decisions regarding placement, services, present level, goals, services, and eligibility of children with disabilities (Kurth et al., 2020). However, there is a gap in the literature regarding the barriers immigrant families who have a child with disabilities face in developing relationships with schools and navigating special education programs and services. The literature indicates communication challenges as a significant barrier to developing meaningful relationships (Haines et al., 2021). Communication barriers must be addressed for families and schools to create a collaborative partnership.

The purpose of this hermeneutic phenomenological study was to understand the lived experiences of immigrant parents who have a child with special needs in the United States public school system. Ten parents who immigrated to the United States from various places worldwide participated in this study. Four participants immigrated from the Philippines, one from the Congo of Africa, one from Samoa, one from Mexico, one from Morocco, one from the Virgin Islands, and one from Puerto Rico. The question guiding this study was, "What are the lived experiences of immigrant families in the United States who have a child with a disability?" The central research question was established based on the theoretical framework of bioecological theory (Bronfenbrenner, 2005). This research contributes to the limited literature regarding the barriers faced by immigrant families navigating special education programs and collaborating with their child's educational team. Pivotal findings from this study include the power of connection, parent perspective and experiences, the advocacy process, and challenges and barriers families face.

## **Interpretation of Findings**

The findings from this study are summarized in the thematic findings developed from data collection, analysis, and thematic development. The summary gives a brief overview of the four themes described in Chapter Four, followed by an interpretation of the findings, relating to theoretical and empirical literature, detailing the new knowledge concerning the lived experiences of immigrant families who have a child with a disability.

## **Summary of Thematic Findings**

The findings revealed that immigrant parents of children with disabilities value connection that supports them personally, socially, and with the professionals who work with their children. Positive relationships were discovered to be a fundamental part of a parent developing their voice to be an educational advocate for their child. The findings revealed that parents are better equipped to advocate for their child when they have a person modeling the advocating process, rely on their faith in God as a guide, and self-educate themselves by researching their child's educational rights. Participants demonstrated a strong emotion of determination as they adjusted to life in a new country while honoring the country and culture they came from, as well as being determined and hopeful about their child's future and being willing to make great sacrifices for their child to have a positive outcome in life.

## Language and Communication

The findings of this research corroborate previous studies that consistently demonstrate that language can be a significant obstacle for immigrant families. This language barrier can hinder parents' ability to actively participate in their child's educational team, resulting in challenges when acting as their child's educational advocate. Several studies, including Adams and Santos (2021), Guerrero and Sobotka (2022), Norheim and Moser (2020), Raymond et al. (2022), and Willemse et al. (2018) document this issue. Rachel reinforced this point when she reported that she would have been more comfortable asking questions and actively participating throughout her daughter's evaluation and follow-up meeting had it been in Tagalog. Therefore, since the meeting was in English, Rachel did not ask questions or express her concerns and remained primarily quiet throughout the evaluation and meeting. The data also provides strong evidence that the inability to speak and understand English fluently is a significant barrier immigrant parents face. The results in this study are in congruence with the communication challenges immigrant families face in developing meaningful partnerships with the teachers and administration (Guerrero & Sobotka, 2022; Haines et al., 2021; Rivard et al., 2020). This research study demonstrated findings similar to those of the research conducted by Rivard and colleagues (2020), where misunderstandings and miscommunication created barriers between families and schools. Participants expressed the challenges and frustrations of understanding the professional language used in IEP meetings and talking with teachers and service providers for EI services. Participants described the limitations they felt in the meetings with the jargon used by the school professionals and EI providers, resulting in confusion, lack of clarity, and unmet

expectations for the parents. Sylvia elaborated on her frustration over using educational jargon and acronyms in meetings that left her confused and unable to follow the conversation. The results of this study solidify that the inability to understand the use of language hinders the development of a collaborative atmosphere for parents (Lim et al., 2020; Patriksson et al., 2018; Rivard et al., 2019).

## **Relationships within the Microsystem**

The research findings provided compelling evidence of stress, feelings of being overwhelmed, and loneliness by immigrant parents raising a child with a disability. Researchers (Shepherd et al., 2021) in New Zealand conducted a study to understand the experiences of parents of children with ASD. They surveyed 658 parents through an online questionnaire and found that the majority of parents experienced clinical levels of psychiatric distress, specifically anxiety (Shepherd et al., 2021). The study's findings are significant, as they highlight the need for increased support and resources for parents of children with ASD. The findings in this study illuminate the challenges faced by parents of children with ASD and corroborate the findings from my study, which also include children with cognitive disabilities, communication delays, and physical and health disabilities. According to Bronfenbrenner's (2005) bioecological theory, development and growth are not a solitary process, but are heavily influenced by those in their microsystem. Novak et al. (2019) and O'Connor et al. (2021) indicate the importance of supporting parents as they navigate through the various stages of emotions, including denial, anger, fear, and sadness, upon receiving the disability diagnosis. The significance of this support can make a difference in parents' feelings of stress, being overwhelmed, and feeling loneliness.

Participants in this study expressed the challenges and the social impact of raising a child with a disability. Sarah expressed embarrassment and frustration regarding her daughter's behaviors in public, "When she has the meltdowns, it was hard. It is hard." The result is that Sarah, like many other parents in the study, limited social interactions, which may result in feelings of loneliness that can be overwhelming and lead to a host of other mental health issues (Macdonald et al., 2018). An overarching theme within the study was the feeling of being alone; alone in a new country and alone in navigating their child's disability. These feelings can be exasperated when a conflict exists between families and schools. Ava described her experience when her child was young, and the intimidation she felt in the IEP meetings from not yet having her education and not being from the United States and described that, "It was a very lonely time." This finding affirms Nowland and colleagues' (2021) conclusions that parental loneliness can have significant and lasting effects on the mental health of both parents and their children across generations.

## Implications

The findings of this study hold significant implications for policy and practice related to educational policymakers, school districts, public schools, staff members, and immigrant parents. These implications are discussed in the following sections, including recommendations for each to support family and school partnerships.

## **Implications for Policy**

Special education services can vary significantly around the world, which can leave immigrant parents feeling confused and overwhelmed with the referral and eligibility process in the United States. Challenges are heightened when information is not provided in a parent's preferred language. The results of this study underscore the critical role of language accessibility for parents in facilitating a collaborative partnership with teachers and the school. The research findings reveal a two-pronged approach: first, providing families with special education resources translated into native languages empowers parents to engage on their terms. The second approach is providing cultural liaisons who act as bilingual and bicultural advocates and go beyond interpreting and can bridge a gap between families and schools; a cultural liaison can assist in minimizing potential misunderstandings and facilitate communication between families and schools (Adams & Santos, 2022; Haines et al., 2018; Rosetti, 2017). The research demonstrated a positive correlation between parental education and their confidence in speaking up and advocating for their child. Parent education programs that offer workshops that focus on navigating the school system, advocating for their child, and special education services can assist immigrant parents as an introduction to the public school system with an emphasis on special education services. Therefore, it is recommended that a policy be developed to require schools to educate parents on the referral process, IEP meetings, and their children's and their rights as parents. Educating parents through workshops designed with awareness of cultural perspectives of disabilities and education with qualified cultural liaisons allows them to hear the specifically designed workshops in their native language. Providing translated presentations, hand-outs, and brochures in multiple languages that are void of education jargon and using clear, concise language can assist in creating informative workshops that educate and empower immigrant families. These trainings will allow parents to play active roles in their child's education, which can be done at the state and district level to ensure that all parents receive the same information and resources in their preferred language and are tailored to the various immigrant communities. **Implications for Practice** 

Findings from this study have implications for practice that administrators, special education teachers, and other general education team members might consider helpful in building communicative collaborative relationships with immigrant families. The findings of this study concur with previous research regarding the struggle between parents and teachers to collaborate to meet the needs of a child with a disability (Camard et al., 2022; Francis et al., 2017; Guerrero & Sobotka, 2022; Rivard et al., 2020; S'lungile et al., 2015). Administrators may want to focus on professional development, emphasizing the importance and "how-to" of building open communication lines between teachers and families to establish collaborative partnerships between school and home with a focus on using plain language communication that avoids all jargon and is clear and concise in addition to using multiple communication channels to reach and improve communication between schools and families.

Another recommendation for schools to focus on with their teams is cultural awareness by organizing cultural competency training to educate the staff on diverse backgrounds, communication, and experiences. Utilizing the community to learn about resources that can connect and benefit families is another way to build trust and rapport between schools and families. The participants in this study spoke extensively of their culture and its influence on how they lived their lives. These results align with research by Esposito and Setoh (2021), who argue that one's culture significantly shapes and impacts all facets of behavior, emphasizing parental beliefs, social expectations, behaviors, and parenting strategies used within families. Organizing events to celebrate cultural diversity and promote practices that help create a welcoming and valued environment can build relationships and break down barriers between families and schools.

Special education teachers are uniquely positioned to work closely with students and parents. Building rapport with parents can be complex due to time constraints, language barriers, and various other challenges. Fialka and colleagues (2012) compared the relationship-building process to learning a new dance and broke it down into five steps: Stop, Look, Listen, Share, and

Take Care. Based on the study's findings, the following is a possible implementation of these steps.

The first step is to stop categorizing and labeling families and educators, which can hinder effective communication and collaboration (Fialka et al., 2012). This study found that categorizing and making assumptions about families can lead to strained relationships with them. Casual conversations through informal interactions can create a shared humanity, help educators find common interests with their students' families, and assist in building rapport and developing partnerships that improve student educational outcomes. By nurturing connections with families, special education teachers can move beyond the labels and welcome a collaborative, supportive partnership with families.

The second step is to look closely at what you are saying and doing in your interactions with families. It is imperative to follow through on the commitments made to parents regarding their child (Fialka et al., 2012); participants in the study shared the frustration they felt when commitments and goals for their child were not followed through. When making a commitment or creating goals for a child, it is crucial that there is follow-through and follow-up with parents. When the commitments were not kept, trust was broken between the parents and teachers, which resulted in frustration and strained relationships.

The third step is to actively listen to the families. One key theme in this study was the importance of language to the participants. Specifically, participants emphasized the feeling of being dismissed because of accents and language barriers. Effective communication is essential when building trust and rapport. Using active listening to summarize critical points for confirmation and encouraging open-ended questions to elicit parental concerns and goals fosters

trust and can bridge the communication gap. Utilizing cultural liaisons as bilingual and bicultural supporters can help navigate communication, cultural barriers, and misunderstandings.

The fourth step is to share the positive with the families. In this study, parents expressed the frustration of not knowing what was going on with their children while they were in school. It is important to share regular updates about students with disabilities that go beyond academic progress and to share about students' daily non-academic functioning, including their emotional well-being, participation within the school environment, and social interactions. Fialka and colleagues (2012) discuss the importance of giving families appreciation and positive feedback as parents often second guess themselves, which aligns with the findings of this study. Expressing and acknowledging parents for supporting their child's education and their efforts in collaborating with teachers and schools can go a long way in building confidence and trust with families.

The final step is to take care of the partnership. Acknowledging when missteps happen is vital in maintaining an open dialogue and collaborative partnership between parents and teachers (Fialka et al., 2012). The participants in this study emphasized the value they placed on professional connections with their children's teachers. When there is trust and rapport between educators and families by following the strategies outlined, teachers can create an environment that allows for challenging conversations to take place safely. They have moved beyond labels and recognize the shared humanity through the relationships they have built, which helps to remind everyone that they are on the same team to help children with disabilities flourish. Acknowledging missteps and fostering a safe and trusting partnership leads to collaboration and better student outcomes.

Finding and navigating resources for children with disabilities can be a daunting and complex task for families, especially immigrant families who often have language and cultural barriers coupled with unfamiliarity with the public school system, which can create obstacles for families in securing services for their children. Families can find resources through the local schools. The special education teams and administration can provide resources regarding evaluations, IEP meetings, interpreters, and relevant specialists. Pediatrician offices are also a resource in assisting parents with connection to community-based organizations, including various resources and disability rights advocacy groups that can provide legal guidance if needed.

## **Theoretical and Empirical Implications**

This section addresses the theoretical and empirical implications of the study. Bronfenbrenner's (2005) bioecological theory was a valuable framework for examining the lives of immigrant families as they navigate the complexity of the public school system and special education services. Applying Bronfenbrenner's (2005) bioecological theory to examine the microsystem between families and schools underscores the complexity of the intricate interconnections and how they can positively or negatively impact a child's development. Prior research reinforces the benefit of relationships and partnerships between schools and families (Camard et al., 2022; Francis et al., 2017; Guerrero & Sobotka, 2021a; Haines et al., 2018; Rivard et al., 2020). This study highlighted the impact on families within their microsystem as they face language barriers, little communication with schools, limited social support, the emotional stress of raising a child with a disability, and the stressors when dealing with conflict with their child's educational team. On the other hand, findings from this study establish the importance of connections within the microsystem. Personal, social, and professional connections were found to positively impact parents by providing support, a sense of belonging, and as a resource. Furthermore, this study emphasizes the need for culturally responsive practices that focus on better understanding cultural differences and how that knowledge can be incorporated into building school partnerships by focusing on communication to prompt trust and collaboration, resulting in better outcomes for children. This study adds to the literature on the relationship between caregivers and educators and the importance of educating and empowering both sides to better serve children with disabilities.

