

MIDDLE EASTERN, NORTH AFRICAN, AND SOUTH ASIAN FAMILIES
EXPERIENCES WITH SPECIAL EDUCATION IN THE UNITED STATES

A DISSERTATION

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DEDICATION

بسم الله الرحمن الرحيم

First and foremost, to the Almighty God (Allah) for His blessings and giving me the opportunity to complete this research and further serve our Ummah (community).

أَفْرَأُ بِاسْمِ رَبِّكَ الَّذِي خَلَقَ

“Read, in the name of your Lord who created.” (Quran 96:1)

To my parents who are now both reunited and watching over us from above, Elsayed Elramly and Fatma Elmasry. While I wish you were still with us to see this day, I know you both believed I would finish and were so excited. I hope I’ve made you proud!

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ABSTRACT

NEHAL E. ELRAMLY

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The parents' role in implementing appropriate educational programming for children with disabilities was written into federal legislation under the Education for All Handicapped Children Act of 1975 (EAHCA). Yet the nuances, legalities, and overly complex language used in special education paperwork has proven to be a deterrent and hindrance to many minority parents and families. This dissertation seeks to add to the current literature on minority families in special education with a specific focus on the underrepresented group of Middle Eastern, North African, and South Asian Americans. Results of this study reinforce the suspicion of lack of understanding of their roles and rights regarding special education and disabilities. Because of the small participant size, findings of this study may not be generalized to the greater population but can provide evidence and guidance to educators working with students from culturally and linguistically diverse backgrounds. Implications and findings will be discussed with further recommendations for future research and educational opportunities.

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CHAPTER I

INTRODUCTION

“Remember, remember always, that all of us, and you and I especially, are descended from immigrants and revolutionists,” said President Roosevelt in 1938 (Krabbendam, 2015). America, from its founding has been known for the fundamental belief in the rights of all people, not based on their backgrounds or ethnicity, but on the strength of their conviction and pursuit of a better life. As an Egyptian-born American, this researcher aims to break down the misconceptions and misunderstandings between public school educators and families of children with disabilities from Middle Eastern, North African, and South Asian communities. This dissertation project was born with the hope of opening lines of dialogue between families and educators serving students with disabilities from all backgrounds and ethnicities. An understanding of disabilities, different cultural experiences and perspectives, and increasing collaboration between school and families, helps ensure that students with disabilities are provided the best opportunities for their success. At the core of developing that understanding, is defining disabilities to all parties of interest. The Americans with Disabilities Act (ADA, 1990) defined disability as:

a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment. (p.7)

A child identified with a disability has the right to an education free of cost to their family under the provisions of the Individuals with Disabilities Education Act (IDEA).

Understanding the background that led to the passage of IDEA begins with recognizing the work and struggles of families leading to these federal provisions. Students with disabilities did not have legal rights to education prior to the passage of the Education for All Handicapped Children (EAHCA) in 1975. Exclusion of children with disabilities was reinforced by cases such as *Watson v. City of Cambridge* (1893) and *Beattie v. Board of Education* (1919). In 1893, the Massachusetts Supreme Judicial Court reinforced that students with disabilities could legally be excluded from regular education settings. The Wisconsin Supreme Court upheld the exclusion ruling of a student with a (physical) disability under *Beattie v. Board of Education*, 1919 (Yell, 2016). The EAHCA was adopted to ensure that students with disabilities had access to educational opportunities, both academically and through related services to best meet their individual needs (EAHCA, 1975). EAHCA (1975) guaranteed that student and parent rights were under federal protection, that Local Education Agencies (LEA) and individual states would receive federal funding to help provide services to these students, and that students were offered a thorough evaluation of their current abilities and specific needs to guide the development of an individualized education plan (IEP) (Yell, 2016).

Upon suspicion of a disability, a student can be referred by their parent and/or a Child Study Team (CST) at their home campus to be considered for a special education evaluation (Kilinger & Harry, 2006). A CST may be referred to by different names across school districts; but herein refers to the team consisting of administrators, general education teachers, special education teachers, parents/guardians, and sometimes an educational diagnostician, licensed specialist in school psychology (LSSP), or social

worker. A special education evaluation includes a battery of assessments designed to identify whether a disability impacts the academic progress for a student; thereby qualifying that student to receive special education services. At the core of this evaluation are standardized assessments in the areas of speech and language, social/emotional/behavioral abilities, cognitive abilities, adaptive behavior (self-help skills), and achievement abilities (academic areas). These formalized assessments are then used to determine if a student meets eligibility criteria for special education services under one of the disability categories listed under IDEA. When a Culturally and Linguistically Diverse (CLD) student is referred for a special education evaluation, additional steps must be taken. For example, prior to referral, a committee (including professionals who are knowledgeable in second language programming needs) must work closely with the students and their families. This committee meets with the CST to ensure that the student was provided appropriate language interventions, accommodations, tiered interventions in areas of deficit, and appropriate instruction in math, reading, and writing prior to considering a special education evaluation (Kilinger & Harry, 2006).

The Individuals with Disabilities Education Improvement Act of 2004 (IDEIA, 2004) outlined the specific process under which a child with disabilities has the right for a full and complete public education. IDEIA (2004) specifically noted that parents are an integral part of the assessment and annual progress update of the child with disabilities. A parent's role includes partnering with the evaluation and education staff in identifying their child's abilities, strengths, weaknesses, and current interests. Understanding these rights and procedures prove to be a challenge to many parents, specifically CLD

parents (Fitzgerald & Watkins, 2006). The EAHCA (1975) and IDEIA (2004) stress the importance of “meaningful parent involvement” (Yell, 2016, p. 262). Meaningful involvement begins with ensuring that parents fully understand the processes and the legal rights afforded to parents and their children with disabilities. Therefore, the LEA is charged with providing a copy of the Procedural Safeguards to parents. Procedural Safeguards outline to parents and guardians the rights of their child and themselves under federal guidelines when special education is considered. Yell (2016) stated the following:

The safeguard notice and subsequent notices must: (a) provide a full explanation of the procedural safeguards, (b) be written in the native language of the parents (unless it is clearly not feasible to do so), (c) be written in an easily understandable manner, and (d) be available to parents of students with disabilities. (p. 265)

This study focuses on the importance of disseminating information to parents and how to ensure understanding of paperwork and procedures. Another important aspect in this study is signifying the importance of parental involvement in the educational process for students with disabilities.

Parental involvement and understanding of disabilities (e.g., services, legal paperwork, education systems), communication between educators and families, and acknowledgement of how impactful parents are in the service and programming needs of students with disabilities, continues to be a running theme in special education research (Gray et al., 2019; Lamorey, 2007). With these themes in mind, an understanding of how families from Middle Eastern, North African (MENA) and South

Asian countries are impacted when they have a child with a disability rightfully needs to be addressed. Hadidi and Al Khateeb (2015) reported that historically, in MENA countries, persons with disabilities have long been considered “burdensome and shameful” (p. 519) to families and societies. With many families struggling to acknowledge that they have a child with disability. This often leads these children to be placed into institutions or hidden at home without services to meet their academic, social, emotional, or physical needs. Despite laws being enacted, a framework through the United Nations Educational, Scientific, and Cultural Organization (1994), and many discussions with advocates for the rights of those with disabilities, the primary model of special education services remains the segregation model in MENA countries (Hadidi & Al Khateeb, 2015). This segregation model is similar to the educational practices in the U.S. prior to the passage of EAHCA (1975) where children with disabilities were legally separated and kept out of general education settings.

Similarly, to MENA countries, South Asian countries have limited reliable data on the prevalence of disabilities and students in schools who should be receiving special education support. India passed the Right to Education (RTE) Act in 2009 which included the right to education for all children ages 6-14 regardless of their level of disability or caste system (family’s socioeconomic status). The education would include access to a physical school setting, teachers, parental involvement, and other resources (Singal, 2015).

A study conducted by Gupta and Singhal (2004) sought out to report the positive perceptions of parents in India and Pakistan with children with disabilities. Gupta and Singhal (2004) explained that with many families, disabilities are seen as having

metaphysical causation resulting from “sins committed by the person or family members in their previous lifetimes” (p. 24). While research pointed out that having a child with a disability brings negative perceptions, social isolation, and physical and financial stresses upon a family; when offered tools, strategies for understanding disability needs and programs, and having social supports and faith driven beliefs, parents are better able to cope with the aspects of caregiving (Gupta & Singhal, 2004). This study will further analyze the impact of support offered through the education system in the U.S.

Statement of Problem

Parents of children with disabilities from CLD backgrounds are faced with challenges including (some) educators limited cultural responsiveness, use of jargon not readily known by the general public, parents' limited understanding of disabilities, limited English proficiency, parents' limited understanding of the public school system, and overall cultural miscommunication (Wolfe & Duran, 2013). Educators have the responsibility to recognize and understand that cultural and language barriers often prevent parents from fully participating in their child's special education planning meetings (Al Khateeb et al., 2015). Wolfe and Duran (2013) stated that it is a lack of understanding that limits parental involvement, rather than simply being disengaged as some would assume.

The researcher of this study chose to further analyze and report the lived experiences and perceptions of MENA and South Asian families following a discovery of a limited amount of research currently available. As a practicing bilingual diagnostician, the researcher has been involved with special education cases of recent migrant families from MENA countries. These experiences raised the importance of

collaboration between educators and families, and further reinforced the need for more current and reliable data into these phenomena.

Purpose of the Study

The United States Department of Education and the Office of Special Education Programs (OSEP), outlines parent rights for a free and appropriate public education (FAPE) for their child with disabilities (IDEIA, 2004). Prior to placement into special education, IDEIA (2004) guarantees parents' right to "informed consent." The term "informed" specifically identifies the parents' rights to understand the entirety of the process for evaluating and providing services for their child under the special education umbrella. Based on the parents' understanding, the parent must agree in writing and state that they understand that their consent for their child to be evaluated and served through special education is voluntary and can be withdrawn at any time (IDEA, 1997; IDEIA, 2004). The question of whether parents fully understand the legalities involved in special education raises the concern about how LEAs, educators, and administrators are ensuring that parents from CLD backgrounds understand their role and their rights in the educational programming of their children. Moreover, joint parent and teacher collaborations are considered by many as a significant determining factor for success in school and beyond for many students (Francis et al., 2017; Lee et al., 2018; Wolfe & Duran, 2013).

Collaboration and work between schools, teachers, and families of children with disabilities has been at the forefront of social education constructs since the passage of EAHCA of 1975. Section 300.111 under IDEIA (2004) Part B stated that it is the sole

responsibility of each LEA to identify and offer special education services to all children suspected of having a disability regardless of their citizenship status.

Helping parents and families understand the process of having their child evaluated for, identified, and offered services under special education falls solely on the LEA. Teachers in the LEA, under the No Child Left Behind (NCLB) Act of 2001, must meet minimum requirements to be considered highly qualified to teach, including being considered highly knowledgeable in their subject area, hold a minimum of a bachelor's degree, and show proficient training in the area of study they will be expected to teach. This includes yearly professional development courses required to maintain current teacher certifications. Teachers are not required to have any specific training in effective communication and/or how to collaborate with CLD families despite the growing numbers of CLD students in today's public classroom (Graham-Clay, 2005; U.S. Department of Education, 2004). The National Center for Education Statistics (NCES, 2022a) reports,

Of the 49.4 million students enrolled in public elementary and secondary schools in fall 2020, some 22.6 million were White, 13.8 million were Hispanic, 7.4 million were Black, 2.7 million were Asian, 2.2 million were of Two or more races, 0.5 million were American Indian/Alaska Native, and 180,000 were Pacific Islander.

(p. 3)

As the number of CLD students continues to rise, the need for culturally relevant pedagogy must rise. Pagan (2022) reported the importance of using "race-conscious multilevel framework" (p.10) during teacher training to help increase social ecology in classrooms. These race-conscious educational practices can be included into degree

programs to increase the level of student-teacher's understanding of CLD families and students. Parents from CLD backgrounds are faced with obstacles (Wolfe & Duran, 2013) such as a limited understanding of U.S. educational practices, limited exposure to formal educational jargon, and a lack of experience in public schools in the U.S. (Gray, et al., 2019). With diverse families and limited educational opportunities offered in college teacher preparation programs, a disconnect between teachers and parents impacts services offered to students.

The growing number of U.S. immigrants brings this topic to the forefront of the conversation in special education. For example, a recent Migration Policy Institute study (2022) found that the U.S. immigrant population had increased from approximately 11.1% of the population in 2000 to 13.6% in 2021. A total of 44.8 million immigrants called the United States home (Budiman et al., 2020). Of that number, 28% are of South, East, and South-East Asian descent and 4% are of Middle East and North African descent (Budiman, 2020). With the growing trends of immigration, schools will continue to see a rise in CLD students entering their doors. Therefore, it is imperative to recognize where the education system plays a role and why there has been a limited understanding, representation, and research on specific groups of immigrants as compared to others.

Delving deeper into educational practices, special education programming, and the rights of CLD students being served through special education, helps LEAs and families know how best to educate students with disabilities. Practitioners and educators must recognize that when working with a child with disabilities, the amount of understanding and partnering between schools and families is imperative to the success

of the child (Fishman & Nickerson, 2015; Pagan, 2022). Therefore, the purpose of this study is to determine and analyze MENA, and South Asian families' lived experiences and perceptions with special education for their children with disabilities. The experiences include initial identification of their child's disability, support through the families' social groups and community, working with their child's school to develop an IEP, and understanding their role throughout the programming implementation meetings for their child. These lived experiences will be defined and explained to assist LEAs and educators to better understand how best to serve the unique, underrepresented group of MENA and South Asian students and their families throughout the special education process.