Research in the field has indicated that immigrant families encounter numerous challenges (VanHook & Glick, 2020), which become even more daunting when the family includes a child with a disability (Camard et al., 2022; Guerrero & Sobotka, 2022; Rivard et al., 2020; Xu et al., 2022). The results from this study align with previous researchers (Guerrero & Sobotka, 2022; Haines et al., 2021; Rivard et al., 2020) who identified unmet expectations, communication challenges, and misunderstandings as the cause of frustration and conflict when working with schools to develop trusting partnerships. However, this study showed that as parents increased their knowledge and educated themselves on their and their children's rights, they felt more empowered to speak up and better advocate for their children. This reinforced prior research findings that when parents are empowered and are active members of their child's educational team, relationships are formed between schools and families and the outcome is collaborative partnerships that benefit the child's outcome (Flores & Kyere, 2020). Results from this study demonstrate the importance of developing relationships between parents and schools

and how educating parents can positively contribute to their being an active participant in their child's education.

## **Limitations and Delimitations**

As with all research efforts, this study inevitably had delimitations and limitations. Delimitations are the intentional boundaries the researcher sets to study the selected phenomenon adequately. Stating the delimitations allows readers to interpret the findings by clearly understanding the study's boundaries. Whereas limitations of a sampling size can affect the reliability or generalizability of a study, acknowledging the limitations in a study allows a critical evaluation of the research and a better understanding of the potential implications from the study.

## Delimitations

For this study, snowball sampling was used to identify participants by asking participants to identify family or friends willing to participate who had rich experience with the phenomenon. Participants in this study had to be over 18 years of age, an immigrant to the United States, and have a child with a disability receiving special educational services. Since the purpose of this study was to describe the lived experience of immigrant families who have a child with a disability, educational professionals who work with the children were not given an opportunity to provide their voice on developing collaborative partnerships with families.

### Limitations

The generalizability of these findings is limited due to the study's small sample size of ten participants. If time and resources had permitted, it would have been preferable to include participants who had immigrated to the United States in their later teen years and beyond to gain greater insight into the struggles of navigating a new country. However, due to time and resource constraints, this study includes two participants who moved to the United States during their elementary years. The research study was initially limited to in-person interviews in Hawaii, but opened up to participants across the United States for virtual and telephone interviews due to the difficulty of finding parents to participate in Hawaii. Six interviews were held in person, three were conducted virtually via Zoom, and one was held over the telephone. This did not interfere with the data collection or the rapport between the researcher and participants. One potential limitation of this study is that the significant majority, 70% of the parents, had a child younger than eight years old. As a result, the study did not adequately capture the voices of parents who have navigated middle and high school special education services with their children.

## **Recommendations for Future Research**

Review of the literature revealed significant gaps in research regarding immigrant families, especially those who have a child with a disability. This study focused only on the experiences of immigrant parents. Further research is needed to explore parents' and teachers' experiences in developing and evaluating effective collaborative partnerships. A case study designed to examine parent education programs that emphasize advocacy training modules and their effectiveness in building a collaborative educational team with parents and families can also be beneficial in closing the gaps for immigrant families. It would also be beneficial to include studies of families who have older children and learn from their experiences in how they have evolved over the years in their advocacy process. Also, studies that examined parent support groups that partnered with schools to increase parent education and participation would benefit parents, teachers, and students.

## Conclusion

This hermeneutic phenomenological study presented the experience of immigrant parents (N = 10) who have a child with a disability receiving special educational services in the United

States. Data were collected through questionnaires, timelines, and 1:1 interviews. Results from this study establish the value of connection and the importance of education in empowering parents to use their voices as advocates for their children. The results from this research were interpreted through the lens of Bronfenbrenner's (2005) Bioecological theory, confirming the impact that the microsystem has at the proximal ecological level, including the home environment and a school setting, directly impacting a child and, therefore, the family. The results from this study also aligned with other research on communication barriers, which has identified the use of educational jargon as a significant challenge for immigrant families in establishing relationships with schools. Implementing professional development for schools emphasizing the importance and "how to" of communicating with families can help break down the barriers in building collaborative relationships and focus on parent education to assist parents in advocating for their children as they collaborate with schools.

#### References

- Acar, S., & Blasco, P. M. (2016). Guidelines for collaborating with interpreters in early intervention/early childhood special education. *Young Exceptional Children*, 21(3), 170–184. https://doi.org/10.1177/1096250616674516
- Adams, N. B., & Santos, R. (2021a). A call for support for refugee families and their children with disabilities. *Exceptionality*, 1–15. https://doi.org/10.1080/09362835.2021.1938059
- Adams, N. B., & Santos, R. (2021b). Resettlement education case managers' roles supporting refugee families with children with disabilities. *The Journal of Special Education*, 56(2), 63–72. https://doi.org/10.1177/00224669211018861
- Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semistructured interviews. JACCP: JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY, 4(10), 1358–1367. https://doi.org/10.1002/jac5.1441
- Anderson, S. E., & Putman, R. S. (2019). Special education teachers' experience, confidence, beliefs, and knowledge about integrating technology. *Journal of Special Education Technology*, 35(1), 37–50. https://doi.org/10.1177/0162643419836409
- Arakelyan, S., & Ager, A. (2020). Annual research review: A multilevel bioecological analysis of factors influencing the mental health and psychosocial well-being of refugee children. *Journal of Child Psychology and Psychiatry*, 62(5), 484–509. https://doi.org/10.1111/jcpp.13355
- Armstrong, A., Johansson-Fua, S., & Armstrong, D. (2021). Reconceptualising inclusive education in the pacific. *International Journal of Inclusive Education*, 1– 14. https://doi.org/10.1080/13603116.2021.1882057

- Balcazar, F. E., Suarez-Balcazar, Y., Adames, S., Keys, C. B., García-Ramírez, M., & Paloma,
  V. (2011). A case study of liberation among latino immigrant families who have children with disabilities. *American Journal of Community Psychology*, 49(1-2), 283–293. https://doi.org/10.1007/s10464-011-9447-9
- Barbour, R. S. (2017). *A new era in focus group research: Challenges, innovation and practice* (1st ed., 2017). Palgrave Macmillan.
- Bešić, E., Paleczek, L., & Gasteiger-Klicpera, B. (2018). Don't forget about us: Attitudes towards the inclusion of refugee children with(out) disabilities. *International Journal of Inclusive Education*, 24(2), 202–217. https://doi.org/10.1080/13603116.2018.1455113
- Blatt, B. 1.-1. (1974). *Christmas in purgatory: A photographic essay on mental retardation*. Human Policy Press.
- Camard, S., Chatenoud, C., & Rivard, M. (2022). "we've got to fight; that's the story of our lives": Advocacy experience of immigrant families of children with autism spectrum disorder. *Early Years*, 1–15. https://doi.org/10.1080/09575146.2022.2047898
- Camoarota, S., & Zeigler, K. (2022). Foreign-born population hits nearly 48 million in September 2022. CIS.org. https://cis.org/Report/ForeignBorn-Population-Hits-Nearly-48-Million-September-2022
- Carew, M. T., Deluca, M., Groce, N., & Kett, M. (2018). The impact of an inclusive education intervention on teacher preparedness to educate children with disabilities within the lakes region of Kenya. *International Journal of Inclusive Education*, 23(3), 229– 244. https://doi.org/10.1080/13603116.2018.1430181
- Ceci, S. J. (2006). Urie bronfenbrenner (1917-2005). American Psychologist, 61(2), 173– 174. https://doi.org/10.1037/0003-066x.61.2.173

- Chinn, P. C. (2004). Brown's far reaching impact. *Multicultural Perspectives*, 6(4), 9–11. https://doi.org/10.1207/s15327892mcp0604\_4
- Chudzik, M., Corr, C., & Wolowiec-Fisher, K. (2022). Trauma: Early childhood special education teachers' attitudes and experiences. *Early Childhood Education Journal*. https://doi.org/10.1007/s10643-021-01302-1

Cigrand, D. L., Fawcett, M., Miyakuni, R., Arredondo, P., & Onderak, G. (2021). A phenomenological study of perseverance and resilience through the migration journey. *Journal of Counseling & Development*, 100(2), 157– 170. https://doi.org/10.1002/jcad.12413

- Clark, H., Coll-Seck, A., Banerjee, A., Peterson, S., Dalglish, S. L., Ameratunga, S., Balabanova, D., Bhan, M., Bhutta, Z. A., Borrazzo, J., Claeson, M., Doherty, T., El-Jardali, F., George, A. S., Gichaga, A., Gram, L., Hipgrave, D. B., Kwamie, A., Meng, Q.,...Costello, A. (2020). A future for the world's children? a who–unicef–lancet commission. *The Lancet*, *395*(10224), 605–658. https://doi.org/10.1016/s0140-6736(19)32540-1
- Collier, M., Kingsley, K. V., Ovitt, B., Lin, Y.-L., & Romero Benavidez, J. (2017). Fostering collaboration with families of children with disabilities: Online professional development for k–12 teachers. *The Teacher Educator*, 52(2), 138– 154. https://doi.org/10.1080/08878730.2016.1273421
- DeMatthews, D. E., Serafini, A., & Watson, T. N. (2020). Leading inclusive schools: Principal perceptions, practices, and challenges to meaningful change. *Educational Administration Quarterly*, 57(1), 3–48. https://doi.org/10.1177/0013161x20913897

Diab, S. Y., Palosaari, E., & Punamäki, R.-L. (2018). Society, individual, family, and school factors contributing to child mental health in war: The ecological-theory perspective. *Child Abuse & Neglect*, 84, 205–

216. https://doi.org/10.1016/j.chiabu.2018.07.033

- Dodgson, J. E. (2020). Quality in research: Asking the right question. *Journal of Human Lactation*, *36*(1), 105–108. https://doi.org/10.1177/0890334419890305
- Douglas, P., Cetron, M., & Spiegel, P. (2019). Definitions matter: Migrants, immigrants, asylum seekers and refugees. *Journal of Travel Medicine*, 26(2). https://doi.org/10.1093/jtm/taz005
- Ediyanto, Maulida, R., Atika, I., & Kawai, N. (2020). The pre-service teachers' attitudes towards inclusive education: An empirical study in yogyakarta city, indonesia. *Discourse and Communication for Sustainable Education*, 11(1), 65–73. https://doi.org/10.2478/dcse-2020-0007
- Eleweke, C., & Rodda, M. (2002). The challenge of enhancing inclusive education in developing countries. *International Journal of Inclusive Education*, 6(2), 113– 126. https://doi.org/10.1080/13603110110067190
- Elkind, D. (1998). Children with special needs: A postmodern perspective. *Journal of Education*, *180*(2), 1–16. https://doi.org/10.1177/002205749818000202
- Fellin, M., King, G., Esses, V., Lindsay, S., & Klassen, A. (2013). Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability. *International Journal of Migration, Health and Social Care*, 9(3), 135–145. https://doi.org/10.1108/ijmhsc-07-2013-0024

- Feriver, Ş., Olgan, R., Teksöz, G., & Barth, M. (2020). Impact of early childhood education settings on the systems thinking skills of preschool children through the lens of bronfenbrenner's theory. *Systems Research and Behavioral Science*, 39(1), 85– 103. https://doi.org/10.1002/sres.2749
- Flores, O. J., & Kyere, E. (2020). Advancing equity-based school leadership: The importance of family–school relationships. *The Urban Review*, 53(1), 127– 144. https://doi.org/10.1007/s11256-020-00557-z
- Francis, G. L., Haines, S. J., & Nagro, S. A. (2017). Developing relationships with immigrant families: Learning by asking the right questions. *TEACHING Exceptional Children*, 50(2), 95–105. https://doi.org/10.1177/0040059917720778
- Gisewhite, R. A., Jeanfreau, M. M., & Holden, C. L. (2019). A call for ecologically-based teacher-parent communication skills training in pre-service teacher education programmes. *Educational Review*, 1–20. https://doi.org/10.1080/00131911.2019.1666794

Grant, C., & Osanloo, A. (2014). Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your "house". *Administrative Issues Journal Education Practice and Research*, 4(2). https://doi.org/10.5929/2014.4.2.9

- Guerrero, M., & Sobotka, S. A. (2022). Understanding the barriers to receiving autism diagnoses for hispanic and latinx families. *Pediatric Annals*, 51(4). https://doi.org/10.3928/19382359-20220322-03
- Haines, S. J., Francis, G. L., Kyzar, K. B., Aldersey, H. M., & Adams, N. B. (2018). Familyprofessional partnerships with refugee families of children with disabilities.

In International review of research in developmental disabilities (pp. 35–70). Elsevier. https://doi.org/10.1016/bs.irrdd.2018.07.002

- Hamilton, R., & Moore, D. (2003). Educational interventions for refugee children. Routledge.
- Hayes, A. M., & Bulat, J. (2017). Disabilities inclusive education systems and policies guide for low- and middle-Income countries. *RTI Press*. https://www.ncbi.nlm.nih.gov/books/NBK554622/ (Reprinted from)
- Hibel, J., & Jasper, A. D. (2012a). Delayed special education placement for learning disabilities among children of immigrants. *Social Forces*, *91*(2), 503–530. https://doi.org/10.1093/sf/sos092
- Hibel, J., & Jasper, A. D. (2012b). Delayed special education placement for learning disabilities among children of immigrants. *Social Forces*, *91*(2), 503–530. https://doi.org/10.1093/sf/sos092
- Hofstetter, J., & Mchugh, M. (2021). Hawaiis immigrant and U.S.-born parents of young and elementary-school-age children: Key sociodemographic characteristics [PDF]. https://www.migrationpolicy.org/sites/default/files/publications/m pi\_nciip\_parents-children-0-4-and-5-10-hi-2021\_final.pdf
- Howard, J. (2018). Bandwagon effect and authority bias. In *Cognitive errors and diagnostic mistakes* (pp. 21–56). Springer International Publishing. https://doi.org/10.1007/978-3-319-93224-8\_3
- Hu, B., Mak, M., Zhang, C., Fan, X., & Zhu, J. (2017). Chinese parents' beliefs about the importance and feasibility of quality early childhood inclusion. *International Journal of Disability, Development and Education*, 65(2), 163–182. https://doi.org/10.1080/1034912x.2017.1358809

Individuals with disabilities act. (2018, May 25). U.S. Department of Education. https://sites.ed.gov/idea/regs/b/a/300.8

- Kast, J., Lehofer, M., Tanzer, N., Hagn, J., & Schwab, S. (2021). Parents' attitudes towards students with a background of migration—does the background of migration matter? *Studies in Educational Evaluation*, 70, 101014. https://doi.org/10.1016/j.stueduc.2021.101014
- Kelty, N. E., & Wakabayashi, T. (2020). Family engagement in schools: Parent, educator, and community perspectives. *SAGE Open*, *10*(4), 215824402097302. https://doi.org/10.1177/2158244020973024
- Khanlou, N., Haque, N., Sheehan, S., & Jones, G. (2014). "it is an issue of not knowing where to go": Service providers' perspectives on challenges in accessing social support and services by immigrant mothers of children with disabilities. *Journal of Immigrant and Minority Health*, 17(6), 1840–1847. https://doi.org/10.1007/s10903-014-0122-8
- Kim, J.-H. (2016). Understanding narrative inquiry: The crafting and analysis of stories as research (1st ed.). SAGE Publications, Inc.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *BMJ*, *311*(7000), 299–302. https://doi.org/10.1136/bmj.311.7000.299
- Kreitzer, L., McMenemy, C., & Yohani, S. (2022). Expanding our understanding of the environmental impacts on refugee resettlement through the application of Bronfenbrenner's bioecological theory. *Local Development & Society*, 1–22. https://doi.org/10.1080/26883597.2022.2087046
- Kubota, H., Raymond, H., Caine, V., & Clandinin, D. (2021). Understanding social inclusion: A narrative inquiry into the experiences of refugee families with young

children. *International Journal of Early Years Education*, *30*(2), 184– 198. https://doi.org/10.1080/09669760.2021.1998885

Kurniawati, F. (2021). Exploring teachers' inclusive education strategies in rural indonesian primary schools. *Educational Research*, 1– 14. https://doi.org/10.1080/00131881.2021.1915698

- Kurth, J. A., Love, H., & Pirtle, J. (2019). Parent perspectives of their involvement in iep development for children with autism. *Focus on Autism and Other Developmental Disabilities*, 35(1), 36–46. https://doi.org/10.1177/1088357619842858
- Majoko, T. (2017). Inclusion of children with autism spectrum disorder in mainstream early childhood development: Zimbabwean parent perspectives. *Early Child Development and Care*, 189(6), 909–925. https://doi.org/10.1080/03004430.2017.1350176
- Malchar, S. E., Praytor, S. E., Wallin, A. C., Bistricky, S. L., & Schanding, G. (2019).
  Evaluating family-school collaboration: A preliminary examination of the family-school collaboration inventory. *Contemporary School Psychology*, 24(2), 206–216. https://doi.org/10.1007/s40688-019-00227-2
- McAuliffe, M., & Ruhs, M. (2018). *World migration report* [PDF]. International organization for migration. https://publications.iom.int/system/files/pdf/wmr\_2018\_en.pdf
- Mokaleng, M., & Möwes, A. D. (2020). Issues affecting the implementation of inclusive education practices in selected secondary schools in the Omaheke region of Namibia. *Journal of Curriculum and Teaching*, *9*(2),

78. https://doi.org/10.5430/jct.v9n2p78

Moschen, S. A., Macke, J., Bebber, S., & Benetti Correa da Silva, M. (2019). Sustainable development of communities: Iso 37120 and un goals. *International Journal of* 

Sustainability in Higher Education, 20(5), 887–900. https://doi.org/10.1108/ijshe-01-2019-0020

Muthukrishna, M., & Henrich, J. (2019). A problem in theory. *Nature Human Behaviour*, 3(3), 221–229. https://doi.org/10.1038/s41562-018-0522-1

Nations, U. (2017). *A/res/71/1: New york declaration for refugees and migrants* [PDF]. https://www.un.org/en/development/desa/population/migration/generala ssembly/docs/globalcompact/A\_RES\_71\_1.pdf

Neuman, S. B. (2016). Opportunities to learn give children a fighting chance. *Literacy Research: Theory, Method, and Practice*, 65(1), 113–

123. https://doi.org/10.1177/2381336916661543

- Norheim, H., & Moser, T. (2020). Barriers and facilitators for partnerships between parents with immigrant backgrounds and professionals in ecec: A review based on empirical research. *European Early Childhood Education Research Journal*, 28(6), 789– 805. https://doi.org/10.1080/1350293x.2020.1836582
- Paat, Y.-F. (2013). Working with immigrant children and their families: An application of Bronfenbrenner's ecological systems theory. *Journal of Human Behavior in the Social Environment*, 23(8), 954–966. https://doi.org/10.1080/10911359.2013.800007
- Preschool: Voices of immigrant parents in preschool settings. (2014). YC Young Children. http://www.jstor.org/stable/ycyoungchildren.69.4.32
- Rabiee, F. (2004). Focus-group interview and data analysis. *Proceedings of the Nutrition Society*, 63(4), 655–660. https://doi.org/10.1079/pns2004399
- Raymond, H., Clandinin, D., Kubota, H., & Caine, V. (2022). Bumping places of social inclusion: A narrative inquiry into the experiences of refugee families who have a child

who is living with a disability. *Equity & Excellence in Education*, 55(1-2), 73–86. https://doi.org/10.1080/10665684.2022.2076781

- Rivard, M., Millau, M., Mello, C., Clément, C., Mejia-Cardenas, C., Boule, M., & Magnan, C. (2020). Immigrant families of children with autism disorder's perceptions of early intensive behavioral intervention services. *Journal of Developmental and Physical Disabilities*, 33(4), 633–651. https://doi.org/10.1007/s10882-020-09764-8
- Rosa, E., & Tudge, J. (2013). Urie bronfenbrenner's theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review*, 5(4), 243–258. https://doi.org/10.1111/jftr.12022
- Rossetti, Z., Story Sauer, J., Bui, O., & Ou, S. (2018). Developing collaborative partnerships with culturally and linguistically diverse families during the iep process. *TEACHING Exceptional Children*, 50(4), 172–182. https://doi.org/10.1177/0040059918758163
- Sangalang, C. C., Becerra, D., Mitchell, F. M., Lechuga-Peña, S., Lopez, K., & Kim, I. (2018). Trauma, post-migration stress, and mental health: A comparative analysis of refugees and immigrants in the United States. *Journal of Immigrant and Minority Health*, 21(5), 909– 919. https://doi.org/10.1007/s10903-018-0826-2
- Schunk, D. H. (2019). Learning theories.
- Sharma, U., Armstrong, A., Merumeru, L., Simi, J., & Yared, H. (2018). Addressing barriers to implementing inclusive education in the pacific. *International Journal of Inclusive Education*, 23(1), 65–78. https://doi.org/10.1080/13603116.2018.1514751
- Sharma, U., Forlin, C., & Loreman, T. (2008). Impact of training on pre-service teachers' attitudes and concerns about inclusive education and sentiments about persons with

disabilities. Disability & Society, 23(7), 773-

785. https://doi.org/10.1080/09687590802469271

- Sigamoney, M. N. (2018). *Inclusive education in south africa and the developing world: The search for an inclusive pedagogy (emerald points)* (3rd ed.). Emerald Publishing Limited.
- Slade, N., Eisenhower, A., Carter, A. S., & Blacher, J. (2018). Satisfaction with individualized education programs among parents of young children with asd (ED598698). ERIC. https://files.eric.ed.gov/fulltext/ED598698.pdf
- Smith, J. A., & Nizza, I. E. (2022). *Essentials of interpretative phenomenological analysis*. American Psychological Association. https://doi.org/10.1037/0000259-000
- Subban, P., & Mahlo, D. (2016). My attitude, my responsibility' investigating the attitudes and intentions of pre-service teachers toward inclusive education between teacher preparation cohorts in Melbourne and Pretoria. *International Journal of Inclusive Education*, 21(4), 441–461. https://doi.org/10.1080/13603116.2016.1197322
- Thwala, S. K., Ntinda, K., & Hlanze, B. (2015). Lived experiences of parents' of children with disabilities in swaziland. *Journal of Education and Training Studies*, 3(4). https://doi.org/10.11114/jets.v3i4.902
- Titzmann, P. F., & Lee, R. M. (2018). Adaptation of young immigrants. *European Psychologist*, 23(1), 72–82. https://doi.org/10.1027/1016-9040/a000313
- Toms, O., Reddig, K., & Jones-Fosu, S. (2019). Assessing the diversity-related professional development needs of pre-service teachers. *Journal for Multicultural Education*, 13(3), 236–248. https://doi.org/10.1108/jme-03-2019-0029
- Tudge, J. H., Navarro, J. L., Merçon-Vargas, E. A., & Payir, A. (2021). The promise and the practice of early childhood educare in the writings of urie bronfenbrenner. In *The*

*influence of theorists and pioneers on early childhood education* (pp. 91–100). Routledge. https://doi.org/10.4324/9781003120216-9

- Van Hook, J., & Glick, J. E. (2020). Spanning borders, cultures, and generations: A decade of research on immigrant families. *Journal of Marriage and Family*, 82(1), 224–243. https://doi.org/10.1111/jomf.12621
- Willemse, T., Thompson, I., Vanderlinde, R., & Mutton, T. (2018). Family-school partnerships:
  A challenge for teacher education. *Journal of Education for Teaching*, 44(3), 252–257. https://doi.org/10.1080/02607476.2018.1465545
- World Health Organization. (2020). *Child maltreatment*. https://www.who.int/news-room/fact-sheets/detail/child-maltreatment
- Xu, Y., Zeng, W., Wang, Y., & Magaña, S. (2022). Barriers to service access for immigrant families of children with developmental disabilities: A scoping review. *Intellectual and Developmental Disabilities*, 60(5), 382–404. https://doi.org/10.1352/1934-9556-60.5.382
- Yamauchi, L. A., Soga, C. L., & Char, S. M. (2022). Professional development to improve interactions with culturally and linguistically diverse children: Reflections on practice. *Journal of Early Childhood Teacher Education*, 1–24. https://doi.org/10.1080/10901027.2022.2032491
- Yell, M. L., Bateman, D., & Shriner, J. (2020). Developing and implementing educationally meaningful and legally sound ieps: Bringing it all together. *TEACHING Exceptional Children*, 52(5), 344–347. https://doi.org/10.1177/0040059920919087
- Zabel, R. H., Teagarden, J., & Kaff, M. (2019). Building healthy relationships: A conversation with dr. ellen mcginnis-smith. *Intervention in School and Clinic*, 55(3), 197–200. https://doi.org/10.1177/1053451219842266

## Appendix A

## **IRB** Approval Letter

IRB #: IRB-FY22-23-1761 Title: THE LIVED EXPERIENCES OF IMMIGRANT FAMILIES WHO HAVE A CHILD WITH A DISABILITY: A HERMENEUTIC PHENOMENOLOGY Creation Date: 6-14-2023 End Date: Status: Approved Principal Investigator: Korin Lopez Review Board: Research Ethics Office Sponsor:

### Study History

Submission Type Initial Review	Type Expedited Decisio	Approved
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## Key Study Contacts

Member Korin Lopez	Role Principal Investigator	Contact
Member Korin Lopez	Role Primary Contact	Contact
Member Lucinda Spaulding	Role Co-Principal Investigator	Contact

Date: 4-14-2024

## **Appendix B**

### **Recruitment Email**

Dear Participant,

As a Ph.D. candidate in the School of Education at Liberty University, I am conducting research as part of the requirements for a Ph.D. in Special Education. The purpose of my research is to describe the lived experiences of immigrant families who have a child in the public school system, and I am writing to invite you to join my study.

Participants must be 18 years of age or older, immigrants to the United States, and parents of a child with a disability enrolled in the public school system and receiving special education services. Participants will be asked to fill out an online survey, create a timeline with the researcher, and participate in an audio-recorded one-on-one individual interview. It should take approximately an hour to complete the procedures listed. Participants will have the opportunity to review their interview transcript for accuracy and this should take approximately 15 minutes. Names and other identifying information will be requested as part of this study, but the information will remain confidential.

To participate, please contact me at the provide the first page you see when receiving the link to the survey. The consent document contains additional information about my research. If you choose to participate, you will need to sign the consent document and submit it before proceeding to the survey.