Research Questions

The countries of MENA and South Asia were chosen for this dissertation due to the frequent overlap of cultural norms, common community involvement, and frequently similar religious practices. Many families come from tribalistic backgrounds, maintain strong extended family ties and traditions, and a majority of the population consider themselves Muslim (Kayyali, 2013). This study will answer the following questions:

RQ1: What are the experiences working with the LEA of MENA and South Asian parents who have a child with disabilities receiving special education services in U.S. public schools?

RQ2: Is there a difference in experiences with the LEA between minority parents educated in the U.S. versus those educated in another country who have a child with disabilities receiving special education services in U.S. public schools?

RQ3: How are participants' perceptions and experiences different from European-American parents who have a child with disabilities receiving special education services?

Significance of the Study

Working with students with disabilities carries responsibilities not only to the student, but to the families as well. Disabilities, specifically significant cognitive and motor disabilities impact the child's life long term. Such as how these disabilities may impact their lives post-formal education and in finding gainful employment. Many families coming from diverse backgrounds may not understand disabilities as much as they would like to, and this impacts the family's involvement in the educational programming of the child (Gray et al., 2019). Some educators, due to a limited amount of research and public awareness, have a limited understanding on how best to work with populations from diverse backgrounds that are significantly different from their own backgrounds (Mchenry & Kelly, 2022). Recognizing that both the educators and families have roles and responsibilities to work best with one another does not come easily. Rather, it is a delicate topic where both sides must come to the table of understanding and acknowledge the necessary work to reach a collaborative, respectful relationship that best meets the needs of the students (Pagan, 2022).

The significance of this research can be summarized in two ways; one, that the families of MENA and South Asian students with disabilities receiving special education services have unique understandings of their roles and rights in the U.S. education system and of their child's disability/disabilities; and second, that public educators working with diverse student bodies recognize the limited scope of education provided

to them prior to entering the classroom on how best to meet the needs of these students and their families (Tenenbaum & Ruck, 2007).

Assumptions

Some assumptions of this study include the notion that families from MENA and South Asian descent have negative perceptions of disabilities and of the public school system. Due to limited quality public education in MENA and South Asian countries and cultures about disabilities, it is assumed that families will sign off on and consent to any required paperwork relating to the education of their child without questioning, and sometimes without fully understanding the impact this has on their child's educational setting. Another assumption is the belief that the parents' limited communication and understanding is due to cultural and linguistic differences. That teachers alone must find ways to meet the needs of these students and their families without much reliance or help from the families. The assumption that teachers hold the sole responsibility of disseminating information and finding ways to ensure parents understand this information, adds to the stress of today's educators who are continuously being blamed in public discourse for education policies and practices that they have little to no control over (Tian & Guo, 2022). The assumption that participants in this study shared their experiences fully and truthfully without reservation or fear of retaliation or misrepresentation of their community in an academic writing. Lastly, the assumption that teachers come into the classroom (post-graduation from college) with an understanding on how to work with and teach CLD students.

Delimitations

This study will investigate the lived experiences of parents (educated in the U.S. and educated abroad) of children with disabilities receiving special education services from MENA and South Asian countries. However, this study will not investigate these parents' perceptions of disabilities and/or how they, themselves were educated on disabilities. This study will not interview current educators working with this population of students, nor will it investigate how public universities can play a role in addressing the lack of guidance on working with children from backgrounds different than Europe and North or South America (primarily Spanish speaking ELL students). Lastly, this study has the limitation of not being generalizable among the general population due to its small sample size.

Summary

This chapter focused on the background of the identified problem and the purpose of the study regarding representation of MENA and South Asian students and their families. The researcher will progress with a review of current research/literature focused on the historical implications of special education law, disability services through public schools, and introductory research from MENA and South Asian countries on disabilities. This dissertation was completed using phenomenological qualitative data, described in further detail in Chapter 3, as well as how the data was collected and analyzed. The remainder of this paper outlines the analyzed key themes identified and summarizes the views and experiences of the participants. The paper ends with a conclusion, reflection, and future recommendations offered to educators and academia.

Definitions

IEP/ARD: Individualized education program or IEP means a written statement for a child with a disability that is developed, reviewed, and revised in accordance with §§300.320 through 300.324. Some local school districts in Texas refer to the annual meeting as the ARD (Annual Review and Dismissal) meeting (IDEIA, 2004).

COVID-19: Coronavirus disease (COVID-19) is an infectious disease caused by the SARS-CoV-2 virus (World Health Organization, 2022).

Elope: to leave a healthcare or educational facility without permission or authorization (Merriam-Webster, 2022).

ECI: Early Childhood Intervention (ECI) is a statewide program within the Texas Health and Human Services Commission for families with children birth up to age 3, with developmental delays, disabilities or certain medical diagnoses that may impact development. ECI services support families as they learn how to help their children grow and learn (Texas Health and Human Services, 2022).

IDEIA: IDEIA is the acronym for a law. Public Law 108-446 is called the “Individuals with Disabilities Education Improvement Act of 2004.”

Imam: 1) the leader of the Muslim community; 2) leader of the congregational prayers. (Muslim Primary Education Board: Glossary of Islamic Terms, 2022).

Khutbah: a speech or sermon; sometimes used to refer to the sermon given during the Friday noon congregational prayer (Muslim Primary Education Board: Glossary of Islamic Terms, 2022).

Masjid: called mosque in English, the Muslim place of prayers and worship. The life of the early Muslims used to revolve around the masjid. Meetings would be held

there, discussions would take place there (Muslim Primary Education Board: Glossary of Islamic Terms, 2022).

Muslim: one who believes in Islam and submits to the rulings of Islam (Muslim Primary Education Board: Glossary of Islamic Terms, 2022).

Salah: an Arabic word meaning a spiritual relationship and communication between the creature and his Creator. It is commonly understood as ritualistic prayers. Salah is one of the five pillars of Islam and is mandated five times a day (Muslim Primary Education Board: Glossary of Islamic Terms, 2022).

Partners PE: “Partners PE is a success-oriented physical education program featuring supervised peer tutors and individualized learning and instruction...designed to meet the unique physical education needs of students with disabilities who cannot meet the TEKS requirements...because of physical, social, emotional, or behavioral limitations” (Plano ISD, Partners P.E., 2022).

Zoom: “...frictionless communications platform is the only one that started with video as its foundation, and have set the standard for innovation ever since.” (Zoom, 2019).

CHAPTER II

REVIEW OF RELATED LITERATURE

This review of literature begins with a historical background of disability laws in the United States, specifically focusing on the parents' legal rights, identification of minority groups in the U.S., and ensuring parental understanding of their rights throughout the special education system. Definitions will be provided on the associated subgroups in this study (i.e., Middle Eastern, North African, and South Asian) followed by a comparison into the laws and perceptions of disabilities in different countries. Additionally, an in-depth review on the views of teachers on educating those with disabilities and how public education agencies can best utilize family collaboration to educate students with disabilities in the general education school environment. The outcomes of this literature review highlight gaps in minority parents' understanding of the special education process, services, and their role in their child's educational programming. This dissertation supports the evidence that bridging the divide between families and schools is imperative in serving culturally and linguistically diverse students with disabilities in the public-school setting.

Historical Considerations of Special Education

Families of children with disabilities have historically been advocating for equal rights for their children for over 50 years in the United States (Yell, 2016). These rights for children with disabilities came on the heels of *Brown v. Board of Education* (1954) and the Elementary and Secondary Education Act (ESEA) of 1965. Almost a decade after *Brown v. Board of Education*, President Lyndon B. Johnson signed into law the ESEA of 1965, ensuring that all students are provided equal access to education

(Doebler, 2019; Yell, 2016) through federally funded public primary and secondary schools. In 1971, the Pennsylvania Association for Retarded Children (PARC) won a case in the U.S. District Court for the Eastern District of Pennsylvania requiring that students with intellectual and learning disabilities be placed in and taught at federally funded public schools (Yell, 2016). In 1975, the United States Congress passed, and President Gerald Ford signed into law, the EAHCA (McLeskey, 2020). Under EAHCA, the federal government was responsible for providing funding to all states to ensure appropriate education for all students with disabilities; including the rights of a free and appropriate public education (FAPE), implementation of IEP, and creating and providing parents a copy of procedural safeguards (Yell, 2016). EAHCA, later to become the IDEA (1997), was put in place to direct public education agencies to apply funds provided by the federal government to safeguard students with disabilities' equitable educational opportunities to their non-disabled peers (Doebler, 2019; Draper, 2022; McLeskey, 2020).

Public education agencies (e.g., K-12 schools) need to abide by specific mandates when receiving federal funding. These mandates guarantee students' education rights, which includes parent participation in all educational planning for their child. Participation means being an active member in all special education service discussions including on topics such as assessments, eligibility determination, goal creation, progress monitoring of goals, behavior support plans, and transition planning (from classrooms to the workforce and adult life; Wolfe & Duran, 2013). In ensuring that parent and student rights are met, conversations between the school and parent must include aspects of what services are being offered and how these services may impact

the student. For example, when a student's placement is changed and they are removed from the general education classroom and placed into a special education classroom, the IEP Committee must determine if this removal could have potential harmful effects (academic or social) on the student. Another scenario is when a child's curriculum is being modified; a parent must be aware of how that will impact the student's graduation plan and high school diploma (U.S. Department of Education, 2020). Wolfe and Duran (2013) referred to the student's IEP as "the backbone of IDEA" (p. 4) which serves as a legal document establishing an agreement for services between schools and parents. A key takeaway is that the IEP must be created with parental involvement, while guaranteeing that the procedural safeguards are followed (Marsico, 2018; McLeskey, 2020) ensuring that a student's individualized needs are met through programming specifically designed for his/her needs.

Procedural Safeguards

The procedural safeguards of the IDEIA include (a) notice and consent requirements, (b) the right to examine relevant records, (c) procedures to protect the rights of a student when parents are unavailable, (d) the independent educational evaluator, (e) voluntary mediation, (f) the opportunity to present a complaint to the state educational agency (SEA), and (g) the due process hearing. Additionally, parents may challenge the actions of a school district and may eventually file suit in state or federal court (IDEIA, 2004). Mahoney (2018) explained that IDEIA provides protections for students ages 3-22 and their families to ensure a FAPE. Under federal mandates, a FAPE not only includes special education services to help students advance from one grade to another, but it also emphasizes the need to prepare students for their post-

secondary lives by providing opportunities to advance their education, understand how to train for and apply for jobs, and provide them the necessary tools to live as independently as possible into adulthood (Blanck, 2019; Doeblner, 2019). Part of ensuring that parents understand these protections, is making certain that parents are provided their parent rights as detailed in the IEP Procedural Safeguards.

Procedural safeguards, as described under Part B of IDEIA, state that parents must be provided information in a language they can understand and must include, in detail, the parents' legal rights as well as the right to a fair education for their child with disabilities (Gray et al., 2019). However, the language of the law does not specify that the information provided must be comprehended by parents. Not only is this a cause for concern for non-English speaking parents, but the limited readability of special education paperwork is also an issue for English speaking parents as well, due to the different special education specific terms that are used. A published study conducted in 2016, collected the procedural safeguard documents from all 50 states and the District of Columbia to determine readability of these documents being provided to parents (Mandic et al., 2016). Mandic et al. (2016) reported findings of the 51 procedural safeguards assessed had scores within a range from 10 to 19 (grade level correlation). The readability scores of the samples taken ranged from the procedural safeguards scored only 6% at a high school level, 55% scored at a college level, and 39% scored in the graduate school reading level (Mandic et al., 2016).

When considering the intent of the legislation passed (with ensuring that parents understand their rights and roles in their child's special education programming), providing understandable documents becomes a legal liability to schools (Fitzgerald &

Watkins, 2006). According to the NCES (2022b), 91.7% of American adults from 25-64 years-old hold a high school diploma but graduating the 12th grade does not mean a person reads at a 12th grade level; in actuality, a person's reading ability can be three to four grade levels below their education level (Fitzgerald & Watkins, 2006). When considering the role parents play in the special education placement and programming of their child with disabilities, understanding these procedures becomes even more important. Because of the parents' role in the shared decision making with their child's school (Mandic et al., 2016), special education advocates, educators, researchers, and legal authorities have shown great interest in the actual understanding of the procedural safeguards (also referred to as Parents' Rights and Responsibilities or Child and Parent Rights in Special Education; Fitzgerald & Watkins, 2006) by parents and families. Moving forward from understanding the legalities of having a child with disabilities being served through special education to understanding how to make sure this child is identified and evaluated appropriately.

Minority Group Classification

The NCES (2022b) reported that between 2009 and 2020, the percentage of public school elementary and secondary students classified as white decreased from 26.7 million to 22.6 million; in contrast, students of Hispanic descent increased from 11.0 million to 13.8 million between 2009 and 2020 (NCES, 2022). While the percentages of ethnic minority students continue to increase, as do students with disabilities (Yamasaki & Luk, 2018). Despite this continuous growth, the "teaching remains a predominantly white and female profession...with 82.7 percent of teachers identified as white, but only 51 percent of students identifying as white" (Redding &

Baker, 2019, p. 1). With limited diversity among educators, misunderstandings between teachers and CLD families often occur. For example, educators may avoid asking questions for fear of insulting families or bringing up previous traumatic experiences (Francis et al., 2017) that the teacher may not fully understand or relate to. Some of these experiences include fleeing from home countries due to war, ethnic minority disparities in home countries, and stress caused by a family's need to uproot and begin their lives without support or understanding of how to do so. However, asking difficult questions and understanding the families' backgrounds helps build trust between educators and families (Francis et al., 2017) and helps bring all parties to the table with a vested interest in the child. Understanding the breakdown and representation in minority groups represented in the U.S. is imperative in understanding these groups' individual needs.