Participation in this study is voluntary, and participants will receive a \$25 gift card. Sincerely,

Korin Lopez Ph.D. Candidate Appendix C

### **Recruitment Flyer**

# **Research Participants Needed**

# THE LIVED EXPERIENCES OF IMMIGRANT FAMILIES WHO HAVE A CHILD WITH A DISABILITY: A HERMENEUTIC PHENOMENOLOGY

- Are you 18 years of age or older?
- Are you an immigrant to the United States?
- Do you have a child with a disability receiving special education services?

If you answered **yes** to each of the questions listed above, you may be eligible to participate in a research study.

The purpose of this research study is to understand the lived experiences for immigrant families in the United States who have a child with disabilities and receive special education services.

Participants will be asked to complete an online survey (15 minutes), create a timeline with me (20 minutes), and participate in an audio-recorded one-on-one interview (45 minutes). Participants will also have the opportunity to review their transcripts (15 minutes).

Participants will receive a \$25 Amazon gift card.

If you would like to participate, please click here or type the you're your browser: https://docs.google.com/forms/d/e/1FAIpQLScEvd5ZSQbsM5cox0c3z0TV3mlmJvdWNKGDingYNHcYi0uoc g/viewform?usp=sf\_link to sign consent and complete the survey. Contact the researcher at the phone number or email address provided below.

A consent document is provided as the first page of the survey.

Korin Lopez, a doctoral candidate in Special Education at School of Education at Liberty University, is conducting this study.

Please contact Korin Lopez at

for more information.

Liberty University IRB – 1971 University Blvd., Green Hall 2845, Lynchburg, VA 24515

#### **Appendix D**

#### **Consent Form**

#### Consent

# Title of the Project: The Lived Experiences of Immigrant Families who have a Child with Disabilities

## Principal Investigator: Korin Lopez, Liberty University, Ph.D. Candidate

#### Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be at least 18 years of age, immigrants to the United States, and have a child with a disability enrolled in the public school system and receiving special education services. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

#### What is the study about and why is it being done?

The purpose of the study is to understand the experiences of immigrant families who have a child with a disability receiving special education services.

#### What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

- 1. Questionnaire: This will be conducted online (15 minutes).
- 2. **Timeline:** Created at the beginning of the interview (20 minutes). You'll be asked to depict important events in your life.
- 3. **Open-ended interview:** This interview will be conducted in person, will be audiorecorded, and take 45-minutes to complete. Participants will have the opportunity to review the interview transcripts accuracy (15 minutes).

#### How could you or others benefit from this study?

Participants should not expect to receive a direct benefit from taking part in this study.

Your participation may significantly contribute to the future training of pre-service teachers and special education teachers currently teaching.

#### What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher and members of the doctoral committee will have access to the records.

- Participant responses will be kept confidential by replacing names with pseudonyms.
- Interviews will be conducted in a location where others will not easily overhear the conversation.
- Data collected from you may be shared with other researchers. If data collected from you is shared, any information that could identify you, if applicable, will be removed beforehand.
- Data will be stored on a password-locked compute and hard copies will be stored in a locked file cabinet. After three years, all electronic records will be deleted, and all hardcopy records will be shredded.
- Recordings will be stored on a password locked computer for three years until participants have reviewed and confirmed the accuracy of the transcripts and then deleted. The researcher and members of the doctoral committee will have access to these recordings.

#### How will you be compensated for being part of the study?

Participants will be compensated for participating in this study with a \$25 Amazon gift card presented upon completion of the study.

#### Is study participation voluntary?

Participation in this study is voluntary. Your decision whether to participate will not affect your current or future relations with Liberty University. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

#### What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please contact the researcher at the email address/phone number included in the next paragraph. Should you choose to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

#### Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Korin Lopez. You may ask any questions you have now. If you have questions later, you are encouraged to contact her at or or or

You may also contact the researcher's faculty sponsor, Lucinda

Spaulding, at



#### Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) is tasked with ensuring that human subjects research will be conducted in an ethical manner as defined and required by federal regulations. The topics covered and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

#### Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

The researcher has my permission to audio-record me as part of my participation in this study.

Printed Subject Name

Signature & Date

Liberty University IRB-FY22-23-1761 Approved on 6-30-2023

## Appendix E

## Questionnaire

## APPENDIX E: DEMOGRAPHIC QUESTIONNAIRE

Name	Date:
Direct	ions: Please answer questions
1.	What is your age?years
2.	Gender: Male Female
3.	Marital status:
	Single Married Divorced
4.	In what country were you born?
5.	Where is your native country?
6.	How long have you lived in the United States?
7.	How old were you when you immigrated to the United States?
8.	What is your citizenship in the United States?
U.	S. Citizen Permanent Resident Have applied for citizenship
9.	What is your native language?
10	. Do you feel fluent in English?
	YesNo
11	. How many children do you have?
12	. Do you have a child with a disability?
	YesNo

13. What is your child's diagnosis?\_\_\_\_\_

14. How would you describe your life **before** moving to the United States?

15. How would you describe your life after moving to the United States?

## Appendix F

## **Timeline Prompt**

## Timeline

The tool for this method is a large piece of paper and colored pens.

- 1. Can you draw a timeline depicting events that were important in your life?
- 2. When did you migrate to the United States?
- 3. When was your child who has a disability born?
- 4. When did you find out about their disability?
- 5. When did your child begin receiving special education services?
- 6. Are there any important events regarding your child's disability or schooling that you would like to add to your timeline?

Do not worry if you miss something, you can go back and fill it in later if needed.

## Appendix G

## **1:1 Interview Questions**

Date:
Location:
Participant:
1. Tell me a few things about yourself. CRQ
2. Please tell me about your family. CRQ (Prompt – Do you do things together or separately?
3. Please tell me about your transition to the United States. CRQ (Prompt- Comparing life before to their life here.)
4. What motivated you to immigrate to the United States? CRQ
5. Please tell me about your children CRQ (Prompt- specifically ask about child with disability.)
6. 6. When and how did you receive the news about your child's diagnosis? CRQ (Prompt – Was the diagnosis received through the health care system (medical diagnosis) or through the school system (educational diagnosis)?)
7. What was your experience with receiving the diagnosis? CRQ
8. How did your family members respond to the diagnosis? CRQ
9. How has your child's disability impacted your life? CRQ
10. Describe your experience interacting with the administration and teachers at your child's school? CRQ
11. How would you describe your treatment as a parent of child with a disability? CRQ
12. How is your child's disability viewed in your culture? SQ 1
13. Describe your role as a participant in your child's education. SQ 1
14. Please describe your relationship with the school administration. SQ 2
15. Please describe your relationship with your child's teacher. SQ 2
16. What type of collaboration have you done with your child's school concerning their education? SQ3

17. How do you feel like collaboration can be beneficial to your experience with your child's school? SQ 3

18. Please describe your experience attending your child's IEP meeting. (Prompts – how, if at all, were you prepared for the meeting? Was there a translator present or offered? What input was requested from you? How did you feel going into the meeting, during the meeting, and after the meeting? SQ 4

19. What opportunities have you had to contribute to your child's IEP? SQ 4

20. Have assessment results and other materials have been translated in time for IEP and have skilled interpretive services been provided for the IEP meeting? SQ 4

Final: Is there anything else you would like to share with me on this topic? Or any questions you thought I might ask about but didn't?

## Appendix H

## Sample Interview Transcript

## Interview Transcript - Sarah

Korin Lopez 0:10 And I record on my phone too just in case one of them stops working. Then I have two copies. I'll be like oh by the way

thank you so much

so thank you for filling out the questionnaire to the second thing we do is a timeline. And so this is just kind of based off of like your life and you can say like, oh, when you were born or graduated high school, moved to the US, married kids, and then with your daughter like when you received her diagnosis, how old she is just kind of just a basic timeline of kind of your life and your experience. And I have these two examples for you to look at. So I just have this paper right here. There's no right or wrong either.

Mother 2:12

Everybody was telling me that she's not responding to name calling. And no, I know, she will not look at you. And I didn't know that, you know, for so long. I thought everything was fine because she older milestones and suddenly before or at the age of two push turns to it's like everybody said, I mean, it's not normal. Yeah. So when we get back from the states

Korin Lopez 3:30 Where were you guys living?

Mother 3:32

We were in **Markov**, okay. In **Markov**. We're leaving there. And when we get back. I see your doctor and the doctor said she probably have autism. And so then I started learning about this and researching and things like that. And finally at age three, age three, three years old. Well, a month after my husband passed. She was diagnosed by Kennedy Krieger Institute in Baltimore.

Korin Lopez 4:30 This is right after your husband passed away.

Mother 4:35 Yeah, it's like less than a month.

Korin Lopez 4:37 Oh my gosh, you get that diagnosis.

Mother 4:41

We did like I think it was eight months or something like that. We waited long. For her to be assessed and diagnosed so that I got depressed and that didn't help her, you know.

Korin Lopez 5:06 Very understandable, though.

Mother 5:08 Finally, like I said in my email, March, March 2020, the school closure I saw what my daughter was, you know, experiencing or what her actually dealing with in school.

Korin Lopez 5:36 And what age was she at this time?

Mother 5:37

She was March 2020. She was six years old. Okay. Yeah, six years old. And so 2017 My husband died, and she was diagnosed three and then finally March 2020. The scope of your life there. They had that virtual learning. And so I didn't have any idea on how my daughter was for acting in school while she was doing the pre K teacher told me that she can count 1-100, 1-50, Things like that. All the progress that you want to hear they will tell that but at age five,

still wearing diaper, going to school wearing diaper and I was like thinking who's changing her diaper, who was helping her go into the bathroom or feeding or eating and nobody, you know, those are the questions that sometimes nobody, you know, really like to answer. Yeah. So during that virtual learning, so what is going on? My daughter was like, walking around back and forth and running around and I turned my office into a classroom for virtual learning. And so I did that was hard because she's not listening. She's not engaging. She's not answering teachers. It's like, you know, you're not there. And so I said, something was be done with her because it's not only for me hard to see, because it added to my stress and worries and my depression. So finally,I said, I'm going to find out what's going on and what's good. You know, you're a mom you want to learn and me if I don't know something I google and self taught myself.

Korin Lopez 8:00 Good for you.

Mother 8:01

Yeah. And so I learn about the FAPE. I learned about the FAPE which is, I guess, free education, public education for people with disabilities.

Korin Lopez 8:17 Oh, FAPE Yes. Mother 8:18

I learned that and so it's just, I guess I'm consider lucky because I can get resources that that nobody is telling me that I have this, that the rights and for my daughters right to have a public education, yes. And what is considered appropriate for her? And so what they gave to for my daughter is not appropriate. So, I started gaining knowledge about what you can do and things like that. But I can't do it on my own because you know, my English is limited language. So I hired me a lawyer and an advocate. Well, I at first only advocate but then my advocate it's like, going for so long, like we I think made eight nine meetings. Wow. Yeah, they just kept giving me an hour and then two hours for them. Every meeting session. But then before that, prior to that, you get to have meetings with your advocate with your attorney which are what what you need to do what you know, the assessments of the well we did private assessment and the school was like, not happy about it. Because they said that, what they use the tools they use the questionnaires and and things like that, you know, there's a lot of different things. That is not the new model. And so the public school did their own assessment, but prior to that, they didn't even care to give my daughter an assessment to see where she's at, because she doesn't have the skills and abilities of a first grader or second. first grader and so, but they did, I think psychological tests but then that's what she was pre K. Then after that they didn't do anything. They should do assessment, like every year and it didn't do that. But nobody will tell you what your what help you can have. What help you can get. You just have to start thinking what you know what is available to you and to your daughter.

Korin Lopez 11:02

So it was a remote setting that kind of helped you see that she her needs weren't being met.

Mother 11:06

Yeah, all my knowledge was like from the internet. I just self taught myself with if you have the money, you can hire an advocate and a lawyer so I did that. Lucky me that I have that resources to fight for my daughter's rights for her public education. Yeah. So then we did that. Before they just let her loose in the classroom in a gen ed classroom.

Korin Lopez 11:36 So she was in a gen ed setting?

Mother 11:38

Yeah. And they said it's a less restrictive environment or learning to go forward. But that's not appropriate for not everyone is generalized. Each and every individual with disability has their own weaknesses. Yeah. So that didn't work because I said that's not appropriate for my daughter. And it's, it's not fair to her and it's not fair to the the typical children in that classroom.

Korin Lopez 12:16 That least restrictive environment doesn't necessarily mean a gen ed setting.

Mother 12:20

Yeah, that's right. So then I did that. And finally, after so many meetings, they agreed on giving my daughter some 26 and a half hour outside of gen-ed classroom, whuch they made a classroom for her. And that's they put two or three more students there. Okay, the boys, but prior to that, where was those boys came from Yeah, if I didn't fight the schools,

Korin Lopez 12:56 They're just in a general setting. Mother 12:58 Then they hire out they outsource people like they outsource one special ed teacher and three IA's like the instructional assistants prior to that. What help did they give to my daughter, nothing? Korin Lopez 13:13 She didn't have an assistant with her in the class. Mother 13:16 No. Korin Lopez 13:17 Well, I bet that was challenging for the teacher too. Mother 13:19 Yes, not only advocating for my daughter but also for the teachers too, because they can not teach and watch my daughter like they're there to teach not to take care or not to babysit. Korin Lopez 13:35 Well, and how long did it take you guys to get to that agreement? Mother 13:39 It was a long battle. I think it was like August 2020. So late 2020 I started assessment. We waited like three months for her to get, you know, to be seen by the doctor. So the assessment, then waited like another month to get that assessment. Korin Lopez 14:03 Such a process. Mother 14:05 Yeah, it was a long process. And finally, mid 2021. It started August 2022. Korin Lopez 14:21 So did you guys move here from ? Yes. And when did you guys get here? Mother 14:35 Okay, late May. They had like two weeks left before the end of school year. Yeah, before summers. Korin Lopez 15:41 How many children do you have? Mother 15:47 Two. My son is ten. And like nine Yeah, Korin Lopez 16:16

Why did you move from the Philippines?

Mother 16:37

So I got married 18 years old. My husband brought me here is he from he's a white American so he brought me to Staten Island New York. So my place was Newark, New Jersey. And we stayed there in Staten Island in one of the boroughs of New York City for like two and a half years. Okay, before we moved to Pennsylvania, that's where I conceived my son after three and a half years well. After that, well, **Determined** was born in Pennsylvania,

Korin Lopez 17:20 okay. And they're pretty close in age. Your son and daughter.

Mother 17:24 Yeah, I conceived when my son was 11 months old.

Korin Lopez 17:29 Oh, yeah, very busy Yeah, and do you work or did you work?

Mother 17:56

Well, never work when my husband is so alive and finally when he died or after he passed I went to school. Oh, did I gosh, I just dragged myself and I got tired do I but I did get my associate degree. But after that, but I would say I'm still in school too. I was doing nursing school but I quit. I quit for a while but I will go back again.

Korin Lopez 18:30 Yeah, well, I imagine it was difficult with two young kids by yourself.

Mother 18:36 Yeah, Yes. But my mom helped me to go to school. Never really work. But now I work at

Korin Lopez 18:51 Oh really?

Mother 20:04 So I rent a room in my friend's house but not really friends we are sisters. Because we're like teenagers when we knew each other. So, we'll see what happens.

Korin Lopez 20:22 Yeah. So I saw on a questionnaire that you speak four languages. What languages do you speak?

Mother 20:27 I speak English. I speak my native tongue.

Korin Lopez 20:32

Is that Tagalog? Mother 20:33 Yeah. And then I speak my mom's language and I speak my dad's language., Korin Lopez 20:38 Oh, what are their languages? Mother 20:41 Because every town or every, every province has their own native language aside from the Tagalog, the nation one. Korin Lopez 20:51 So well, so you speak both of theirs. Wow. And do your children speak? Mother 20:56 No, because my husband didn't like for me to teach them my language, And he said that he was he thinks that it will confuse them, Korin Lopez 21:09 Do you think you'll teach them now that they're a little bit older? Mother 21:16 You know, my son actually, when me and my mom's speak with each other's my son would like understand, but he can't speak. Korin Lopez 21:26 But he is starting to understand it? Mother 21:27 Yeah. Korin Lopez 21:28 So was it a big transition when you moved from the Philippines to the US? Mother 21:46 A cultural shock. It was really different than I used to know in the Philippines. I grew up with a lot of people around me. And suddenly when I got to United states, it's just me and my husband. So it was an adjustment, period. It's a long adjustment. Korin Lopez 22:09 Yeah, it's a big one. Mother 22:11 Yeah. And he does didn't want me to get out because there's a lot of bystanders in New York City. So I just stay there in the house while he works.

Korin Lopez 22:23 That was hard I bet. Mother 22:26 But I don't know why I just stayed in the house at that time when I didn't have the kids yet. I was fully dependent with my husband. Yeah. I'm trying to, you know, get myself better. Because I'm the only one that my kids will look up to me now. So I'm trying to be strong and do everything I can for them. Yeah, especially with my daughter. Korin Lopez 23:04 Yeah, she's lucky to have you. You're an advocate for her. So did you learn English in the Philippines or when you came to the US? Mother 23:11 Philippines we have the curriculum, okay. In English and most of the people there speaks English. You know, our TV speaks you know, people that you watch speak English to. Korin Lopez 23:27 So you had a lot of exposure. Yeah. Oh, that is nice. So what motivated you you came here with your husband? That's the reason he moved to the US. If you hadn't married him, do you think you would have came or do you think he would have stayed. Mother 23:41 Stayed there. But, you know, it was a dream. So yeah. A lot of people in my country dream of coming to United States to work and be able to pursue their dream. But me I didn't know why I didn't pursue. I was like dependent on him. Korin Lopez 24:01 Yeah, well, you were so young when you made the transition to a new country as a wife. When you receive diagnosis. Did she start early intervention like preschool through those schools? Mother 24:59 She did a special speech and OT goes to our home. Korin Lopez 25:13 okay Mother 25:17 But that was before three, but that didn't last. After the diagnosis at three, they started or before

that. They started coming to our house a few months. And then when she reached three, we have the option to go to public school or stay with them. So I decided to stay with them until I decided to go back to the Philippines. I didn't know how to come back. So they removed in that early intervention, that when I get back I put her in public school

Korin Lopez 26:05 What was your experience when you started the public school? Did you guys had an IEP meeting?

Mother 26:11

Yeah. And how was the meeting is just IEP meeting is like less than 15 minutes. And it's just everything was like predetermined. It's like everything was said and you just have to say yes or no.

Korin Lopez 26:30 Okay, so you're not really a part of it?

Mother 26:32

No, you're not really part of the team because they already made their decision that this and that and you just there they were just inform you on what what decisions they have made already.

Korin Lopez 26:46 Okay. Interesting. And so was it like that every like every year annual every year?

Mother 26:51

Yeah. Until the fight with the school. Yeah, yeah. You want you might want look at this (showing email document).

Korin Lopez 26:57 Tell me about that.

Mother 27:17

Because they don't care. How can my daughter like, learn in school? If they don't, nobody is there to help her. Eat, drink or go to the bathroom? My daughter will come home with dirty diaper. Number two in there and it's hard to know when it was there when she did and it was hard. There comes a time I said I'm not going to put my daughter to school because of this. Yeah, it's hard. She rather not learn anything not go to the school if she will be neglected like this.

Korin Lopez 28:02 So was that in preschool or when she got a little bit older?

Mother 28:05 Preschool kindergarten.

Korin Lopez 28:08

So the whole time. I see that you have communication so you are not communicating with them. They weren't sending notes or talking. "No" Wow. And so you didn't know like her lunch? You had no idea how much she was eating in school. And does she...

Mother 28:23 I always pack her lunch? And it's always untouched because nobody helped her to eat.

Korin Lopez 28:29 Does she have any language at this time? Could she talk and say like I'm hungry?

Mother 28:39 No.

Korin Lopez 28:39 nothing like that?

Mother 28:40 Now she's considered nonverbal.

Korin Lopez 28:43 Okay. Is she still nonverbal?

Mother 28:45

Yes. But when you speak or talk to her she understands. Yes, sometimes she would, you know, you know that she understands us.

Korin Lopez 28:56 Yeah. But they weren't using a communication device or visuals?

Mother 29:01 They did, but doesn't use that.

Korin Lopez 29:05 She wasn't trained on it?

Mother 29:09

No, they used it then and now. and the simple picture exchange. Yeah. And we use that too. But my daughter is not interested in using those things. It's just hard to enforce it because I'm a mother and I know what my daughter was, like needed at home. So I give in or sometimes most of the time my daughter will just take my hand to whatever she wants. But right now she's pretty independent going to the bathroom. "Oh, good", but she cannot clean herself. Yeah. So I have to like, clean her after her.

Korin Lopez 29:59 So be aware of when she's using it and stuff.

Mother 30:02 And I still give her a showers. You know, make her food and just hand it to her.

Korin Lopez 30:11

Yeah, for sure. Especially when they don't have the language to tell you you need to ensure that that's been taken. care of at school. Because yeah, I agree. Um, so when you received her diagnosis of autism, how did you feel about that?

Mother 30:26 I feel a shock and shock that what's going to happen she's not going to marry and she's not going to have family and she'll be with me forever. What if I die? All kinds of worries. I have to stop worrying.

Korin Lopez 30:48 And when you talk to did you talk to your family about it or who did you share the news with?

Mother 30:53

Share with my mom and my mom was kept in denial. So it's always okay, she's out growing and she's gonna do this and that, and that didn't help me because it made me more depressed. It got me depressed.

Korin Lopez 31:14 Yeah, that's understandable. Do you feel your mom's reaction is more her age like or more cultural?

Mother 31:24 I think culture.

Korin Lopez 31:26 Can you tell me more about that.

Mother 31:27 Yeah, I think this like oh, it's gonna be okay. It's not really isn't really me the reality we don't look at the reality.

Korin Lopez 31:39 How is autism looked at in the Philippines.

Mother 31:45 Before even me I didn't know about autism, and it's not really there is no it's not really wide. They don't know about it. Yeah, we don't know.

Korin Lopez 32:00 So you didn't have any friends growing up or it was siblings with autism that you knew about?

Mother 32:06 No, no.

Korin Lopez 32:07 So not in your school? Do they have special education in schools? Mother 32:10

Yes, but there I didn't know about. When I was in school in the Philippines, I didn't learn about disability learning disability or anything. I didn't see it.

Korin Lopez 32:25

So they were like the children are kept kind of more secluded. Are they in the same schools or do they go to a different schools?

Mother 32:32

Same school, but just there's no like, like they will say there have different classroom. So you won't know. Well, it's not really we're not aware?

Korin Lopez 32:49

Yes. And so do they have like early intervention services?

Mother 32:55

Well, last, last year, when I took my my daughter there, was hoping to get her educated there and hire a special teacher. I learned about Autism Society Philippines Autism Society and there's a lot of kids that is, you know, has autism. And they just the the Philippine Public School only have the the hearing or blind school. They have a special school for that. But for autism, they don't have it. And that's, you know, it's hard because you have to have your own resource to educate your kids with the same. They don't accept that in in the public school system. But right now, the school in where I was raised, they said they have their autism. Now they they're aware now that they're kids that has autism and a, learning, disability or problem difficult learning. So they considered that but still, they don't give you know, a special teacher, things like that. All they do is like speech OT But you have to pay for it.

Korin Lopez 34:44

So when you were to send her to a school in the Philippines, she would just go into a classroom and what would they do?

Mother 34:52

I hired somebody to teach her. But I didn't find that's the thing too. There is a lack of special education teachers. You have to go to more like you need to go to big cities to have that services. But in our area, is really very limited. The the teachers from Manila, the capital of the Philippines, goes to the provinces, the city provinces to, you know, to, to assess to diagnose to teach, because we lack teachers The teachers that do sidework work in the work in school, and then they do on the side. So that's what I found. They come to the house, two hours, I guess. Three days a week. Or something like that. Within that I never found teacher or a personal private teacher for her. That's why I decided to bring her back to United States.

Korin Lopez 36:14 Just a lack of resources?

Mother 36:16

Yeah, even you have the money to pay for it. There is no teachers. And awareness to their the awareness of their condition. Yes. They don't know about it.

Korin Lopez 37:24 Do you feel like the awareness is of growing in the Philippines

Mother 37:37

Mostly for the rich people only for the remote areas they don't know. In the US. They're like they live in a very remote area in the island, somewhere. And on the news. Think it's a girl and they don't get the they don't want their clothes on. And they are like tied in in the ankle and tied by the door so they don't get out and they just screaming and because they don't know how to handle it.

Korin Lopez 38:21 Oh, that's heartbreaking,

Mother 38:23

Heartbreaking. So that my daughter is still lucky because we found out you know, we're aware of her condition now. Versus those people that they don't, they think the boy is just crazy.

Korin Lopez 38:41 Yeah. Bless his heart. So how did the rest of your family members respond to the diagnosis of

Mother 38:52 I guess no.

Korin Lopez 38:54 They just accepted it.

Mother 39:00

I didn't cry. I didn't feel the support or anything like that. emotionally and mentally. It's just me handling everything.

Korin Lopez 39:12

Wow. It's a lot. I read a study that talked I was at a New Zealand and they looked at parents. It was a huge study to that looked at parents of children with autism. And it showed that the majority of them were has experienced clinical depression or anxiety because of the stress of having a child with autism. Because it's so much and I think sometimes we people that don't have a child they really do not realize how much.

Mother 39:40 They don't feel what we feel and experience.

Korin Lopez 39:45

Yeah, I don't have a child with autism. My nephew is autistic, and he is 13 and he has some big emotions some days. It can be very challenging for my sister.

Mother 40:13

Even for my daughter, my daughter when she's starts the meltdowns, it was hard. It was hard. Especially she gets also not really hit but basically you get the hurt because she's doing this and she's pulling your hand and sometimes my hand breaks like (bends hand backwards)

Korin Lopez 40:35 Kids are strong.

Mother 40:38

Just don't know how to respond. Just leave it Yeah. Get away because sometimes, you know, especially during the night and I just getting my sleep and I don't I can't control myself all the time.

Korin Lopez 40:59

Yeah, it gets Yeah, it gets frustrating. Yeah for sure. So how has her disability impacted your life?

Mother 41:12

I want to do things for myself and I can't do because I'm tied to her. Especially here in the United States. You can't hire people here because it's so expensive. Versus in the PhilIppines I hired her a nanny, and it only cost me \$300. Actually, it's 150 at \$150 a month, you can hire a nanny Well, a full time nanny for her. Yes, in the Philippines, but then I doubled that because my daughter is autism plus, you know, Samantha have the money for that.