To understand the breakdown of migrant identification in the U.S., one must go back into history to understand how minority groups were identified and counted. The U.S. Census counts under the Office of Management and Budget (OMB) would operate to identify separate and specify races that represent the American population and provide guidance on law and public policy (Kayyali, 2013). The U.S. Census Bureau began collecting data on race and ethnic origin from its inception in 1790 (U.S. Census Bureau, 2015). The accuracy of these counts has long been debated for recognition of specific minority groups, such as Arab Americans. For the purpose of this research, Arab American history through the OMB and the Census will be analyzed further.

Current research reports that Americans who identify as MENA have been under-identified by as much as 1.72 million people in Census counts because of the

OMB's racial and ethnic categories currently classifying this group as white (Kayyali, 2013). Efforts led by the Arab American Institute (AAI Foundation, 2018) under what was called the "Get-Out-The-Count" campaign attempted to change the categorization of MENA Americans. The most recent Census counts (2020) continue to list MENA Americans under the Caucasian/White racial identity group. To understand the reasoning behind why the Census categorizes this group as white, a review of events leading to the 19th century when Arab migration to the U.S. began is necessary.

"Between 1880 and 1924, an estimated half million Arab migrants left the Ottoman Empire to live and work in the Americas" (Fahrenthold, 2019, p. 1). As the fall of the Ottoman Empire began following World War I, migrants began looking for work as farming and textile work became harder to sustain (Fahrenthold, 2019). Around this same time, the United States experienced strong anti-Asian xenophobia leading to Congressional legislation restricting Asians becoming U.S. citizens (Kayyali, 2013). A key example is the Chinese Exclusion Act of 1882 (Chin & Karthikeyan, 2002), which halted migration from China due to limited labor jobs available to Americans. To exempt themselves from the anti-Asian immigration restrictions, Syrian and Turkish migrants went to the U.S. Courts to prove that they were of Semitic and Caucasian descent respectively rather than Asian (Gualtieri, 2009). Through U.S. Court rulings between 1909 and 1915, Arab migrants were able to prove their "whiteness" and were granted U.S. citizenship (Gualtieri, 2009; Kayyali, 2013). In 1915, the Georgia Court of Appeals considered those coming from Syria to be classified as white persons (Stephan, 2021). Later to be followed by the OMB issuing Directive 15 in 1977 (Kayyali, 2013) classifying Americans who descended from Europe, the Middle East, and North Africa as white.

Thereby beginning the classification of MENA Americans as racially Caucasian/white in the U.S. Census counts.

To gain more appropriate representation counts, MENA American research conducted in 2015 by the National Content Test (NCT) found that when the racial category of MENA is included in the Census, Americans with Middle Eastern or North African heritage were more likely to choose that option over white or SOM (some other race; Kayyali, 2013). When considering how this impacts the education of students from diverse backgrounds, representation or lack thereof comes into play. Current research does not accurately represent minority students due to a limited number of accurate counts of minority representation. Ford (2012) stated “to paraphrase an old saying, if we do not examine the past, we are doomed to repeat it. The future is here and our racially, ethnically, and linguistically different students are worthy of an equitable education” (p. 403). Because of this limited and inaccurate count of MENA Americans, “statistical blindness” (Kayyali, 2013, p.1315) and a lack of understanding of social service needs for this population continues to grow. As of the 2020 Census, Americans from MENA countries were still expected to check off “white” as their race category without a distinction to their true ethnic background (Kayyali, 2013).

The countries of MENA and South Asia were chosen for this research due to the frequent overlap of cultures and communities, specifically religious practice. Many people coming from MENA and South Asian countries consider their religion as more than their faith practices, it is seen by many as their cultural identity and plays a role in their everyday lives and decision making (Hadidi & Al Khateeb, 2015). Countries included in the South Asia category include Bangladesh, Bhutan, India, the Maldives,

Nepal, Pakistan, and Sri Lanka (Berglee, 2012). Countries represented in the MENA category include Algeria, Bahrain, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Syria, Tunisia, Turkey, United Arab Emirates (UAE), and Yemen (Berglee, 2021; Istizada, 2020). It should be noted that the term MENA is also referred to as the Greater Middle East and/or the Arab region. Except for Turkey and Iran, all countries listed in MENA have Arabic as the primary or secondary official language of the country (Istizada, 2020). Hadidi and Al Khateeb (2015) explained the diversity seen among Arab countries, including but not limited to language dialects, ethnic identity, familial and tribal backgrounds, religion, social norms, and the history of conflict in the region.

Special Education/Disabilities Identification Process

United States federal regulations and guidelines provide parents and public schools with guidance on how to find and identify students with disabilities. Under IDEIA Regulations (34 C.F.R. § 300.111{a}), known as Child Find, school districts have an obligation to identify all children residing in their district suspected of having a disability, a need for special education services, or a need for related service, “regardless of the severity of the disability” (Yell, 2016, p. 194). A disability can be identified as a physical handicap, medically diagnosed disability, or upon suspicion of a disability, the public education agency, teacher, or parent may request an evaluation be conducted to determine the student’s current educational performance, cognitive abilities, functional skills, and potential need for specialized instruction under special education (IDEIA, 2004; Mahoney, 2018). A student qualifies for special education services when he/she meets specific criteria as specified in IDEIA and shows a need for specially designed

instruction that can only be served through special education (IDEIA, 2004). A child is determined to qualify for services if 1) a committee made up of general education teacher, special education teacher, campus administrator, parent, and evaluation specialist determine that the student presents a need for special education services, and 2) this decision is made following receipt of a thorough evaluation presented to this committee that documents the child meets eligibility criteria in one or more of the disability categories listed under IDEIA. Furthermore, the educational data received must prove that the special rule for eligibility and exclusionary factors are not the primary reason for the child's lack of progress. The exclusionary factors include a lack of appropriate instruction in reading, math, or limited English language proficiency (IDEIA 34 CFR, §300.306, 2004).

The special education referral process typically begins when a teacher (or parent) voices concern about a student's lack of progress in a specific subject area to a child study team (sometimes referred to as the Response to Intervention [RtI] of Child Study Team [CST]; Klinger & Harry, 2006). Under IDEIA §300.8, interpretation of all presented data must include a variety of sources such as aptitude and achievement tests, parent and teacher input and recommendations, and information from the child's physical, social, emotional, cultural background, and adaptive behavior abilities (referred to as pre-assessment data). All of which must be provided to the CST committee for consideration and will be used later by the evaluation team in determination of eligibility. An evaluation may be proposed after parents, school administrators, general education teachers, and an evaluator (i.e., someone who is qualified to complete evaluations), have met and determined that a referral for a special

education evaluation is warranted (Klinger & Harry, 2006; Yell, 2016). If it is determined that an evaluation is appropriate, the parents are provided with a written consent before any testing may begin (Yell, 2016). The evaluator, after receipt of signed parental consent, uses observational and standardized testing data to complete a formal evaluation (Klinger & Harry, 2006). The pre-assessment data collected helps evaluators ensure that a student's academic deficits are not primarily caused by a lack of appropriate educational opportunities or limited English proficiency. These assessments measure a student's language, cognitive, adaptive, and academic abilities to help with determination of special education supports. Upon identification of a disability (as outlined in the above paragraph), an IEP is proposed to the parents offering specialized services for the student under the umbrella of special education (Conroy et al., 2010). Mahoney (2018) explained that after a child meets eligibility criteria, the IEP team determines which services or supports are appropriate to ensure the child's success in academic and social skills. Special education supports cover a range of supports available to students under FAPE; including social skills instruction, academic remediation, accommodations in all areas of academics and/or non-academic classes, speech and language therapy supports, and social/emotional counseling as needed. Some students qualify for related services such as occupational and physical therapy, vision services, and accommodations for the deaf/hard of hearing. All necessary supports and services under special education are discussed and agreed upon by the student's IEP team.

Minority Student Identification Into Special Education

Unlike medically diagnosed disabilities, a learning disability is primarily identified through teacher information, historical educational background, and an assessment by school psychologists or educational diagnosticians (Ortiz et al., 2011). IDEA (2004), Section 300.8 (c) (10) defines a specific learning disability as:

(i) General. Specific learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken, or written, that may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations, including conditions such as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia; (ii) Disorders not included. Specific learning disability does not include learning problems that are primarily the result of visual, hearing, or motor disabilities, of intellectual disability, of emotional disturbance, or of environmental, cultural, or economic disadvantage.

Minority and second language students have unique needs, in that their language development is often overlooked and considered a communication disorder rather than developmentally appropriate acquisition of language (Ford, 2012; Yamasaki & Luk, 2018). Some teachers have “little patience for students who are not yet proficient in English,” (Ford, 2012, p. 397). In fact, a study conducted in 2007 found that teachers had more positive expectations for European American students as compared to their expectations for minority students (Tenenbaum & Ruck, 2007).

A CLD student is often referred for evaluation for a learning disability because some teachers may misinterpret a student’s lack of English proficiency as low

intelligence or a disability (Klinger & Harry, 2006). Some general education teachers feel that they were inadequately prepared for teaching English Learners (EL) resulting in an over referral and overrepresentation of EL students stemming from limited understanding of second language proficiency versus a true learning disability (Yamasaki & Luk, 2018).

Interpretation and Language Brokering

Part of understanding how best to educate all students is recognizing that each student, native and non-native English speaker's language development is unique to that student. A CLD person is described as someone whose primary language is not English and/or who is not considered European American (Wolfe & Duran, 2013). Along with recognizing a student's language abilities, educators also consider the student's cultural background. Understanding that one's language is not the only factor to consider in communication, educators must also consider culture to begin to understand the background and perceptions of families from different racial and ethnic backgrounds. Lo (2012) explained that service providers and educators carry the responsibility of "defining and explaining" (p. 15) the IEP process for CLD parents. One suggestion made is for schools to find and connect parents with groups who speak their language and have been through or understand the IEP process to help facilitate understanding. Tuttle and Johnson (2018) researched the concept of language brokering as compared to translating and interpreting. Clear and appropriate communication between schools and families must take all language needs into consideration. An interpreter or translator is a person who works in spoken, written, or sign language to convert information from one language to another. Whereas a

language broker is seen as a mediator between two parties, helping both sides understand what is being said as well as having background understanding of both cultures (Tuttle & Johnson, 2018).

In, *The Spirit Catches You and You Fall Down*, a book about a Hmong refugee family from Laos in the 1980s describes the misunderstandings between American doctors and the family in the treatment of their child with epilepsy (Fadiman, 1997). As defined, a cultural broker helps a family with understanding the English language as well as helping the medical staff and child welfare workers with understanding the cultural barriers and beliefs of the Hmong people. What is often overlooked in our public schools is the lack of cultural understanding between staff and families (Tuttle & Johnson, 2018). In response, Francis et al. (2017) proposed that schools with high immigrant populations reach out to local refugee resettlement agencies (such as Catholic Charities, USA) to help identify resources to help bridge the divide of understanding between families and education agencies (Francis et al., 2017). These education agencies can implement practices that offer families greater understanding of how their children are being educated.

With the appropriate supports in place, Lo (2012) suggested that schools move from simply offering a translator to offering a cultural broker with CLD students and parents. For example, educators conducting a meeting should be cognizant of the type of questions that are asked. Lo (2012) recommended that open-ended questions are used more frequently than yes/no questions. Educators should recognize that yes/no questions are an easy response for parents while open-ended questions might require parents to ask clarifying questions for further understanding and offer opportunities for

enhancing the conversation. Additionally, Lo (2012) recommended that educators should be very aware of the verbal and nonverbal cues that parents emit. Being more aware of parents' nonverbal cues can allow the educator to be alerted to the parents' becoming uncomfortable or confused during the meeting. Finally, be sure to invite parents to ask questions frequently and continually check for parent understanding to ensure that the information is communicated in a way that is accessible for all parties involved. As migrant Americans continue their acculturation into American society, these nonverbal modes of communication may not be as critical as a means of understanding the parents.

Educators have the responsibility to understand that language barriers often prevent parents from being able to fully participate in their child's special education planning (Al Khateeb et al., 2014). Wolfe and Duran (2013) described barriers to parents fully participating due to professionals'/teachers' lack of cultural responsiveness, parents' own limited English proficiency, and cross-cultural miscommunication. Some parents have sought out training to help them understand their child's IEP, but still could not fully engage during the actual meeting (Wolfe & Duran, 2013). As educators, we must be willing to spend the time necessary learning about our student's cultural backgrounds to fully understand how best to serve both the student and their family.

Special Education and Disabilities in MENA Countries

To begin to understand how disabilities and special education are seen and served in the country of origin, one must understand the perceptions of parents from differing backgrounds. MENA Americans are estimated to be between 1.9 million to 3.7 million in the United States (AAI Foundation, 2022). The AAI Foundation reported that

due to an inaccurate representation in U.S. Census reporting, it is not possible to have an accurate number of MENA American counts. The 3.7 million estimation is an approximation based on research by AAI. With increasing numbers of diverse populations, the educational community must understand the different levels of acculturation, spiritual beliefs, and cultural views on disabilities to truly understand how best to serve these families (Zidan & Chan, 2019). Zidan (2012) explained that although a specific law providing an education system to those with disabilities passed in Egypt in 1956, it was not until the late 1960s when facilities and centers to serve this population began to be provided. Despite passage of disability rights laws, most nonprofit nongovernmental organizations (NGOs) serving those with disabilities did not open until the late 1980s and 1990s (Zidan, 2012). Despite these NGOs and facilities meant to help with educating those with disabilities, most MENA countries are considerably behind the western world in the services and understanding of disabilities (Hadidi & Al Khateeb, 2015).