Korin Lopez 41:58 Yeah. And did you have to did you give her any extra training? Just kind of just told her

Mother 42:05 Yeah, yeah. Just told her what to do and how to handle things.

Korin Lopez 42:08 And how does she deal with her?

Mother 42:10

She did fine. Until we moved back to me. Yeah, that is what I missed the, you know, the resources there that I have. I have a nanny for her. I have a tutor for her for everything. But then I don't have a house there. So my life is here. I have to. I have to live in one place, either here or there. Yeah. And the resources that are here. And I know that because I've been there. Yeah. And you have to go and big city to be able to find a teacher or to find resources. Even a speech and OT, these really hard to come by there. You have to wait in line.

Korin Lopez 42:59

Because they're just so few of them. That's that's a challenge. How does how has autism impacted your son?

#### Mother 43:10

I think that it impacted him too kind of because sometimes, you know, my son would say mommy hug me. Why you always hug why you always take care of her? Hug Me too.

### Korin Lopez 43:27

That is hard. Though, because the child that is so demanding sometimes is the one that gets the most attention. So how would you describe like your treatment as a parent with a child with a disability like when you guys go out to restaurants or places do you feel how do you feel?

### Mother 43:47

Sometimes I don't go out I just give in to my daughters wants. She was like, we have to give what she wants. Or else she will cry.

Korin Lopez 43:59 Yeah. Have you ever had anybody say anything to you?

### Mother 44:05

Oh, yes, like you can see the look when you she gives you the meltdowns and even outside with your inabilities with my family, my relatives. I feel the you know, the judgment and though I don't know the you feel uncomfortable with with the things that's going on with your daughter.. And you. I don't take her to parties. I don't you know, since she was diagnosed, I don't because one time there was like a birthday party and my daughter was like, stand on the table and the husband of my friend just like get your daughter off my table. Things like that was saying, from that day on I didn't take my daughter or my son or me to parties. Yeah, because of the I guess I'm embarrass kind of and you get to like, a wish your daughter will behave differently, but you can't control it.

Korin Lopez 45:22

Yeah. I think that's probably a common feeling. That's hard though. And so does your son he ever like feel bad that you guys don't go places or does he notice yet?

Mother 45:37

Not really, because when we were in, in **Section**, I take them to because I don't work. So I take we always every weekends and every few weekdays. I take them to YMCA. Every Saturday they learn to swim lessons. So both of them even my daughter. She has a one on one teacher as your teacher. So they get their lessons both of them I tried to give like I tried to treat them the same. Yeah. But sometimes it's hard. So I put my my son also to like soccer. I make him busy so he will not notice my my my lack of affection. Tired I'm tired. Of the catering to my daughter and yeah, and sometimes I don't give attention to my son. "Yeah, it's hard." What I do is put him in soccer, put him in karate class put in, you know put him in this...

Korin Lopez 46:42

Yeah, you create a lot of opportunities. Yeah. And they need to get the energy out. I have two boys and when they were younger, so the more I kept them active, the less like behaviors I had with him.

### Mother 46:54

That's definitely true because right now All He asks me Give me the ipad but still I don't want him using iPad all day. Yeah. But now they have a turtle now so they take care of the turtle. "Oh", him and that my daughter's I mean my my friend's son. Oh, so they have that pet. But then it's just hard here is a new we're still adjusting things like it's way way different here.

#### Korin Lopez 48:03

Yes, I agree, it is a much slower pace here. So what was your experience interacting with administration and teacher like when you first started after COVID You started asking questions.

Mother 48:20

I feel like everybody was like, I feel their, their facial expression was like, kind of mean and like, maybe they're questioning why I'm questioning them. I'm trying to be objective on what's going on with my daughter. But sometimes it's just hard because that's your daughter is like very personal. Yeah. So the objective is kind of gone sometimes. Yeah. And I can't help it.

Korin Lopez 48:49 She's your child.

Mother 48:51

So sometimes I get personal I don't blame teachers it's a failed system. Because teachers there just do their job. They don't give you the job don't they don't really get they don't really tell you what to do, or, or what can help you or the sources that you have or you have you have this and that you can ask for it for. For everything. That you know, and you have to be to show data on why you needed Why do you want to things like that.

Korin Lopez 49:38 What have they done differently? Are they giving you better reports now?

Mother 49:46

They'll give you reports because she'll write it was like it was way below her level. Yes, it's not. There's no progress. It's all the same thing. They will give you the they say they will do this because I get to learn how to read the IEP. Yeah. So before I was hard for me to do this, like there's 80% of the time does this. It was really hard because I'm not familiar to any of those languages that they use. I'm not I don't understand what they're talking about. So I got to learn that myself.

Korin Lopez 50:55

Yes. So you said when you would go into the IEP meetings and they would already have everything kind of like written out and ready to go without any of your input?

Mother 51:04

Yes. That's not what the law says. Now, I know.

Korin Lopez 51:08 So how long were you guys in the Philippines? This last time?

Mother 51:16

Me. My daughter. Was like, one year okay. May I think made me she was one year and a half. But me I went back and I left my daughter so that I can go to nursing school. Oh yeah. Yeah, but there's I didn't I can't do it to my my daughter. Yes. She's on my mind over times. And they call me and I can't just leave without my daughter. Yeah, so i brought her. So we're all together now. And I'm not gonna do it again for my self fulfillment. Yeah, that I thought that's what I needed because I was depressed. I needed to do something for myself. Because I go to school and it takes a lot of a lot for me. So I fought to school and I was the mean guy because I fought the school. That's the school that you, you, you fought to get what you want. And it's not for me, it's for my daughter. Yeah, they don't. They know what your daughter needs. But then they don't give it right away. You have to fight for it or you have to ask for it. I think the word is not asking. I think you really have to dig into what and then prove to them that your daughter needs it. Yeah.

Korin Lopez 52:50

And so when you were like interacting, would you who did you interact with the principal, the teacher,

Mother 52:55

the principal and most, most? Most of the time? It's the special education supervisor. Or the director of the super, I mean, the director of special education, because that's the guy that make decisions for your daughter. But then you have to have teachers, the principal, everybody,

Korin Lopez 53:22 yeah. So when did you guys go to due process or did you guys settle before

Mother 53:26 before due process okay, that if they did not because the last meeting I told them, You guys because they're giving me a hard time. Yeah. Of what I wanted. They don't want to give it

Korin Lopez 53:38 and what you wanted was her to have some time in a self contained room. Yeah. With some more support. Yes.

Mother 53:46

I told them, especially I mean, gen ed classroom. It's not going to work for her. Yeah. And they are like, holding the ground they don't want to give in and finally the last meeting prior to where they decide what to do, I said, if you guys not gonna help because they keep asking. They keep prolonging or stalling the decisions. So I would give up. I say, I'm gonna file due process after this meeting. If you guys won't give me an answer, or just make decisions right

now, because they're going to do we went to several meetings like eight or nine meetings. Wow. And they kept stalling Oh, they make me want to cost more money for me for my advocate and for my lawyer. Yeah. And plus, right away if you have a lawyer they will have a lawyer too.

Korin Lopez 54:45 Yeah.

Mother 54:48 Yeah. So was before.

Korin Lopez 54:50 You had to pay all of that out of your own pocket?

Mother 54:53

Yes. Because it's my choice. It's my decision to fight the school. It's because they don't they don't give what they know that what the students really needs what appropriate.

Korin Lopez 55:06 Yeah. And so her when they so then they finally wrote a new IEP that gave her that support. And then when they wrote it, were you part of it?

Mother 55:16 Yes. In fact Yes. My advocate told them that it needs to be put in in the IEP. All of that parental input.

Korin Lopez 55:31 Yes. So and so did she get ABA therapy?

Mother 55:39

Yes, it was privately. But the school said they have their ABA psychologist, ABA slash psychologists, teachers, so we don't need the ABA. So I didn't argue with it. But they give three times of speech eight times a week and OT I think six times a month. Versus they have Samantha was like getting one speech a week. One OT a week.

Korin Lopez 56:11 For a child that's non verbal?

Mother 56:15 Only 30 Minutes. Yeah, what's gonna happen.

Korin Lopez 56:18 So this, what grade was this for ??

Mother 56:24 She was in first grade, Korin Lopez 56:25 when they started the new IEP.

Mother 56:28 Oh, when I fought the school

Korin Lopez 56:30, oh, when you fought the school so it was her second grade year. Did she have that new IEP? And how did that year go for you?

Mother 56:36

It did went smoothly because my I started seeing the changes to my daughter's behavior. Like she wanted to go to school already. And she's happy and she's not really grumpy when she gets home. The teacher was good. The teacher was very helpful. And because you start seeing the changes and the way they treat you, they they're not really mean but they're, like fair on everything versus before. Oh, they don't care. They don't. They don't do you don't know you they don't they don't talk to you. But then after that, they just get the you know, they make time for to explain how things go away and things like that.

Korin Lopez 58:53 And how was your relationship with your principal during the second grade year?

Mother 58:58

Not really good. I don't care if she like don't like me because because I you know, they have to give compensatory services for for like, almost a year of instruction that my daughter miss. And they really don't like me and I get that and it's not my you know, I can't help that. I'm just advocating for my daughter.

Korin Lopez 59:25 Yeah, you're doing it for your daughter. When her next IEP came up, how was the collaboration with that?

Mother 59:34

Our last one's like April of last year, and after the April of last year. I decided to take my daughter and myself and my son to vacation. So after that Samantha didn't finish the school year. It was three weeks of because I had to. I had to get myself better because I got into depression. I got more depressed because of fighting and stress and a lot of stress from fighting the school. So I decided I had to get away or I'm going to lose my sanity.

Korin Lopez 1:00:14 So you went to the Philippines?

Mother 1:00:17 Yeah. Took a break from everything. It was really stressful. It was hard enough to fight the school and while you're fighting the school, be there and be there for your two kids. Korin Lopez 1:00:32 Yeah, it sounds really challenging. When you went to the Philippines, did you enroll them in school there or do you just have the tutor? Mother 1:00:40 but for my son, I took him back with me. The tutor for Korin Lopez 1:00:46 So he went back to school. Okay. So since you've got here now how has been your collaboration for special education? Does she have an active IEP right now? Mother 1:00:57 No. In fact, we haven't done the IEP meeting and they said they will do so. I'm waiting for that. already told me that we will have an IEP meeting and asked if we're gonna have they're gonna have assessment the prior to have the IEP meeting. And he said no, because most of the assessment are like pretty new. So I'm not sure yet. Korin Lopez 1:01:26 Dot you feel comfortable to advocate now and say that this is what you need?. Mother 1:01:32 Oh yes, because I'm not new with all that vocabulary. Korin Lopez 1:01:43 That's awesome. I'm so glad that when you collaborated with the teacher, that you were able to see her growth at home, as well as in the school. So when you were doing the IEP, did you ever need an interpreter ? Mother 1:02:40 Did not need it Korin Lopez 1:02:41 How did you find your advocate Mother 1:02:57 In our neighborhood my son goes in a different school. So, my son went to private school. And so one of his classmates is lives in the same neighborhood. So we get to talk and, you know, they're my son and her are, like, playmates, they go one afternoon played, right. So I get to know the mother and the mother started you know, we get to talk. I shared that my daughter has autism. And she shared that her son had autism too, and they had to fight the school too. And they're they won and he is older. I think their son was like a teenager. But then they fought with the school, I don't know, which school but they fought the school, and they won the son goes to specialist school, a special private school for autism, yes. So they got that because the public school cannot provide appropriate education for their son. So I didn't know

all the details, but she recommend to that I get an advocate.

Korin Lopez 1:04:28 Wow. So moms helping moms. I love that.

Mother 1:04:33 And that advocate is really, really good, really, but she's really expensive.

Korin Lopez 1:04:39

They're very expensive. My sister had to get an advocate for her daughter, but she had this advocate and I was in the IEP meeting because it was on Zoom. And he would say, "Well, let me ask a question." And you could see their reaction was not thrilled.

Mother 1:05:07

They don't like that if you ask questions. They expect you to be tame and not talk that you just keep nodding what they want. Like I said, I had an IEP meeting last not even 15 minutes. That's after probate. And prior to that COVID to go basically in that office room. They said after 10 minutes we're done.

Korin Lopez 1:05:37 Wow. And so the last IEP meeting where you guys were like collaborating and getting it was it? Did you ask a lot of questions or how did how did you do it?

Mother 1:05:48 My advocate did. They don't like that, it's a waste of their time. I guess but I don't know.

Korin Lopez 1:06:02 But worth the fight?.

Mother 1:06:04

Yeah. Just it's also because the you know that she will not be just be neglected in the classroom. And you know that she has somebody there to help her. Because my daughter wanders runs her. And I don't expect teachers to to babysit my daughter. They're there to teach not to babysit.

Korin Lopez 1:06:33 Oh, I love your view on it. So is there **a**nything else you would like to share about being a mother with autism and advocate?

Mother 1:06:44 Say, just hang in there it'll get better. It's getting better. Once you know they're getting older. They're my daughter starts to say more more words now.

Korin Lopez 1:06:59 Thank you so much for your time and sharing your story with me.