While many developing countries in the Middle East and North Africa have passed laws protecting and providing equality rights to persons with disabilities (Crabtree, 2007), the negative perception and limited understanding is heavily ingrained into society. Laws such as in the UAE, Section 25 of the Constitution stating “those with disabilities are therefore regarded as equal in legal status” (Crabtree, 2007, p. 248). Despite such laws in place, in parts of the Middle East such as Egypt, Lebanon, Palestine, Israel, and others, having a family member with a disability is considered a smear on the family’s reputation and honor and often believed to be caused supernaturally (Crabtree, 2007). Countries such as the UAE have written into their

Constitution that those with disabilities have equal legal status and rights (Crabtree, 2007; Dukmak, 2010). Despite progressive concepts in religion developing acceptance and equitable treatment of those with disabilities, the stigma and feelings of guilt and shame continue in families from MENA descent (Crabtree, 2007; Sharifzadeh, 1998). For example, the mothers are seen as solely responsible for causing the disability and left to carry the load of full responsibility for the child (Boukhari, 1997). Because of the tribalist nature of these regions, having a family member who may be perceived as “weak” or unable to provide for and serve the family’s well-being is seen as a flaw for the entire family and/or tribe (community) (Crabtree, 2007). These perceptions have been part of the social make-up of this region for centuries; despite higher levels of educational opportunities among the greater population, many people from MENA regions still find shame and resist the idea that their child may be different or have a disability. Along with these limitations to understanding about disabilities and how best to integrate these individuals into society, a lack of social services also prevents further societal growth on this topic.

Hadidi and Al Khateeb (2015) sought to understand the current challenges faced by Arab countries, yet research on Arab and Middle Eastern children with disabilities remains extremely limited (Al Khateeb et al., 2014). Despite the laws currently in place, most of the countries do not have an agreed upon strategy for special education services (Hadidi & Al Khateeb, 2015). In many MENA countries, those with disabilities are continuously discriminated against and placed in segregated settings or kept at home without any chance of receiving an education (Hadidi & Al Khateeb, 2015). Dukmak (2010) found that in the UAE, due to the limitations of special education service

providers, students identified as having a disability were served through fourth grade, and then integrated into the general education population. In addition to understanding how disabilities are perceived and served, an understanding of the family dynamics within this region is also necessary.

Family Dynamics in the MENA Region

Citizens of MENA countries have a strong connection to family values; it is considered normal to involve the entire extended family rather than nuclear families in day-to-day decision making. Children are seen as an extension of their parents and the family unit is seen as the most important social and economic institution for most Arabs (Al Khateeb et al., 2014). In societies in the Arab world as well as MENA immigrants in western countries, the reliance on the extended family is seen as normal and expected. When a family has a need, illness, or any type of struggle, they often find emotional and financial support that comes from their extended family (Al Khateeb et al., 2014). As in many countries, mothers from MENA descent often assume the primary responsibility of raising and taking care of the children. With this primary responsibility falling on the mothers; mothers are also usually blamed for a child being born with a disability (Al Khateeb et al., 2014).

Unfortunately, just as with the “refrigerator mother” phenomenon here in the U.S. (Cohmer, 2014), in the broad Middle East, having a child with a disability is sometimes seen as the fault of the mother and ends up significantly impacting the mother (Al Khateeb et al., 2014; Crabtree, 2007; Zidan, 2012). To date, disabilities in the Arab world are seen as burdensome and bring shame to the family. For example, some families from Egypt hide their disabled family members for fear of stigmatization

(Crabtree, 2007). Because many of these cultures begin from tribal backgrounds, practices still seen today are considered an extension of folkloric practices, which have no association with religion or government roles (Zidan, 2012). Cultural practices and religious principles are at the helm of positive changes for those with disabilities in MENA countries.

Crabtree (2007) defended the fact that Islamic (the primary religion of all MENA countries) principles encourage Muslims to care for those with disabilities and those in need. Although there has been a rise in progressive Islamic jurisprudence, families from Middle Eastern countries in the United States continue to consider having a child born with a disability as a “shame on the family and carry the burden of responsibility and guilt with them” (Crabtree, 2007, p. 248). Understanding these misconceptions and recognizing that the practice of hiding family members with disabilities into institutions (Hadidi & Al Khateeb, 2015) is still practiced to this day, is important in understanding how best to communicate with American families of MENA descent about their child’s disability.

Special Education and Disabilities in South Asian Countries

In 2015, the United Nations Convention of the Rights of Persons with Disabilities (UN, 2008) brought together 150 countries to influence how persons with disabilities are seen, treated, and educated (Singal, 2016). In India the 2009 RTE Act passed and recognizes the fundamental right to an education for all children from 6-14 years of age regardless of class or disability (Singal, 2016). Legal rights aside, South Asian countries have a history of perceiving having a family member with a disability as a “tragedy,” with some going so far as to consider death a better option than being disabled (Gupta &

Singhal, 2004, p. 23). Similarly to views held in the Middle East and North Africa, people in South Asian countries believed that having a member with a disability is caused by past life karma or God's anger, often it was seen as a curse caused by previous sins (Gupta & Singhal, 2004). Recent research highlights the need for supported advocacy work to help families learning to support a relative with a disability (Fazil et al., 2004). Reports from the World Bank in 2009 showed that the number of NGOs in India continues to grow; in 2004/2005 there were approximately 470 NGOs and by 2007, that number had almost doubled to 800. With an increase in organizations working to teach the population how to serve those with disabilities, a greater awareness and acceptance could be seen soon. These non-government affiliated organizations are helping increase positive public discourse regarding disabilities as well as provide resources for services and education (Singal, 2016). While awareness and acceptance continue to increase in the Middle East, North Africa, and South Asia, there is still more work to do in the United States to ensure diverse students with disabilities are educated appropriately.

Culturally Responsive Pedagogy

Ladson-Billings (1995) coined the term culturally relevant pedagogy (CRP) with an aim at educating teachers on working with CLD students (Pagan, 2022). Culturally responsive pedagogy begins when a student's cultural background is considered in day-to-day educational planning. Ladson-Billings referred to a term used by Au and Jordan (1981), "culturally appropriate" when describing teachers who "incorporated aspects of student's cultural backgrounds into their reading instruction...were able to help students achieve at higher than predicted levels on standardized reading tests" (1995, p.466). It

is through the implementation of culturally relevant and appropriate instruction do educators reach students from varying backgrounds and help them reach academic success.

CRP is a teaching approach that encompasses attitudes and practices aimed at supporting racially, culturally, and linguistically diverse learners. Over the past four decades, a wide range of labels has been applied to this set of attitudes and practices, such as culturally responsive teaching (Gay, 2000), culturally relevant education (Dover, 2013), multicultural education (Banks, 1995), culturally sustaining pedagogy (Paris, 2012), and culturally relevant pedagogy (Ladson-Billings, 1995; Sleeter, 2012). The adoption of one term over another is not one for debate, rather the entirety of the model of teaching practices that incorporates the students' academics with their background to bring about success.

Educators, specifically bilingual education teachers, play an important role in supporting struggling students and ensuring that interventions and language accommodations are put into place and used with fidelity prior to referring for special education (Ortiz et al., 2011). Klinger and Artiles (2003) described the decades-long concern among educators that CLD students have been overrepresented in special education while underrepresented in gifted and talented programs. Pagan (2022) emphasized that incorporating CRP requires strong support from administration to allow teachers the opportunity for higher levels of collaboration to include “collective efficacy beliefs, which in turn are associated with higher levels of student achievement” (p.10) and cognitive development (Pickl, 2011).

Summary

This chapter offered a general overview of the historical backgrounds and implications of special education and disabilities in MENA and South Asian countries. The complexities associated with developing an understanding into this specific population and the role family dynamics helps clarify some misunderstandings. The research completed for this study amplifies the lack of current research and data available into this minority group. With limited data, educators in U.S. public schools are at a disadvantage with understanding how to serve this group of students. This study will aim to highlight the specific needs and experiences of families with children currently served through special education in U.S. public schools.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore, define, and give voice to the experiences and perceptions of MENA and South Asian families who have children with disabilities being educated in public schools in the United States. A qualitative study using a phenomenological research approach was chosen to explore the experiences of MENA families that have children receiving special education services in U.S. public schools. The phenomenological framework was selected because the goal of this research was to bring about understanding of the lived experiences these families have described. As the British author, Douglas Adams stated, “Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so,” (Neubauer et al., 2019, p. 90). The idea of a phenomenon is simply a lived experience; while phenomenological research attempts to make sense of specific people’s experiences, find their commonalities, and interpret the meanings of these phenomena (Bloomberg & Volpe, 2019). In doing so, phenomenologists work to describe the meanings and essence of lived experiences (Bloomberg & Volpe, 2019) as to provide a greater understanding to society.

Phenomenological research triangulates data representative of events that occurred in a person’s life and works to help build a better understanding of such phenomena. A phenomenological qualitative study begins by identifying participants from a sampling of the population (i.e., families from a MENA or South Asia background with a child receiving special education services in U.S. public schools), collecting survey information, conducting in-depth interviews with open-ended questions,

reviewing and organizing researcher memos and anecdotal notes, and finally analyzing the collected data in an attempt to identify patterns or themes in the perceptions and experiences of the participants (Bloomberg & Volpe, 2019). This research aimed to explore the lived experiences of families during the entire special education process and offer recommendations for how to better integrate MENA and South Asian families into the public-school special education system. This researcher believed phenomenological data was the most appropriate research design to offer insight for future studies into this specific demographic and/or other underrepresented minority groups. Through phenomenological research, the lived experiences of participants are reported and analyzed for themes based on each phenomenon.

Researcher Positionality

Holmes (2020) described researcher positionality as potentially being fixed such as a person's "gender, race, skin-color, nationality...while others such as political views, personal life-history, and experiences are more fluid, subjective" (p. 2). This researcher aimed to be forthcoming with positionality views which may have influenced or contributed to specific interpretations of people's lived experiences. For complete transparency in this study, descriptions of experiences that may have impacted the researcher's personal positionality views will be brought forth and addressed.

The researcher is what some sociologists call the generation one and a half (Budiman, 2020), meaning that the person was born in another country (i.e., Egypt) but came to the United States as a young child; sharing many of the similarities of second generation as well as first generation Americans. The researcher's experiences as an immigrant, non-native English speaker, Muslim-born and raised, minority female has

impacted every aspect of her life. Her family moved to the U.S. when she was 6 years old; because of their experiences with the education system in Egypt, the researcher's parents believed that their children should be placed into private schools to have the best educational opportunities in this country. It would not be until high school that the researcher would be introduced to, and experience, what an actual public education here in America was. The private schools offered an understanding of the English language and how to blend into a new society where many immigrants often felt as though they did not fit in. Entering public schools at the age of 13 (i.e., ninth grade), the realization came that diversity in education was possible. Though having been raised in a very small town (population less than 23,000) and having small class sizes (eighth grade graduating class of <16 students; 12th grade graduating class <250 students), the diversity in California proved that it was okay to not look like everyone else or have a name that sounded like everyone else.

Although the researcher had some basic understanding of English when first moving to the U.S., entering school was completely different. The researcher was a limited English proficient (LEP) speaker who would go days and weeks without speaking to anyone. While the researcher often felt as though she wasn't as smart as the others or that fitting in would be near impossible, there remained a hunger and drive to succeed, and that would be enough to carry through. Eventually the researcher would become the first in her immediate family to graduate college, become the first to earn a graduate degree, and soon to be the first in her immediate and extended family to hold a Ph.D. The experiences as a young immigrant, second language learner, and minority in race and religion have shaped the researcher to feel obligated to offer support to

other minority communities. These experiences motivated and drove a desire to conduct this research study to bring a voice to those who feel unable to speak, much as the researcher did as a child.

This study aimed to explore, describe, and define the lived experiences of MENA and South Asian families to offer a deeper understanding of their views and perceptions (Bloomberg & Volpe, 2019). Part of the limitation to this research method is the difficulties of bracketing personal experiences while trying to fully understand and represent the experiences of the participants. Member checking through interviewee transcription review will be implemented between the interviewer and participants to ensure an accurate report of the lived experiences.

Participants

A total of $N = 7$ participants were recruited for this research study who identify as parents of MENA or South Asian descent with children identified with disabilities who are currently or were previously served in a U.S. public school under special education. A minimum of $N = 3$ participants were recruited that migrated to the U.S. and completed their primary education abroad (MENA or South Asia) and $N = 3$ participants that were primarily educated in the U.S. No limitations were set on the type of disability or the ages of their children. Exclusionary factors included parents with intellectual disabilities, parents of children who have not yet entered school, and parents from other nationalities not mentioned above.

Procedures

Upon receipt of Institutional Review Board (IRB) approval (see Appendix A), a flyer (see Appendix B) was shared with local organizations serving families of children

with disabilities in the American Muslim community. Following receipt of interested participants, informed consent (see Appendix C) was provided, explained, and obtained from each participant. This consent included information about the entirety of the study, how long of a time commitment participants can expect through their participation, as well as how all communication and documentation would be provided and shared. Following the World Health Organization (WHO) guidelines, the consent form also included ways in which the researcher would prevent spread of COVID-19 using masks during in-person interviews. The consent informed the participants that their interviews would be recorded for accurate transcription of their responses, and recording would later be deleted following a post-interview transcript review between the researcher and participant. Following the explanation of and receipt of the signed consent forms, all participants were given pseudonyms to ensure confidentiality. This offered an added layer of anonymity to participants when sharing experiences in relation to their child's disability.