# Appendix I

### Theme Development (Codes)

The Value of Connection	<ul> <li>Alone</li> <li>Support systems</li> <li>Connections-support</li> <li>Connections</li> <li>Keeping culture strong</li> <li>Support - culture</li> <li>Family responsibility</li> <li>Extended family</li> <li>Family unit</li> <li>Connection through social media</li> <li>Trust in family-school partnership</li> <li>Trust in service providers</li> <li>Working together - collaboration</li> <li>Connection- collaboration</li> <li>Social impact of disability</li> <li>Trusted team</li> </ul>
Parent Perspective and Experiences	<ul> <li>Looking for good</li> <li>Resources</li> <li>Hope</li> <li>Determination</li> <li>Growth mindset</li> <li>Perspective</li> <li>Diagnosis brought clarity</li> <li>Faith</li> <li>Sacrifice</li> <li>Dedication</li> <li>Stress</li> <li>Overwhelmed</li> <li>Depression</li> <li>Worry</li> </ul>
The Advocacy Process	<ul> <li>Speaking up</li> <li>Advocate</li> <li>Confidence</li> <li>Fear</li> <li>Self-educate</li> <li>Resources</li> <li>Empowered through education</li> <li>Educating yourself- empowering</li> <li>Voice</li> <li>Fight</li> <li>Example from others</li> </ul>
Challenge and Barriers Faced by Families	<ul><li>Guilt</li><li>Self-blame</li></ul>

	<ul> <li>Frustration</li> <li>Diagnosis</li> <li>Worry</li> <li>Stress</li> <li>Blame</li> <li>Framing disability</li> <li>Disability</li> <li>Cultural shock</li> <li>Language barriers</li> <li>Adjusting</li> <li>Expectations</li> <li>Discrimination</li> </ul>
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# Appendix I

### Themes and Sub-Themes with Significant Statements

Themes	Sub-Themes	Significant Statements
The Value of Connections	Personal Connection	"When you moved here, it's different. It's you feel like alienated. It was hard. I was being supported by my mom back in the Philippines. But when I moved here, I didn't have any support."
		"I was young. And I was just used to my experiences, you know, my culture, how we viewed things because, you know, it's islanders against everybody else, or it will be like islanders against, like, what you deem the white people who are taking over or come to, like, take away your culture or, you know, instill themselves in it. So it's like, now I have this child. I'm already intimidated because they're already seen as kind of like better, you know, more educated. You know, they have the expertise. I didn't have much education at that time. So it was a very lonely time."
		"I feel like now it's becoming more normal to have a child with autism, but a lot of people still don't understand until it happens to them. They don't feel what we feel and experience." "I feel, you know, the judgment, and though I don't feel uncomfortable with the things that are going on with my daughter. I don't take her to parties. I haven't since she was diagnosed."
		"It was challenging in Kansas. I think we met two people who spoke Spanish. That was it. I don't remember like having a community. We were more than looking for the Latino community; it was most challenging."
		"Good thing we have friends over there, our friends are the ones that helped us out."
	Social Connection	"He really liked teach me like, Hey, this is what you have to do. You have to work hard in America. If you want to make it. You know, coming from Africa. You don't know anything and finding someone who help you and pushing you it's like it's a blessing."

	"You know, when you feel like oh my gosh, I don't have anybody. God was like, Hey, I got you and they send him to me and he was like my, my other parents. You know, when I met him I would say God's got you know, he will teach me stuff."
	"So he's the one who find me people from my country. He said you have to keep up with your culture. It's very important. Yeah, he find me Congolese people and they're like one of my Congolese family people."
	"So, there we have a big Filipino community there. That's where I got my support."
Professional Connection	"You guys come to help. Not you coming to harm the kid. No, you're coming to give help like as much as you can. So this kid can get better on whatever concern the parents have. So the parent has to open up and be like, hey, this and that, you know, and hey, we noticed this." "They're helping me but so they're not telling me what to do. But they're helping me realize that what are the things that I can work with my daughter"
	"The teacher was good. The teacher was very helpful. They just get the you know, they make time to explain how things go."
	"I have a great relationship with his therapist, and his school teachers and staff. And every time I get a chance to see them, talk to them. I always do."
	"I think they see parents as like the enemy and they're not interested in like, you know, building good relationships because I guess they feel like maybe they're giving you ammunition to sue later. And you know, so I don't feel that supported, especially now."
	"I don't care if she don't like me because you know, they have to give compensatory services for like, almost a year of instruction that my daughter miss. And they really don't like me, and I get that, and you know, I can't help that. I'm just advocating for my daughter."

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Parent Perspective and Experiences	Relying on God to Guide Parenting	"I really factored into my faith and like I'm like, really my biggest prayers just like, Okay, Lord, You trusted me with her. You have to give me what I need in order to be a good mom to her and make sure that you know she is where she needs to be and what I need to say to people and like, give me the courage because sometimes it's scary even when you're saying it."
		"When you are by yourself and God bless you with people that who can help you. You have to take the opportunity. So I took the opportunity."
		"I'm pretty sure God moved me over here because over there, I don't know if he would still be alive. But I thank God he moved me over here because over here you have more opportunities and more resources."
		"Yes, we can do this, we're blessed. And we're going to turn that blessing into a way of thanking God for having you, so we're gonna give you the time. So, our best way to thank God for you is to give you time because we were blessed with it."
		"It's still hard, but I look at the stuff from the right angle. I always say that God knows why he allowed that to happen."
	Acceptance of disability diagnosis	"Yeah, I cried the whole time. But then you realize that you have to go on."
	ulagnosis	"It's really different knowing what he gots now, but it feels good. Also, that he got diagnosed. We know now. We know how to communicate with him now. Regarding my patience with him because before I didn't know what do do anymore,but now like, it's okay, more patience."
		"We're like, nothing is gonna surprise us now. Like with the rest of our kids. It's just like, yeah, let's just go with, just go with it."
		"I said we've been through a lot because it's not just his diagnosis it's the rest that comes with it."
		"Well, we had no idea what was going on. So it was very new for us. And then we have a lot of

	recommendations, and you have to do this, and you have to do that we're just following what the doctors and everybody was saying. But it's been, it's been a journey. It's been tough. It's been very, very difficult."
	"He doesn't have anything, wrong with his health. Nothing is wrong with his appearance. But it's just it made me feel sad because, you know, in our society now. Some people are not nice."
	"When he got diagnosed, I got scared. Cuz you know, what, if the people that likes him, stop liking him."
	"Like are our whole world just like stopped, like, you know in the movies like they can hear, but not understand. And then they say oh, what's that? I'm sorry. Like it took a minute for me to understand the doctor giving us my son's diagnosis"
Parents Experiences of Feeling Guilt and	"And then, like, as a mom, like, I panic. Oh my god. I don't know if I'm teaching him. If I'm teaching him the stuff they taught him how to do; sometimes, I just do this."
	"Kind of hit me that maybe the reason why she has delays is because of me."
	"The services we received did not help her, and so we kind of blamed ourselves. The reason why she's falling behind is because we'll buy her toys, but we don't play with her. So, in the Philippines, we saw a big difference. So I know it was more of us."
	"Sometimes it's hard. So, I put my son into things like soccer. I make him busy so he will not notice my lack of affection. I'm tired. Tired of the catering to my daughter and yeah, and sometimes I don't give attention to my son. What I do is put him in soccer, put him in karate class, put in, you know, put him in this and put him in that."
	"It's draining, you're tired. And then feeling the guilt of like, you have to give all this extra attention to this child and like hoping that your other children are not like oh, why did she get that or why? You know how come you're always taking off to go with her or why you

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		always so just a lot of that like drain of like, Am I doing enough? Am I good enough? Have I done enough?"
The Advocacy Process	Building Advocacy Skills Through Role Models	"Yeah, his awesome homebound teacher he's had since he was five she was the one that was fighting for everything. I asked her to come to every IEP meeting, she's been a blessing and loves my boy."
		"Her resource teacher was the first teacher that ever mentioned the word advocate to me. And that was the first time I heard \ advocate and the first time I heard about like, you can deny this, and you can say no to this, and like what she has in her IEP. So she would stop and pause and say, " Mom, did you really understand what they just said?" You know, and I know they would give her dagger eyes, but she would stop and ask, and that was the start of my journey of like, okay, I need to look and see and more of what it looks like to advocate for my daughter."
		"You know what one thing I said is, I will do anything it takes for that kid to have everything he needs. If I have to do two jobs if I have to work 20 hours or 24 hours, if I have to go sleepless for the kid to get to that level, when he does not have any problem to have a great life. We will do it. It is how my parents raised me."
		"So I got to know the mother of my son's friend, and I shared that my daughter has autism, and she shared that her son had autism too, and they had to fight the school too. And that they won, and she recommended that I get an advocate, so I hired an advocate."
		"Now, because in the Philippines, I've seen celebrities they're very vocal, and I think they're trying to advocate for autism because there's a lot of kids that have like autism and are diagnosed with autism, verbal and nonverbal. And I've seen like, people would post like all you know, a lot of you know, my daughter has autism, but I just want to let you guys know that, you know, she overcame that situation, and now that she's going to our regular school. It also kind of like gives me hope."
		"I like here with America you will see people who has like a kid with disability they will put them , alot of

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	them I see on tik tok talking about like if you notice this or you notice that in your children you know, by the fact of having the courage to post their kid to put them there to encourage other parents it's it's a big thing for me. When I look at those parents, I was like they're strong, and they really love their children." "I see on tik tok talking about like if you notice this or you notice that in your children you know, by the fact of having the courage to post their kid to put them there to encourage other parents t's it's a big thing for me. When I look at those parents, I was like they're strong and they really love their children"
Developing Your Voice	"So finally, I said, I'm going to find out what's going on and what's good. You know, you're a mom you have to learn and me if I don't know something I google and I self taught myself."
	"All my knowledge was like from the internet. I just self-taught myself if you have the money, you can hire an advocate and a lawyer, so I did that. Lucky me, I have the resources to fight for my daughter's right to her public education."
	"That's the thing that you as a mother, you have to choose to look search and learn about all of the things for your kids." "Our friends were like, how can you get them diagnosed right away, you should have just waited, you know, I said no, because, you know, as a mom, we know there's something wrong. And I want to offer, my child, the best thing we could like to offer him, which is, you know, whatever he needs, therapies and stuff like that."
	"In the beginning, you are nervous to ask questions, or you just don't know what questions to ask. Yeah, I didn't know what questions to ask. Because sometimes they say a lot of acronyms. And I hate that because I don't know all that stuff. And they are still doing it. But now I know more, or I can ask what that means. But before, I don't know what to ask; I don't know what he needs. First, I didn't know about accommodations or, you know, all that stuff that he was meeting."

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	Building Courage to Speak Up	"I write out what I expect to see, like what I'm hoping to see for her based on the last IEP. And I do ask a lot of questions. And I'm not as afraid to challenge like when a teacher says something I don't agree with, I say, why are you doing this?"
		"And I'm like, no, they, you know, they work for us, you know, basically, or you know, they're here for our daughter, and but, yeah, so, because of that experience and how upset I was about that. That pushed me a little bit more to like, learn more, and do more. And then once that other thing happened, I was more prepared to say, hey, you know, you can't just say these things and show me where it says so and have it in writing."
		"So that you know I learned the hard way, of course, that if you don't scream or you don't raise your voice, people don't listen to you, especially if you are brown or black. They think that or they assume that you're stupid or ignorant."
		"It doesn't hurt anybody's feelings. Like, I mean, everybody understands, like, if you say something, you know, like, you don't always have to say yes. Or like, stay quiet about things. So I'm getting much better."
		"They don't like that if you ask questions. They expect you to be tame and not talk that you just keep nodding what they want. You're not really part of the team because they already made their decision that this and that, and you are just there. They were just informing you what decisions they have made already."
		"You have the money, you can hire an advocate and a lawyer so I did that. Lucky me that I have that resources to fight for my daughter's rights for her public education"
		"So that you know I learned the hard way, of course, that if you don't scream or you don't raise your voice, people don't listen to you, especially if you are brown or black. They think that you they assume that you're stupid or ignorant."

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	Empowered to Collaborate	"Day one I expressed what I wanted and what I was expecting, and they knew that okay, this is not an easy family."
		"I write out what I expect to see, like what I'm hoping to see for her based on the last IEP. And I do ask a lot of questions. And I'm not as afraid to challenge like when a teacher says something I don't agree with, I say, why are you doing this?"
		"It just came across as we're not going to work on teaching these sounds because she's black, and there's no need to work on this with a black person. So I was offended by that because it was like you have yet to get to know us, to know how well or not well we speak. I was just saying, like, it's not fair for you to say 100% of black people do these things with sounds. Show me in writing where it says you can't."
		"My relationship with the principal is not really good. I don't care if she likes me or doesn't like me because I'm just advocating for my daughter. So I fought the school, and I was the mean guy because I fought the school. And it's not for me, it's for my daughter. They know what my daughter needs, but then they don't give it right away. You have to fight for it, or you have to ask for it. I think the word is not asking. I think you really have to dig into what your child needs and then prove to them that your child needs it."
		"My biggest prayer is just like, okay, Lord, you trusted me with her. You have to give me what I need in order to be a good mom to her and make sure that you know she is where she needs to be and what I need to say to people and, like, give me the courage because sometimes it's scary even when you're saying it. You know, you're like, I hope this is not coming out stupid. Or, you know, I hope I don't make a fool of myself by asking this, but I have to because she can't, you know, so it's still scary."
Challenges and Barriers Faced by Families	Recognizing and Valuing the Importance of Language	"It was really hard because I'm not familiar to any of those languages that they use. I don't understand what they're talking about. I can't do it on my own because, you know, my English is a limited language."