Upon participant identification, a questionnaire (see Appendix D) was sent via email to establish pre-interview questions that confirmed that participants met the inclusion criteria for the study. The questionnaire included demographic information on the families (i.e., ethnicity, marital status, education level, ages of children, and home language), number of children currently or previously served under special education. The results from this initial questionnaire were deemed a necessary first step for the researcher to understand the backgrounds of potential participants. Use of a holistic approach to identifying and defining the experiences and perceptions of each participant is at the core of a phenomenological qualitative study. This researcher chose to follow

the framework described by Braun and Clarke (2016), which describes thematic analysis of a phenomenological qualitative study as a flexible method of analysis allowing for diversity in data collection and theme identification. Because of the limited number of participants, the researcher expected to find, it was deemed necessary to use a framework that offers credibility to the study as well as potential expansion of identified themes in later research.

The questionnaire offered the researcher with the initial inclusion criteria necessary for participation which included parents from MENA or South Asian descent and having a child currently and/or previously served through special education in a U.S. public school. There was no specific time frame set for when participant's children were identified and/or began receiving services as a requirement for participation in this study. Because of the small sampling size and limited number of participants available from this specific demographic group, the researcher included parents of children who had been identified within the past school year or had been identified multiple years prior and had been receiving services for several years.

Identified participants were provided a 5-point Likert scale survey to measure parental satisfaction and understanding of special education. The survey was created by the researcher of this study with feedback from a fellow doctoral candidate; later and before submission, feedback and ethical approval was received from the dissertation committee and IRB. The researcher's 19-year background in public education offered insight and understanding on the questions most often seen and asked among minority groups with children in special education. Interrater reliability was established through collaboration with the researcher's fellow doctoral candidate's partnership. Ethical

considerations, including research ethics when completing a qualitative study involving person-to-person interviews were analyzed and considered in the creation of and edits made to the survey. The survey listed satisfaction levels ranging from strongly disagree, disagree, neutral, agree, and strongly agree. Satisfaction levels of parents included being offered choices for their child's services, collaboration with the school, and having active roles in educational planning. Rossetti et al. (2021) described parents' understanding of their child's programming and services having negative consequences to the advocacy rights. The Likert scale survey included questions relating to how comfortable the participants felt throughout their child's evaluation and services through special education (see Appendix E).

Following receipt and completion of this survey, the researcher contacted each participant for interview scheduling. An agreed-upon time and platform (Zoom, telephone call, or in-person) was established and scheduled to conduct individual interviews. The researcher explained to the participants that following the interviews, each participant would be completing Respondent Validation (RV) through Interviewee Transcript Review (ITR) of the full transcriptions (Rowlands, 2021). Rowlands (2021) explained that through the lens of social sciences, participants had the right to review their records (i.e., interview transcripts) to ensure validity of their recorded responses. RV as used in this study is a type of member-checking in qualitative studies offered to participants to "review and then respond to interview transcripts, by agreeing or disagreeing and proposing changes" (Rowlands, 2021, p. 1).

Each interview began with the researcher reviewing the participants' survey responses. Following the core framework of phenomenological research, review of

these survey results enhanced the researcher's ability to reflect on and interpret the participant's experiences prior to presenting the participants with personal questions during the interviews. The interviews were then continued to include open-ended questions to identify and define the participants' experiences in receiving appropriate educational programming for their children with disabilities. Open-ended questions during interviews were chosen to allow for additional information to come from discussions that may not have been considered previously. It also allows the researcher to gather more data and storytelling like responses from the participants that would not be possible with closed questioning. Questions included:

(a) What type(s) of services did/does your local education agency (LEA) provide to your child?; (b) Describe your experience (within the school and in your social group) since discovering that your child has a disability; (c) Describe the support you receive for yourself and/or your child from family, friends, or community; (d) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team. (e) Did any part during the evaluation process and later, annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding? (f) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in [country of origin]).

Interviews (both in person and virtual) ran for roughly 45-90 minutes at a time. Each participant was offered different options for settings (i.e., in-person, virtual, phone) for the interview and an agreed upon time was set. For the participants who chose a

virtual interview, a password protected Zoom invitation was sent. The researcher explained to the participants that the Zoom sessions would be locked to prevent others from entering, the meeting was recorded for review of transcription, and upon completion of transcript reviews, the recordings were deleted. The questions above were asked allowing for a natural flow of conversation to continue. Prior to ending the interview, each participant was asked if they preferred an in person, email, or virtual follow-up with the researcher to check for accuracy of the interview transcription. Every participant chose to have a typed transcript of the interviews emailed and would respond back via email with additions and/or corrections to their reporting and answers. Use of this verification strategy called ITR as described by Rowlands (2021) was chosen as a method of “enhancing accuracy...acknowledging the contribution of participants” (p. 2) while allowing the participants to identify misspellings in their transcripts to help improve accuracy.

Following receipt of follow-up emails by the participants, the researcher verified that all information provided was transcribed correctly and offered a thorough understanding/picture of the experiences had by each participant. Following the interviews and review of transcripts, the researcher assigned codes to classify and organize specific points and phenomena revealed through the gathered data (Bloomberg & Volpe, 2019). These data were also reviewed by the researcher and participant (participant verification) to ensure that interpretations transcribed were accurate.

Validity/Trustworthiness

Phenomenological reflection (Van Manen, 1990) was used between the participants and the researcher to ensure correct descriptions of experiences addressed throughout the interviews. Through ITR (as described above), the gathering of data for analysis was complete. The researcher then used a thematic analysis approach to identify themes and patterns in the data collected to not only describe, but to interpret and make sense of the experiences unique to each participant (Maguire & Delahunt, 2017). Through this method of thematic analysis, the researcher benefits from allowing unanticipated themes to arise during interviews which can bring about greater understanding of participants' experiences and personal stories. Along with a collection of and identification of similar themes, using a qualitative approach allows participants' experiences to be reported in a manner that does not necessarily fit into a predetermined outcome.

Data Analysis

The purpose of this study was to describe the essence of lived experiences as recounted by participants. A phenomenological approach to research was deemed appropriate due to the fluidity of information (offered during open-ended questioning interviews) and unique accounts by each participant. The researcher aimed to preserve the individual accounts and undetermined themes that may arise. Through thematic analysis, the researcher was afforded flexibility in a methodology that can later be used to diversify the current work and expand in future research projects (Maguire & Delahunt, 2017).

The first step in gathering data was completed upon receipt of survey responses. The surveys were then used to extract text that can be used to begin coding data to find themes within the received information. Initially, the researcher manually entered the survey questions into a Microsoft Excel spreadsheet with a focus on finding categories/themes. Each question was then placed into one of three categories that covered the range of processes participants underwent through identifying and beginning (continuing) special education services for this child. Through further analysis of this data, the categories became the three primary themes of the study: parent rights and involvement, the special education procedures, and native/home languages. The data gathered from the surveys were later input into the data analysis software program called NVivo. The software program identified similar themes as were identified through the Excel organization of data.

Following the initial analysis of survey results, each participant completed a one-on-one interview with the researcher where themes retrieved from the surveys were reviewed and extended upon to build the narrative of the participant's stories. Following the interviews, the researcher completed a process of member checking of data through participant review and feedback of transcripts (as described above). The transcripts were then added to the initial coded data gathered from the surveys and the final analysis was completed.

Analysis was conducted through a triangulation of collected data to ensure the complete scope of participants' experiences was identified and described meaningfully. The three pieces of data used were surveys, interviews, and member checking. Through this analysis, the researcher was able to describe participants' backgrounds

(with the use of questionnaire and survey results), report on one-on-one interviews covering participant experiences, and finally use member checking to ensure high levels of ethical considerations (through participant verification) of the transcribed interviews. Triangulation was performed to identify and understand inconsistencies found across collected data (between survey results and interview findings) as well as offering further credibility of results. This type of analysis offers researchers deeper insights into the phenomenon being studied (Patton, 1999). Through the triangulation of data in phenomenological studies, the researcher becomes the “research instrument insofar as his or her ability to understand, describe, and interpret experiences and perceptions...” to offer meaning to participants' circumstances as recalled and reported (Maguire & Delahunt, 2017, p. 3351). The themes and sub-themes identified through this analysis of data can be used for future recommendations in educational practices. These recommendations will be provided to the reader in Chapter 5 of this study.

Future Considerations

The findings of this study will enable practitioners, educators, and LEAs to better understand this unique population and how best to communicate with and serve MENA and South Asian children through special education. Through defining the phenomena of each family, the researcher aims have a greater knowledge into their needs, to provide training for local Muslim communities to help engage and educate families on their rights within the public school system. Professional development opportunities will also be offered to LEAs to provide data driven, culturally relevant information and training to educators working with EL/CLD students. Through the findings of this study, the researcher hopes that more academics and researchers will consider conducting

studies specifically targeting a larger demographic of minority groups. Through learning the different nuances of certain cultural groups, teacher education programs can provide student-teachers with more exposure and greater understanding of all minority groups, rather than just the majority minority groups studied thus far.

Summary

This chapter outlines the methods to implement a qualitative phenomenological research study through triangulation of data findings. The researcher included a positionality section for complete transparency regarding the potential limitations of bracketing of experiences based on the researcher's own lived experiences. The qualitative design of interviewing participants aims to capture experiences of this population and offer a medium to share their voices and stories in a manner that has not yet been explored. In recognition of the doubts and controversies in conducting credible qualitative research and data analysis (Patton, 1999), the researcher of this study followed the recommendations of Gunawan (2015) who stated:

...to ensure the trustworthiness, the role of triangulation must again be emphasized, in this context to reduce the effect of investigator bias. Detail emerging methodological description enables the readers to determine how far the data and constructs emerging from it may be accepted. Additionally, the utilization of detailed transcription techniques, schematic plan of systematic coding by means of computer programs, as well as counting in qualitative research are the modalities to ensure rigor and trustworthiness. (p. 11)

This researcher maintained the goal of ensuring the results and reporting throughout this study accurately reflect the experiences of each participant.

CHAPTER IV

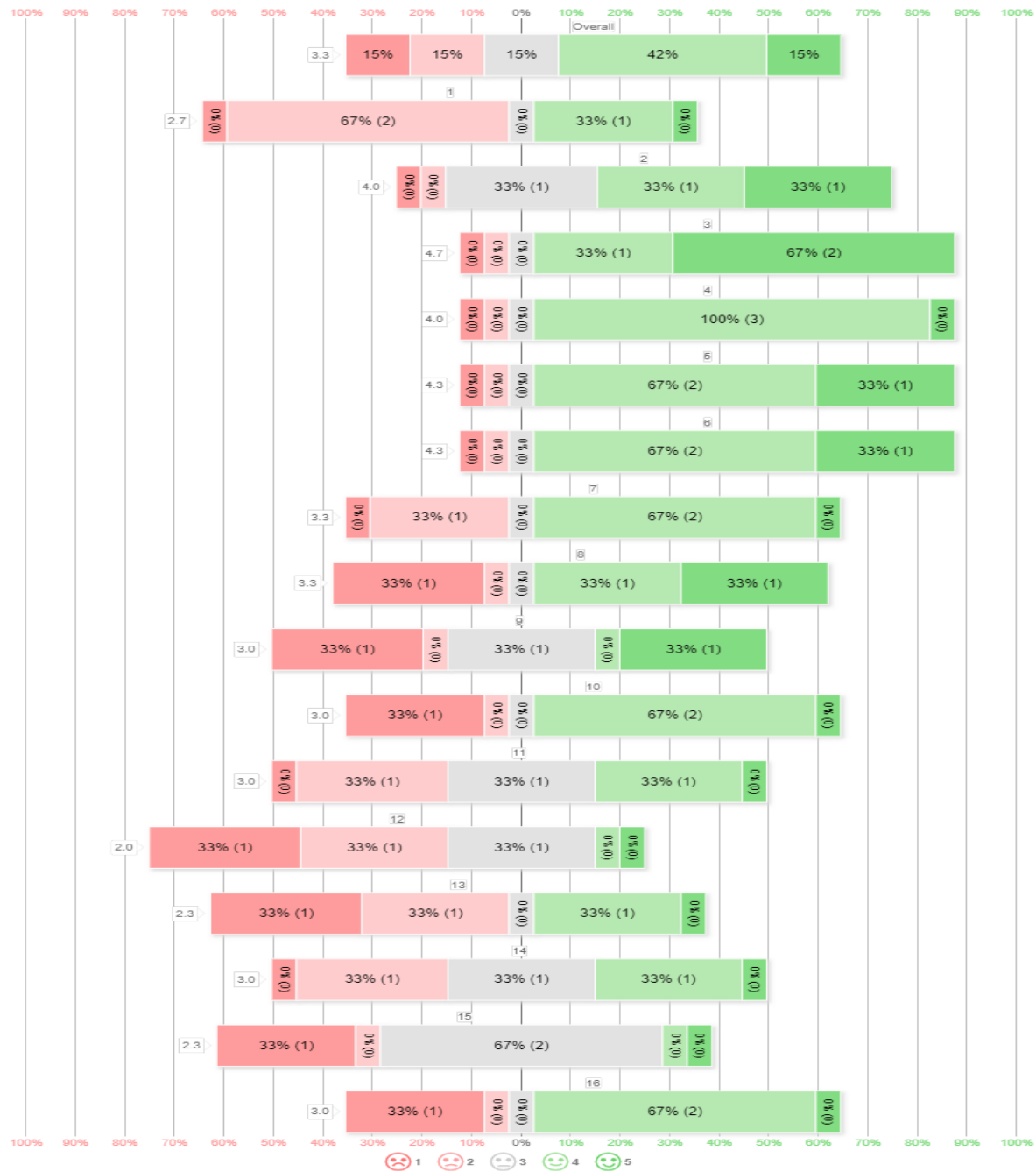
RESULTS

Introduction

This study was designed to bring about understanding and representation of an under identified population in U.S. public schools. The primary investigator sought to clarify misunderstandings between educators and families from MENA and South Asian descent with children that receive special education services. A qualitative phenomenological study closely examines patterns and themes in the analysis of findings (Bloomberg & Volpe, 2019) to uncover trends to allow for discussions and further research. The findings of the survey results along with the interview questions led to establishing three themes and six sub-themes. For purposes of this study and to bring order and meaning to the data obtained, the researcher used the Microsoft Excel and the NVivo software program to analyze themes, code the data, and verify dependable and accurate data representation. Findings were then imported into visual charts for ease of understanding (see Figures 1 and 2 below). This analysis was described in greater detail in Chapter 3 of this study.