"But a lot of people they test your your intellectual on how good you speak in English. So, I'm afraid to not be able to speak good English and be judged, and that's why I stay quiet."
"We don't speak the same language. And it's really hard for us, you know, to learn another language, and then medical language and the language of special education. Sometimes they say that I don't understand or they don't want to listen to you because they think that you are just another person that comes from another Hispanic place or that you speak another language since you have an accent and that you are not smart. And you don't know what you are talking about, you know, because you cannot express that the right way or because you have an accent doesn't mean that, but you know, a lot of people think like that."
"I wish I did request for Tagolog because it's more personal for me, and then I could ask a lot more questions. I feel it's more personal, and you get comfortable easier because most of the time, I forget words that I wanted to say, and then sometimes they end up filling in the words that you're missing because you can't think of the right term and you just settle for yes, just because you can't of think of them."
"They thought I don't speak English or don't understand English well, so they would talk to me like really slow and loud. I never corrected them more. I never say like you can speak to me normal English because I maybe I was just too afraid to like tell them that I know how to speak in English."
"My kids ask me why do you say yes, Mommy, if you don't know. Well, because it's easier to not let them know that you don't know."
"Yeah, I didn't know what questions to ask. Because sometimes they say a lot of acronyms. And I hate that because I don't know all that stuff. And they are still doing it. "
"Because I have my accent, I tried to use some words that make me look smart."

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	Impact of Strained Family- Professional Relationships	"I was always fighting with the school, and all the goals that they had for him were just unreal. Unreal because they tried to justify, and I am not sure of this, but I'm sure they didn't do what they're supposed to because I cannot see their results. If you don't do it, there's no way you can see results. So I am very sure that they did not do what they were saying. So yeah, that was very frustrating for me. It was not just one school; it was several schools that he attended."
		"It just came across as we're not going to work on teaching these sounds because she's black, and there's no need to work on this with a black person. So I was offended by that because it was like you have yet to get to know us, to know how well or not well we speak. I was just saying, like, it's not fair for you to say 100% of black people do these things with sounds. Show me in writing where it says you can't."
		"Because they don't care. How can my daughter like, learn in school? If they don't, nobody is there to help her. Eat, drink, or go to the bathroom? My daughter will come home with a dirty diaper. Number two in there, and it's hard to know when it was there when she did, and it was hard. There came a time when I said I was not going to put my daughter to school because of this. Yeah, it's hard. She rather not learn anything then go to school if she is neglected like this."
		"When he went to middle school, we had to have an IEP meeting because they had to rearrange things for him at school and told us what they were going to do. They didn't do it. The first day, they didn't have anything; he didn't have a desk and had to write on his lap. They didn't have anything, you know, and he feels so bad that he didn't want to go back."
		"I wasn't very happy because the therapists and the teachers, they say, for example, they say that my son said something that I know it is not true. So they were trying to lie to us to try to make us believe that he is making great progress, and that really really made me mad because instead of saying, Oh, he's not making progress, they would make things up but have no proof. That was one of the things that really made it very frustrating to me.

Toll o Health	n Mental h	"I decided to take my daughter and my son on vacation. So, after that, my daughter didn't finish the school year. It was three weeks because I had to. I had to get myself better because I got into depression. I got more depressed because of fighting and stress and a lot of stress from fighting the school. So I decided I had to get away, or I would lose my sanity "I just don't know how to respond because sometimes, you know, especially during the night, and I am trying to get my sleep, and I don't, I can't control myself all the
		you know, especially during the night, and I am trying
		time."
		I'm always doing my best. So, sometimes I felt like less than a mom or just like, man, no matter what I do, it's not enough. I feel worried because I know, even now, that she'll always have to have someone in her corner. And I know I'm not always going to be there. And no matter how many things I teach her, she's still going always to need that and the worry and the fear as a mom, like, I'm not doing enough. I'm not doing enough to get her where she needs to be so that the day comes when I'm no longer here. You know, how's she going to do without me, so there's a lot of fear and worry in the emotional piece of, like seeing the same thing over and over in different ways and knowing that she hasn't gotten it she's not gonna get it until she's ready to get it. It's draining, I'm tired.

#### Appendix K

#### **Exploratory Notes on Participants**

**Anna-** A soft spoken woman whose voice would become even softer when she spoke up the hardships she had endured in her life and transition to the US. Her voice got a little louder and she sat up taller when she talked about the classes she took at the college surrounding women rights. The smile that lit up her face and the compassion in her voice when she told about watching the children with disabilities in the cafeteria being taken care of so kindly by their classroom staff and how she thought "what a beautiful country" Anna's faith came through in our conversation as she mentioned relying on God, trusting in God's plan, and getting through the hurt and pain of loss by believing in God. Her face lit up when she talked about going to the Catholic church because she could feel her Godfather in there because he loved church and sometimes she would go just to be able to feel him.

**Rachel-** It felt at times that she was trying to convince herself that she did the right thing giving up her career in order to be more available for her daughter. She would say something regarding it and then follow up with repeating it in a softer voice with her head tilting and eyes dropping. She talked about the challenges of being a soldier and caring for her family and all the work she did daily. She painted a clear picture of what it would look like the minute she walked in the door to include where she hung her jacket and the steps she took to prepare the food for her family. She discussed gender roles and then reiterated that she liked gender roles because that's the way she was raised, but added her mom had help at home in the Philippines, but that she had no help here. It seemed a lot of her self-worth is tied up in taking care of her family. She mentioned that if the house wasn't clean and food prepared, that she would feel like she was failing her family, especially now that she was staying home with her daughter. It

felt like she had lost her identity somewhere along the way but was trying to convince herself that it didn't matter because she had a family to take care of.

**Tara-** The diagnosis of autism was only a week old at the time of the interview and the emotions were raw in Tara, and at times I felt my own emotions listening and feeling the rawness of this new view of the world Tara was now seeing and feeling. She talked about the heaviness of the autism diagnosis and tears would feel her eyes and she fidgeted with the corner of the couch pillow, and then she would shift in her seat and correct herself by saying not wrong, just different when discussing some of her son's behavior. The worry she felt for her son's future could be felt as the tears filled her eyes and her voice often became choked up. At times she would turn and ask her husband in Tagalog for a word or explanation she was looking for in English to tell me about her son's disability or the reaction others in her culture had to disabilities. The fire would come into her voice when she talked about her son not being included or the unwanted opinion of others regarding seeking a diagnosis, and then it would shrink down as she worried about the way society would accept him with "the autism" Sarah - Similar to many parents Sarah explained that she was unaware of any delays in her daughter even though she had an older son, and it wasn't until others pointed out the delays that she became aware. Sarah's life had been difficult with losing her husband a month before losing her daughter turned three and received an autism diagnosis. Sarah spoke of the mental toll and stress she felt from being a single mother, having moved her family from the East Coast to Hawaii, and debating if she wanted to stay in Hawaii or move to the Philippines. During covid Sarah became aware that her daughter was not receiving a FAPE and that the general education class was not an appropriate fit for her. She discussed her journey to fighting for her daughter. She used the word "fought" six times, "battle" two times, "hard" 16 times,

"care" referring to the school not caring eight times. I could feel the burden and heaviness that Sarah was carrying as our conversation went on and she talked about the frustrations she felt with her daughter's lack of communication and behavior outbursts, but through it all I could also feel the love she had for her daughter the determination to ensure that her daughter's needs were met and she received the education she deserved.

**Kyle** - During the interview Kyle was very soft spoken and would often turn to his wife and ask a question in Tagalog to clarify the answer he was giving me. Kyle and his family worried that leaving the Philippines and not being near family was part of the reason that their son struggled because he didn't have the examples and interactions with cousins and family members that their older daughter had when she was his age. Kyle talked about the lack of knowledge and resources for individuals with autism in the Philippines - and said that most children, especially boys are considered to be "just late." Now that they live in the US they are wanting to assimilate to the culture and appreciated EI coming into their home because of a different way of supporting their son and introducing him to how different cultures learn and do things.

Tahina - I am going through Tahina's analysis (Exploratory Notes In Vivo,

a retrospective of your writing and thinking process as you work through a problem) portion and she is talking about cultural beliefs regarding disabilities and it reminded me of the book I read The Spirit Catches You and You Fall Down; A Hmong Child and Her American Doctors, and the Collision of Two Cultures about a little girl Lia Lee and the different lenses regarding disability. I have mentioned that almost every parent I have interviewed has mentioned the "just late" when talking about their child and other children with disabilities and how at first I was asking myself if they were in denial about their child's development but as I recalled this book I went back in to my email (it was recommended by Dr. Spaulding) and looked at an email I sent her when I finished the book: I keep reflecting on the Lee family and how the communication breakdown led to so much turmoil and heartbreak for the family and the doctors, and it has made me more diligent in asking questions to hopefully better understand them and to ensure we are on the same page with strategies and interventions for their child. I need to stay curious and explore why my bias was to think denial and I guess it is through my "Western lens" I equate a child not hitting developmental milestones as a delay. I definitely want to be more aware and actively working on my cultural competence. "Cultural competence is the ability to understand, appreciate, and interact with people from cultures or belief systems" different from your own (DeAngelis, 2015, para.1)

Adam - Our interview took place over the phone and took some coordination as I am in Hawaii and Adam is stationed in Korea. Adam told of growing up in Morocco surrounded by many different cultures and the family spoke four different languages in the home while he was growing up. Adam's son was diagnosed with autism at two and he felt happy with early diagnosis because it allowed him and his wife to seek services early for him and they had witnessed "huge" improvements in his son's progress. Adam spoke extensively on the blessing a child is to a family. In my analysis of Adam's interview I wrote: Feelings on disability: Offer kids unconditional love and help them to see their potential and not to view them or allow them to view themselves as victims of society or of their circumstances. Believes many of the barriers can be overcome by early services, resources, time, and love poured into the child. **Jose -** The participant today Jose said that he had no problem speaking up during IEP meetings because he is an "educated man" and he knew and had expectations for his son and for the school. 33% of the participants have a college education at the time their child entered school and all three made comments about feeling comfortable speaking up. I went back and looked through the codes/meaning units and I believe that education is a sub-theme under Give me a Voice. (This prospect makes me very excited!) Jose talked about picking up his whole family and moving from Texas to the East Coast searching for the best possible treatment for his son. Jose is a passionate man and emphasized that as a parent you need to do whatever it takes to help your child be successful and for him that meant moving across the country in order for his son to be treated by the best doctors and autism specialists.

**Sylvia** - As soon as our conversation started via zoom I could feel the love Sylvia had for her son. As she talked about the day she received his diagnosis Spinal Muscular Atrophy the tears began to fall from her and she said that sometimes the pain and worry felt as fresh as the first day she learned of the struggles her son would face. She acknowledged the hardships she faced as a mother of a child with complex health needs but emphasized how brave her son is, how proud she is of him, and how much she loves him. I was so impressed and touched with her love and devotion to her son.Sylvia is one participant that started out accepting whatever the professionals told her and then as she began to learn more she began to take more ownership in her role as an active team member to her son's education.This is from my analysis/interpretive data: Yeah, I think you have to to learn you have to search for yourself about a lot of stuff. If you want your son, to be successful you know what they mean." I wrote in my interpretation: Importance of taking ownership and not relying on others to "tell you" what is best for your child.

**Ava -** As I am reading Ava's interview she is talking about how she asks a lot of questions now during the IEP meeting and is not afraid to challenge things she doesn't agree with. In my interpretive notes I wrote: Confidence and being able to recognize that you have a role in this meeting and you are your child's biggest advocate. As I was reflecting on this it occurred to me that what she is doing is being her child's voice, she is speaking, questioning, challenging others for her child because her child cannot. I do not know why I have never viewed advocacy in this way before but it really changes the way I think about the word advocate or advocacy. I am analyzing Ava's interview and she speaks of how she relies on the Lord raising her daughter and with speaking up and advocating for her. It made me think of how many other parents have commented on the importance of their faith and the role it plays in being a parent, especially one who has a child with extra needs.

# Appendix L

### Analysis Steps

Read and Reread Interviews	Each interview was recorded through the Otter Voice Meeting Notes website, which automatically transcribed the interview. I listened to each interview and edited the errors in the transcription. I then reread it to capture the essence of the interview.	
Exploratory notes	I wrote thoughts to gain a deeper understanding of each participant after transcribing and reading and rereading their interviews.	
In Vivo Codes	I selected and highlighted in yellow direct quotes from the participants that related to the research questions. I repeatedly referred back to the research questions to ensure that it was the focus of the chosen statements.	
Experiential Statement	I wrote my interpretation on each selected in vivo codes in red.	
Emergent Themes	I wrote emergent themes from my experiential statements.	
Color coded	I took each emergent theme and color coded it by participant and put it into a google sheet.	
Cluster into groupings	I clustered the emergent themes into groupings that were similar and moved them around based on the central research questions and sub- question.	
Themes	The clustered emergent themes were then reviewed in their groupings with the questions and themes and sub-themes were developed.	
Supporting Themes	As themes and sub-themes were established they were supported through significant statements by the participants.	