Figure 1

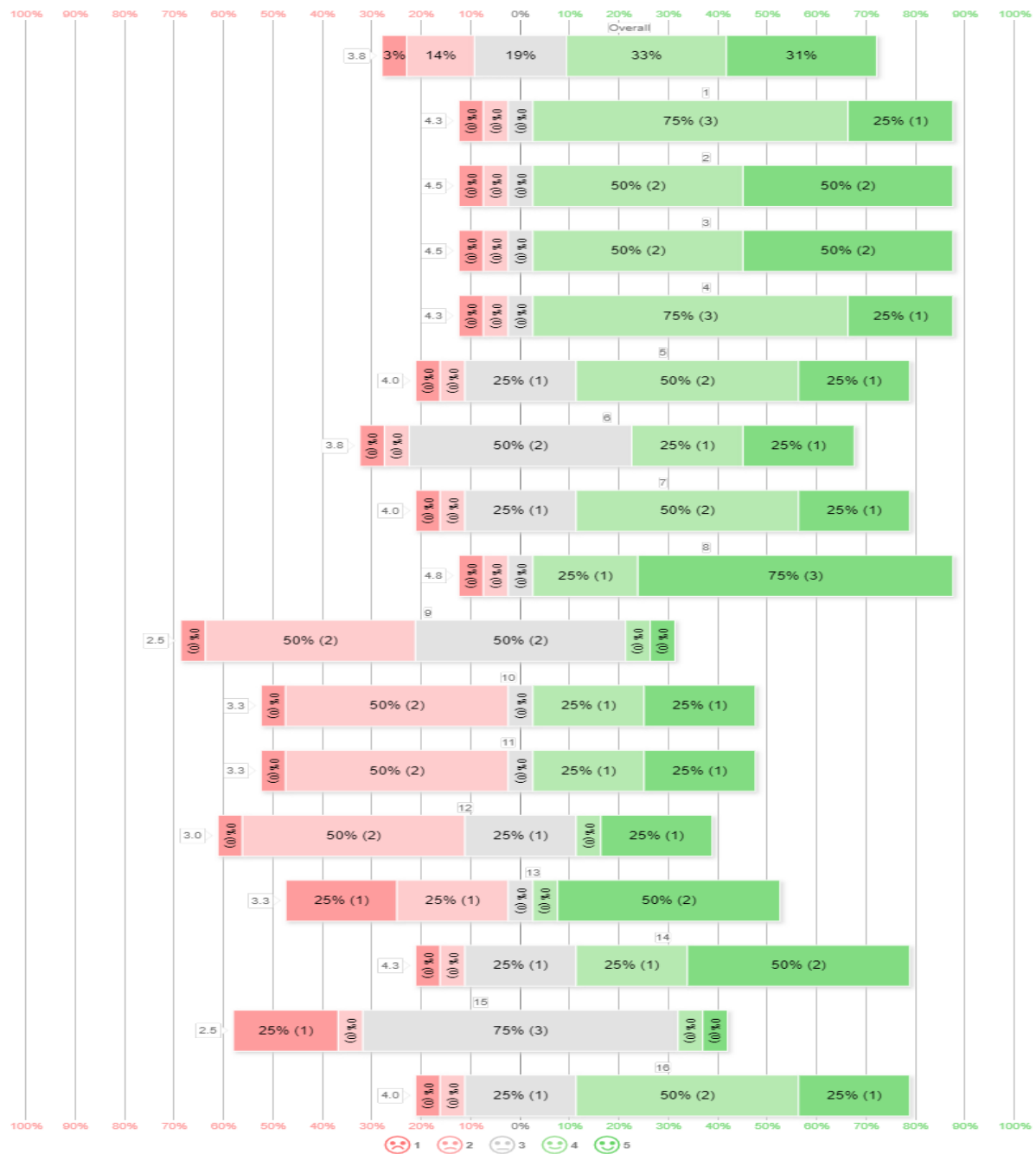
U.S. Educated Participants Survey Responses



Note. 1: Strongly Disagree 2: Disagree 3: Neutral 4: Agree 5: Strongly Agree

Figure 2

MENA/South Asia Educated Participants Survey Responses



Note. 1: Strongly Disagree 2: Disagree 3: Neutral 4: Agree 5: Strongly Agree

This chapter begins with introducing the reader to each participant including demographic/background information and a brief description on their child(ren) receiving special education services. The participants of this study were initially asked to complete a questionnaire (see Appendix D) covering demographic information to ensure that each respondent met inclusion criteria (as described in Chapter 3) to participate in the study. Following the questionnaire, each participant completed a 16-question Likert scale survey (see Appendix E) covering several aspects of special education. The survey included questions about:

- a) initial referral and evaluation,
- b) understanding of the (child's) disability,
- c) placement decisions (specific classroom settings) and service options available and offered,
- d) receipt of parent rights and explanations of understanding of rights,
- e) understanding different classrooms (resource/inclusion),
- f) and how comfortable participants feel advocating for, asking questions, and disagreeing with proposed plans for their children's education.

The responses to the above questions/survey were used to begin finding similar themes between the two groups. This chapter begins by providing the reader an introduction to each participant including background and demographic information, as well as a brief summary of their child(ren) currently receiving special education services. The participant introduction will be followed by survey results and findings. The results of these surveys collected allowed the researcher to have sufficient background information into each participant's experiences. This information was later used to begin

the one-on-one interviews. Following the analysis and summary of survey findings, a description of the themes identified through survey analysis are offered. Lastly, this chapter provides a thorough account of the interview transcripts of each participant. The researcher chose to lay out this chapter with the interviews transcribed last to help build each participant's individual story offering readers insight into background information that would not otherwise be available.

Results from the collected surveys, one-on-one interviews, and post-interview member checking were compiled to answer the research questions:

RQ1: What are the experiences working with the LEA of MENA and South Asian parents who have a child with disabilities receiving special education services in U.S. public schools?

RQ2: Is there a difference in experiences with the LEA between minority parents educated in the United States versus those educated in another country who have a child with disabilities receiving special education services in U.S. public schools?

RQ3: How are participants' perceptions and experiences different from European-American parents who have a child with disabilities receiving special education services?

Triangulation of the data included an analysis of surveys, one-on-one interviews, and post-interview participant verification (member checking) through ITR to ensure accuracy of transcript reporting. RQ3 was summarized in a later section through current literature findings and member checking between the researcher and participants.

Participant Demographics

This section will describe the demographic and background information of included participants to help build overall understanding of experiences and expectations. All participants were female who chose to include their stories in “hope to help others understand us better” (Amal). Four of the seven participants were between the ages of 41-50, one was between 20-30 years of age, and two were between 31-40. Five of the seven participants were married, one was recently widowed, and one was going through divorce at the time of this study. The children receiving special education services ranged from early childhood (3 children; ages 0-5), (2) aged 6-10, (3) ages 11-14, and (1) ages 15-21. Three of the seven participants were of South Asian descent and four of Middle Eastern/North African descent. Five participants held bachelor’s degrees and two held master’s degrees. Of all participants, two households reported English as the primary language spoken, two reported Urdu, one reported Arabic, and two reported both Arabic and English being spoken in the home. Three participants were educated in the U.S., two were educated in Pakistan, one was educated in Egypt, and one was educated in Jordan. All participants were fluent in English and demonstrated comfort in responding to survey questions and interview questions provided in English only. Each participant described below is listed by their pseudonym.

Aminah, a U.S.-born and raised South Asian of Bangladeshi descent. Aminah is married, above 40 years of age, holds a bachelor’s degree and is currently completing a master’s program; she has one child 11 years old receiving special education services and reports that English is the primary language spoken in the home. Aminah’s daughter has a medical condition which requires constant monitoring and

accommodations as she is considered medically high-risk. Aminah chose to participate in this study because,

...this subject is near and dear to my heart; having experienced what we went through following my daughter's diagnosis, I knew things had to change. As a local community leader and mentor to upcoming Muslim leaders, I felt responsible to sharing my experiences and struggles in hopes that others don't face the same.

Hadiya, was born and raised in Pakistan and moved to the U.S. after completing 3 years of college for her bachelor's degree. Upon moving to the U.S. Hadiya completed a bachelor's degree program at a Southern California university. She has four children with ages ranging from 12-19 with only one currently receiving special education services. Her youngest son (age 12) has multiple disabilities and is considered physically fragile. Hadiya reports that Urdu is the primary language spoken at home. Hadiya chose to participate in this study because she wanted to,

...better the chances of parents and kiddos. We all lose hope at some point, but hopefully...your study will bring more light in one place to see how different parents and their kiddos with different abilities coming from different backgrounds and struggles will manage to survive.

Karima, was born and raised in Pakistan and completed her master's degree in Pakistan before moving to the U.S. Karima reports that Urdu is the primary language spoken at home; she has two children (ages 15 and 19), both with disabilities. Karima's youngest, her 15-year-old son, currently receives special education services. Karima chose to participate in this study because she wanted to,

...share my opinion and experience about the education system in the U.S., what problems are faced by Muslim parents, as well as recognizing all the support I have received being a mom of special needs kids.

Layla, is U.S. born and raised of Egyptian (MENA) descent. Layla is married with one child currently receiving special education services and a second younger child (toddler age/non-disabled). Layla's older son (4 years old) was recently evaluated and identified with autism; he receives services in a special education classroom in the district's early childhood school. Layla holds a master's degree and her husband holds a Ph.D., both educated in the U.S. She reports that English is the primary language spoken in the home and this is the first year her son receives special education services. Layla chose to participate in this study because:

I have multiple reasons. Since I was a social science major back in my day, I know the challenges of finding participants for academic research studies and have always tried to make it a point to contribute if I'm able to. Secondly, my husband wrapped up his dissertation a few years ago and I witnessed first-hand the seemingly never-ending obstacles that would pop up along his path, so sympathize with other graduate students looking to wrap their work up and get on to the next phase of their careers. And thirdly, which is what made sure I didn't leave this study out of my time, was to ensure that my son and those that come from our Muslim, minority, and brown communities, would have an included voice in the discussion of disability resources. Research tends to favor the white, male, Christian, participant, and any chance I have to be able to offer a wider consideration of needs, I do feel it a personal obligation to attempt to do so. The

fact that it deals with my own son's disorder and his ability to receive resources, just made it that much more personal to pursue. I want the best for him. I want the best for all children and their families that find themselves on this journey in their lives. What we as parents previously imagined for our children before having them is entirely different than the reality of raising them, knowing (or suspecting) developmental or intellectual disabilities...at the very least, we should be ensuring all people in this country receive the information, resources, and legal rights they are supposedly entitled to.

Ruby, is a Palestinian/Jordanian (MENA) born, raised, and educated in Jordan. Ruby is married and has one child currently receiving special education services. Ruby's son was identified as having autism following a referral from their pediatrician at his third birthday check-up. Her son is now 8 years old and attends their neighborhood elementary school where he receives special education services. Ruby holds a bachelor's degree and reports that Arabic is the primary language spoken in the home. She reports that she believes that teaching her son Arabic while he's learning primarily in English at school is very important to her and her husband. Ruby chose to participate in this study because,

I experienced great difficulties during the initial years of my son's diagnosis and initial start of services. I want to share my story so others can have it easier than I did.

Amal was raised and educated in the U.S. but born in Lebanon (MENA) and came to the U.S. as a young child with her parents. Amal is married and holds a bachelor's degree; she reports that both Arabic and English are spoken in their home

because “I want to make sure my children are fluent in our native language.” Amal’s daughter was identified as having autism when she was 3 years old through an evaluation conducted at her district’s early childhood school. Amal’s daughter is now 5 years old and going to the neighborhood elementary school where she receives services through special education. Amal chose to participate in this study because,

I know how little teachers understand about our culture and community and I want to help them understand us better. I’ve received wonderful support from my child’s school, but I know they felt overwhelmed when they found out we spoke Arabic. It’s still so foreign to them! I’m hoping this study will help more people understand that we’re not so different from everyone else.

Jannah was born in the U.S. to Egyptian and Syrian parents but completed her primary education in Egypt. Jannah moved back to the U.S. during her college years and completed a bachelor’s degree. She is widowed and has two children currently receiving special education services, ages 7¹ and 10. Jannah’s daughter, now 10 years old was diagnosed with autism when she was five-years old. Her son, now 7 years old, was identified with autism at the age of three. Jannah says that “because of my experiences with my daughter, recognizing the same characteristics in my son wasn’t difficult.” Jannah reports both English and Arabic spoken in her home. Jannah says she chose to participate in this study

...because I have seen how many people automatically assume I don’t understand paperwork, or that I shouldn’t understand English, or that I probably

¹ *Jannah’s son was six at the time of the interview, he turned seven before this study was finalized and documented.*

don't really know the needs of my kids...because I wear a scarf and have a little bit of an accent. I want to be a part of the narrative instead of having a narrative written about us that doesn't include us.

Participant Demographic Rationale

The primary investigator of this study chose to include the educational background of all participants because of a seldom addressed bias in education where teachers hold less favorable expectations of students from diverse backgrounds as compared to their European-American counterparts (Tenenbaum & Ruck, 2007; Yamasaki & Luk, 2018). Several participants in this study made comments such as, “because of the way I dress and my head scarf, teachers assume I don't understand English or don't have an adequate education” (participant Ruby). Pagan (2022) quoted Staats (2016) when referring to unconscious racial biases being defined as the attitudes or stereotypes all people hold that affect understanding of and decisions towards those who are racially different from us. Through multiple interviews, it became apparent that many families from MENA and South Asian descent experienced biases towards their backgrounds and experienced many educators who spoke to them as though they had limited intellectual abilities. Table 1 (below) summarizes the basic demographics and education level of participants.

Table 1*Participant (Parent) Demographical Information*

Participant name (pseudonym)	Nationality	Education Level	Number of children receiving special education services	Educational background (U.S. vs overseas)
Aminah	South Asian	Bachelor's Degree	1	U.S.
Hadiya	South Asian	Bachelor's Degree	1	Pakistan
Karima	South Asian	Master's Degree	2	Pakistan
Layla	MENA	Master's Degree	1	U.S.
Ruby	MENA	Bachelor's Degree	1	Jordan
Amal	MENA	Bachelor's Degree	1	U.S.
Jannah	MENA	Bachelor's Degree	2	Egypt

Note. Names listed represent pseudonym used in study

Analysis of Post-Survey Themes**Survey Summary**

Each participant completed a 16-question Likert scale survey (see Appendix E), which covered similar themes as the themes discovered during the follow-up interview. This survey was checked for face validity through the dissertation committee of the researcher and a fellow doctoral candidate with a background in special education prior

to IRB submission and approval. Table 2 (below) offers a summary of the themes and sub-themes identified through the coded data analysis of survey findings completed using NVivo and Excel. The identified themes were further investigated during the interviews between the participants and the researcher.

Table 2

Themes and Sub-Themes Identified Through Survey Results

Parent rights/ involvement	Special education procedures	Native/Home language
During the ARD Process	During the ARD Process	Paperwork received
Understanding paperwork/ legal rights	Understanding paperwork/ legal rights	Translator/ Interpreter offered during meetings
Ease of communication	Ease of communication	
Feelings of inclusion and value of ideas		

Parent Rights and Involvement

One of the first themes that emerged from the study is parent rights and involvement, these themes are at the core of understanding the services offered to students with disabilities. The survey asked in Questions 8, 9, and 10 directly about

receipt of parent rights and explanations or understanding of said rights. As previously stated, IDEA stressed the importance of “meaningful parent involvement” (Yell, 2006, p. 262) throughout the entirety of beginning, implementing, and changing services for students with disabilities. Questions 13 and 14 focused on understanding participant’s views on understanding different classrooms being spoken about during IEP meetings and how comfortable parents feel advocating for, asking questions, and disagreeing with proposed plans (see Figures 1 & 2 and Appendix E).

When asked questions regarding their legal parent rights (Procedural Safeguards), participants who reported being educated abroad responded with a positive (agree/strongly agree) to six of the questions and responded with a negative (disagree/strongly disagree) to four of the questions with having their legal rights provided and explained to them. The participants who reported that they were themselves educated in the U.S. responded with five positive and three negative scores regarding their rights being provided and explained. Participants educated abroad had a more favorable response to feeling they understood placements and could disagree with, or question proposed plans. Those educated in the U.S. had three disagree/strongly disagree responses and only two responded in agreement.

Special Education Procedures

Survey Questions 1-7, 12, and 13 covered different aspects of special education procedures. From initial referral and evaluation, understanding the disability, to placement decisions and service options available and offered. Information gathered from participants who were educated abroad showed an overall positive view on their understanding of the evaluation process, their child’s disability, services offered and

available, and the needs of their child with regards to specialized needs for specific disabilities. The questions covering specific placement and classroom settings were answered with split sentiment. Four responses disagreed, three agreed, and one had a neutral response. Of the participants who were educated in the U.S, the overall sentiment was more positive responses; although, more participants disagreed with several of the questions. These questions included help received in understanding the referral/evaluation process, services recommended, classroom setting options, and how decisions are made regarding educational programming (See Figures 1 & 2 and Appendix E).

Native Language

Questions 9, 10, and 15 of the survey covered participant's experiences with the availability of documents, explanations, and interpreters for meetings. The participants who were educated in the U.S. primarily responded neutral while participants who were educated abroad all answered with disagreement or neutrality. When asked about this specific topic during our interviews, the participants explained that because they were orally fluent in English, it was never brought to their attention that the paperwork can be offered in their native language.

RQ3: Based on current research, how are participants' perceptions and experiences different from European-American parents who have a child with disabilities being served through special education?

A limitation of this study was not including European-American participants and instead using current research to answer the last research question. Rossetti et al. (2021) describes the assumed nature of parents participating in their children's

educational programming and IEP meetings, especially considering the importance of such participation as spelled out under IDEA. Yet the fact remains that,

...although educational laws should have reduced the need for parents to advocate, there is today, an implicit and explicit expectation of involvement based on European-American middle class value systems, as well as an understanding among parents that they will need to advocate. (Lalvanie, 2012, p. 483-484).

Although themes stemming from these findings and interviews primarily focused on the CLD parent experience, current research shows European-American parents describe two of the three themes as challenges to their experiences as well. Families described the struggles of understanding special education procedures and ensuring that their involvement and parent rights were met. Ruby reports, “the entire process in the beginning seemed very confusing. There was always so much paperwork and so many forms to complete.” Rossetti et al. (2021) quoted Mlawer (1993), “Is it possible that, by attempting to help parents become skilled educational advocates for their children, we have created an advocacy expectation that makes life even more difficult for many parents, families, and children?” (p 106).

Rosetti et al. (2021) stated that parents described their need to advocate for their children’s rights as an “obligation” (p. 439) to ensure that their children and other children would have access to required services. The parents described that through their advocacy, they gained a greater understanding into their child’s disability, the parents felt the need to constantly “fight” (p. 439) the education system leading to unnecessary stress upon the family (Rossetti et al., 2021). The parents continued to

describe the social capital and advantages they experience when sharing the same cultural background as educators as compared to families who do not share the same cultural experiences being at a disadvantage. Study participant, Layla describes her experiences (having been educated in the U.S. and not looking foreign) as:

My language was an asset in this case, not just my unaccented English, but my knowledge of medical and psychological terms. They [the school evaluation team] repeatedly commended me on, “being so helpful with what you’re sharing with us”. I did wonder throughout the process if I hadn’t had those exposures or experiences, if I would have felt as clear on what was being discussed for my son.

Interview Findings

Following completion of the surveys, participants were asked open-ended questions regarding their experiences with special education services for their children.

(a) What type(s) of services did/does your LEA provide to your child?

Aminah

She was allowed trips to the nurse as needed for sugar level management. She began with 504 services for diabetes but was evaluated again during the COVID-19 Pandemic and qualified for services under pragmatic language disorder. We take her to an outside counselor, and we really feel that her anxiety is much more likely the cause of her struggles at school.

Hadiya

Speech [therapy], occupational therapy, physical therapy, Applied PE [Physical Education] – currently in Elevate classroom. [The Elevate classroom is the self-

contained classroom in their school district for students with disabilities requiring more support.]

Karima

Speech therapy, Adapted PE, Elevate [school district's self-contained classroom], and ESY [Extended School Year] but only in kindergarten. We have also attended summer programs for children with disabilities through our local rec center and programs under the Texas Workforce Commission.

Ruby

He gets lots of services it seems. The teachers send home a notebook with him every day that talks about how his day was. He has a teacher or a teacher assistant with him in most of his classes, I think. He gets overwhelmed with the loud noise in the cafeteria or the gym, so they allow him to wear headphones. He used to get OT service, but he graduated from that.

Amal

My baby is just starting this whole special education program thing. She's been offered speech therapy and in class support to help her learn to socialize better. She hates to write so they're helping her with that too. But not officially, like not occupational therapy help, just from her case manager and teacher. She has a choice board and earns rewards too when she does well. I figured there would be more complex services as she grows and needs more. For now, she's pretty easy going.

Layla

His school offers speech therapy, occupational therapy, and potentially they will look into feeding therapy. They also have a part time preschool classroom with other children on the spectrum (only this class) with exposure of 10 minutes a day with the general preschool population.

Jannah

My daughter is now in fifth grade. She received speech therapy twice a week for 25 minutes each time, and resource classes for Reading and Language Arts. She does really well in math and other classes, so she has a special education teacher go check on her in her classroom every day for extra help if needed. She also has accommodations so that she can get extra time to finish assignments if needed. She hardly ever uses it, but it is there to help her if needed. My son, who is in the first grade, receives all his education in a self-contained classroom. He receives speech therapy twice a week and has a social skills classroom. All his classes are adapted to his level, and the focus of his education is to build functional skills. He was unable to care for his own toileting needs until last year, but he is now able to do it most of the time.

(b) Describe your experience (within the school and in your social group) since discovering that your child has a disability.

Aminah

When my daughter was initially diagnosed at the age of 14 months, our community was not very welcoming. We did find those in our community and others who have a family member with needs to be very compassionate and

welcoming. Others would make comments to me like, “why are you telling people she has diabetes? She’ll never get married...” This was very hard because we were still mourning for our child knowing the difficulties she will face. Sadly, the general community where we lived was not inclusive and not supportive. Because many didn’t understand, there was a lot of mom blaming, “did you do something while you were pregnant?” It all seemed very old school and backwards, just because they didn’t understand, they had to find blame.

Hadiya

When I found out about his diagnosis, he was about 2.5 years old. I had already been doing early intervention and therapies with him since he was 7 months old. People who would find out, stayed neutral. I am not sure it was because it was not something common. At the time he was only diagnosed with tetrasomy 18p, and no one knew about it. People still don’t know but now I can often say to them that he is also diagnosed with autism.

Karima

Within the school, it has been supportive. Socially, you can sense when people don’t like to interact with your child. It takes a long time to get used to people staring and judging you and your child. When traveling back to Pakistan, within our own family, the kids are accepted. But socially, there is only slight improvement. The government does not support special education. But there are a lot of people that have begun donating and opening schools specifically serving special education kids. No laws are in place (that I know of) to support or protect disabilities.

Ruby

The school has been great. They seem very supportive and understanding even when I ask a lot of questions. (My son) was referred by his pediatrician when he was 3. I didn't know what I was doing and was very confused. I felt guilty because I thought I caused this in my son. But I'm learning more and more and I'm finding more friends. It's not easy in our community. We are starting to get more support when we go out in public, but it's taken so many years. In the beginning, I felt very alone. I didn't know many other Muslims with a child with a disability. Now I know so many and we are like another family together. Alhamdulillah [thank God].

Amal

Socially, I guess my friends and I have known each other so long that nothing really shakes us. When my daughter was born and when we started noticing that she was different, it was just, "well this is just her personality." I think we're all pretty western thinking so we don't get scared of disabilities or someone who might look a little different.

Layla

This has been a particularly beautiful and painful experience within our social group. It feels like there was almost no middle ground once we found out our son had a disability. We encountered friends who were skeptical of his diagnosis "but he doesn't look like he has autism", who made comments that were insensitive, "it's impossible for a doctor to be able to diagnose him before he's five" or "doctors are stupid and don't know what they're talking about", said by other

doctors, and “doctors are stupid, and they always get this wrong”. And the most hurtful phrase, “Are you sure? But are you really sure? How do you know? Are you sure? Are you sure?”, as if I had to now prove my son’s diagnosis, in the midst of it being a fresh, overwhelming experience I was going through. Needing to become an overnight expert on all things autism and prepare a defense for my son’s disability, those were some of the hardest interactions I had, and I repeatedly felt heartbroken and shattered, rather than the kind, reassuring, supportive or helpful words I was looking for. The part that stung the most, was that in these social groups, they were themselves other Middle Eastern or Southeast Asian Muslim physicians, or in one case, a licensed therapist, challenging the discretion of the experts around my son, as well as my own ability to instinctively feel that something was off with my son. I just could not believe the immediate level I was met with argumentation, incredible skepticism, and challenges to what should’ve been a very understandably challenging time. I kept wondering if parents with children diagnosed with cancer or an otherwise “visible” disability, if they were also facing this level of skepticism of the diagnosis.

On the other side I did have a positive reception from individuals who made sure to come across as concerned or caring and supportive. Friends who would ask how things are going, would send over money, food, or coffee, and check in with us or make play dates so that our kids could have my son included with theirs. These were very meaningful, impactful moments and I felt grateful for being well cared for in those times. But, at the same time, I did feel like I was placing too

much weight on these individuals, and I was fearful of collapsing their ability to support us by burdening them with our situation too much, and in fact, one such friendship did eventually turn out this way. This other friend who was very close and helpful during my time of need, ended up having a scare of her own for her son's health and her reaction and response for her son was to assume a total hands-off approach. She decided that there was nothing wrong, that there wasn't a need for intervention, that her "role as a parent had no bearing on how my son would turn out", that the situation he faced was not as alarming- even though her son is four years old, had a seizure in his preschool class, and had to be taken to the emergency room in an ambulance in front of his other friends, and she herself is a physician as well as her husband... so once her son's situation came to light and she was dealing with these things, rather than jumping to action or coming up with a plan to address his needs, or even just talk about how he was doing or how she herself was doing, she inevitably shut down and as a result also shut down in all other aspects. She was no longer sensitive or sympathetic on a whole. She was no longer approachable or someone I could turn to for advice or insight or support as it seemed that talking about my own son's situation drew anger in her, as there was a stark contrast on how she was dealing with her young son's situation. She became combative and insistent that her role as a mother had nothing to do with how her son would turn out- despite her knowing how difficult my parents' toxic treatment of me and my siblings in childhood weighed on me.

Jannah

There is a history of autism in my maternal side of the family, so my family was understanding and helped me with the emotional part. Without having a husband, or a partner to help, working and taking care of my kids is all I do. Making friends has been difficult. Not only for them, but also for me. If I am not working, I am spending what little time I have left trying to manage the needs of the household. I found a job that is now remote, and that allows me to have more flexibility when it comes to commuting, but it is also very isolating. Finding care for them when I Am off so I can socialize is near impossible due to my son's level of care. My daughter tries to help me with her brother, but he can be aggressive towards her as well. I found a local network of parents of kids with autism, but due to the pandemic, the meetings stopped, and I was not able to keep up with the connections I made there. It is a shame because I felt less alone around them.

(b) Describe the support you receive for yourself and/or your child from family, friends, or community.

Aminah

We quickly realized that we had to become our own advocates, we couldn't count on help or education from others, so we created our own community inside of the community. Because of the stigma involved, people are not able to be honest about their challenges, medical diagnoses, or disabilities, for themselves or their family members. I became a member of the [xxx] Walk [Type 1 Diabetes support group] and soon, year after year, more community leaders and imams started joining in the walks. Initially, I think it was because I was seen as a community

leader and they wanted to support me, but it eventually grew into the community at large supporting the efforts. I think the most important lesson I've learned is that we have to be our own advocates, but many people are just in survival mode. There are lots of abuse cases in families that I've seen and been asked to intervene with just because people are too overwhelmed. They end up just turning to task-oriented relationships between spouses rather than one of love and support. Resentment then sets in because you don't get a break, you don't have a chance to care for your own personal health and well-being. As a parent of a special needs kid, you can't just drop off the child for a mom's night out or for daycare. You always have to be close by at all times just in case there is an emergency, like I have to be close to her school all the time in case there's an emergency with her sugar levels and I have to run over there. This is where [Support Group (name)] and the [Support Group (name)] special needs support group really grew from. This need for support and a network.

Hadiya

The support I received without knowing any diagnoses back in Boston was excellent. I am not sure why I felt that was, but there was a heart connection with people and the community in Boston. I missed all that after moving to Plano. The community here was different. They were nice but different. Seemed like their point of view was to move on and not worry. Treat and live as if there is nothing. I did not approve of that. I am not sure about the family support. As long as I did what they wanted, they were ok, otherwise not.

Karima

We have great close family and friends. Through (Mosque) [Islamic Association], we are part of the special needs group and have mom's day out sometimes. We sometimes try to plan dinner and lunch dates just for us moms too.

Ruby

Lately we've felt like we have a lot more support. Our community now has some organizations to help families like us. We have (organization name) and we have (organization name) that seem to really want to make our masajid (mosque) more kid and family friendly and accepting of those with disabilities. We have some imams even speaking on how to include everyone during their khutbah (lecture). It's been nice. Our family has been very understanding. They love our son very very much and are understanding about his needs alhamdulillah [thank God].

Amal

We haven't really needed much support from people so I'm not sure I can answer this question. I don't think my daughter's disability has been a hardship on my husband and I at all. Again, maybe when she gets older and it gets harder, it'll be different. But for now, we don't ask for support, and we don't really need it. Our family and friends are there as anyone else's family and friends are there for them. It's just our normal I guess.

Layla

They generally took his diagnosis well- the adults showered him with more affection and tenderness, and the children we told of his diagnosis suddenly

appeared less bothered by his idiosyncrasies. Our family would ask questions or look into the resources we passed on or allowed me to be the expert in all things (my son), so to speak. Before it would be a lot of questions, like why does he do that or why don't you try this or why don't you try that, but his diagnosis empowered me with the ability to say this is what my son prefers this is how my son works this is what helps my son and this doesn't help my son. I became somebody that could speak without judgment on the needs of my son. Whereas I felt frequently judged as a mother for (my son's) behavior before his diagnosis. In terms of the community, I'm going to refer to the Muslim community. I haven't had too many encounters with other Muslims after (my son's) diagnosis (mainly from COVID but also from not being able to figure out logistically how to be able to pray, while one parent watches one son, and the other making sure he doesn't run off). But the few community engagements that I have had, included those other Muslim friends who I mentioned before, who made very abhorrent comments or belittling remarks about his condition. Some of those friends who were dismissive of a two-and-a-half-year-old having a neurodivergent mind, later found out that he also has a coinciding autoimmune disorder of inflammation in his brain, and suddenly felt sufficiently explained with what (my son) might be dealing with. It seemed that as long as there was a technically "medical" and "physical" disability for my young son, they were satisfied believing we were challenged in some way. That, since we had a "medical" explanation, that could be "seen" from the outside (on bloodwork and other lab tests), then it might be "ok" to assume there's something in the way he thinks that's different than other

kids his age...This was also painful to deal with. We did have one instance recently, where we took him to a community barbecue at the (local Islamic) Institute. The BBQ was open for kids to run around, so that wasn't as much of an issue, but after the salah (prayer), there was a khutbah (small talk) for a few minutes. It was during this khutbah that we really saw what taking a young child on the spectrum would be like to a large gathering at the musallah (prayer hall). This was really the first time that we brought (my son) out and about because of COVID, and prior to COVID he wasn't much older than an infant, so he was in our laps or you know, was able to be contained. So, during this khutbah, he was running through the men and women's sections, running between the rows, pushing people, popping men on the head, running by and giving high-fives, and grabbing other people's water bottles, right in front of the speaker, and just overall disrupting the khutbah for all maybe 200 people, sitting quietly with their young kids as well. Now, granted this was at (local Islamic) Institute, rather than a neighborhood masjid, where we felt more comfortable having our son there, understanding their overall mission of inclusivity and accessible Islamic knowledge, rather than some of the stiffer rules on decorum we might expect from other masjids, but it was still salah and a khutbah after all. But it was what happened during the lecture and right afterwards that really touched my fearful mama heart. The adults held out their hands to give my son high-fives. They extended their arms, if he was trying to climb them for a hug. They acted as another pair of "goalie" hands, trying to scoop him up if I was unable to keep up chasing him. They did not reprimand him or yell at him for "misbehaving". The

speaker was the (local youth) organization creator, (name), and he specifically gave us a lot of grace during and after the khutbah. When (my son) tipped a giant bowl of prayer beads over and made a mess, along with disrupting the congregation, (name) made comments in his talk not about how to discipline your kids or how to have obedient children- but instead spoke on how “this was his home. This is where children should be allowed to be comfortable,” and “this is where they should grow up not feeling isolated, not feeling shunned, or reprimanded for just being children, in a space that they feel comfortable in.” Afterwards was an especially pointed experience that will likely remain with me in my life during harder times...because even though (name) was an acquaintance of ours, we never had any real socializing together, let alone the chance to tell him of our son’s diagnosis. But his response was so warm and caring and comforting; he rolled on the floor with (my son), he gave him hugs and tickles, and spoke to him with such honor and respect. He spoke to us with such admiration and respect. He was kind to hear our concerns but also said that “no, no, this is his home. He is always welcomed here,” and “if there were more Laylas and (name) [us parents], able to bring their children out, people would learn how to interact with them.” He was clearly knowledgeable on ASD and its effect on an individual and their family, so he was able to speak to the things that would make us all comfortable and feel included. This conversation really spoke volumes to me and made me feel especially at ease, because until this moment, we almost resigned to the idea of taking our son to community gatherings, let alone weekly Friday prayers. Anytime we’ve attempted to take him in the past, he

was sure to be overwhelmed by the large crowd, to certainly try to run away and elope. When there is a large group or when there's a large space (such as the mall or park), he wants to see what's in the other rooms or what is outside of the building...which can be extremely nerve wracking and dangerous, since most of the time these prayer halls leave the doors wide open so people can come and people can come and go, but they lead right out to the street where there's traffic or a parking lot, with no safety measures to contain a child that's running without fear. We still have not brought him back since then, but I do feel comfortable if I should want to. And this feeling, I cannot describe.

Jannah

My family has been supportive, but they live in Egypt so their help is limited. I am not able to make friends due to being a one parent household, and the little community I have is made up of some coworkers who do not understand my home struggles, or friends from our mosque who support me emotionally when I ask for it. Finding care for my children so I can go out is impossible. When my parents come to visit, they encourage me to go out and connect with other adults, but my son doesn't do well with changes in routine, so it becomes easier for me to be there. Recently, I heard through a parent network that the state offers respite care, and I have been considering applying for that to help me as needed.

(d) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

Aminah

No, my daughters was a medical diagnosis.

Hadiya

I was often confused. It was all new to me. The early intervention staff that came to my place was very personal. The school was different. I was lucked out. The people, the staff, and everyone were outstanding. The principal at his campus always knew everything about my son. They really catered to his needs and looked out for him. Anytime I had questions or concerns the staff was always there to help and guide me. The principal for the first 3 years at (the elementary school)...even took the initiative to have a meeting with me when music teachers showed her concern about why I did not want him to be in music. And together, we decided on things he could do in music and could not do due to religious boundaries. As I said, I am grateful to Allah (God) for everything.

Karima

No, not for my kids.

Ruby

No, we asked the school to test our son after his doctor recommended it. Maybe our culture and language were more of a shock to them because they don't seem to have much experience working with Arabs and Muslims. They asked us as many questions as we asked them, it seems.

Amal

No, we look pretty much like everyone else, so I don't think our culture really played a part in any of this. The only time I think language was really in play was

when we told the school that we purposely speak both Arabic and English at home. They thought we were confusing our daughter since language was hard for her. But I'm pretty strong-willed and insisted that I'm not changing my mind. I grew up speaking and understanding both Arabic and English and plan the same for my kids. I want to make sure my children are fluent in our native language. It's a non-negotiable for me.

Layla

I honestly felt well respected on the day of my son's evaluation and then his ARD meeting, but I attribute it to my working knowledge and general understating of what they might be looking for in discussing his behaviors and needs (my psych background and work with college students securing accommodations led me to this- not from any preparations made by ECI or the school district). My language was an asset in this case, not just my unaccented English, but my knowledge of medical and psychological terms. They repeatedly commended me on, "being so helpful with what you're sharing with us". I did wonder throughout the process if I hadn't had those exposures or experiences, if I would have felt as clear on what was being discussed for my son.

Jannah

Yes, I think that some people automatically assumed my daughter's speech delay was due to language differences [between English and Arabic], or they thought she was "confused" by the use of both languages in my home. I also felt like I had a harder time advocating for them, because I was quickly dismissed and told they just needed more time to get used to [school] in this country, even

though they were born here. Through time, I have learned to be more vocal about their needs, and not let people's misconceptions of my culture and my accent delay the help my kids need. I was much stronger by the time my son needed the help, and it was me that pushed for finding help early on.

(e) Did any part during the evaluation process and later, annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

Aminah

Our current school is very good. The previous one was very bad. There was so much lack of communication. There were times I had to go ask friends who understood special education for help because I was getting nowhere with the school. It was a very frustrating time.

Hadiya

Not really, I made sure I learned all I could very early so I'm not fighting to get my son the service he needs. I'm not afraid to ask for help or to ask questions and the schools have been very understanding.

Karima

The staff has always stopped the meeting and explained all the points. They send home draft goals three days ahead of the meeting to review. And they always change or update them when I ask during the meeting.

Ruby

The entire process in the beginning seemed very confusing. There was always so much paperwork and so many forms to complete. It was like we were buying a

house again with how many signatures you kept asking for. I didn't know they can give us papers in Arabic. Maybe that would have been nice. My husband and I speak and understand English just fine, but it would have been nice to at least been asked if we wanted it.

Amal

The school was always wonderful, they seem to have so much on their plates though. And there's so much paperwork. It wasn't that it was confusing, per say, it was just a lot. I get that they have to do this to cover themselves from lawsuits, but maybe there's an easier way to not make them have so much paperwork and now have so much paperwork for us too.

Layla

Working with the school district overall was chaotic. We live along the district lines of two school ISDs [Independent School District]. We were first told by our ECI OT that we belonged to the [one] ISD, then no, actually it was the [two] ISD...The meeting with the school district rep (a speech pathologist) went fine, but I didn't fully understand how things would work- everything was left for "when you have your evaluation and ARD". I tried to get more details from my ECI OT [occupational therapist], but there were still large gaps in what I understood. The date of the actual evaluation was also months later instead of when it was supposed to have been held; we filed the paperwork through ECI in February, spoke with the school district speech therapist in March, and were told to expect an evaluation date in May, no later than June, as my son's third birthday was in August, and we were filling relatively early. Months went by and I heard nothing. I

had no way to follow-up other than asking my ECI OT to see if she could find out what was going on or to try to get ahold of the school district. They eventually did contact me (but only days before my son's third birthday) at the end of August. I asked what happened and they explained that there was staff turnover in the summer, so my son's evaluation request somehow fell through the cracks. I was so outraged and unsure of how something like this could happen. People come and go from jobs all the time, how could my son's legal rights to resources be so easily dropped? What about other children about to turn three? There was no way for me to follow-up or be given any information, I was only instructed to wait to hear from them. How could I know this wouldn't keep happening as I dealt with the school district? I had little trust that this would not be an issue again- they could not ensure anything, since he was already supposed to be on their list to contact.

On the day of his evaluation, it was a bit chaotic. There were just a lot of things happening at once, a lot of people interacting with us at once, and we were hustled from one room to the next. I didn't feel fully prepared. I tried to get as many details as possible out of my ECI OT (not everything was offered off the bat) but was not informed of the various diagnoses and paperwork that would be required to be sent over to help establish my son's diagnosis or that anything would be required of us before arriving. So far, any time we've had an evaluation (through therapists, schools, doctor's offices), we would only show up and have my son actually evaluated...not use the documentation of others. Then afterwards, because of the very short window of time to get everything prepared

by his third birthday (I think we were literally like four days away, with a weekend in between), they asked for everything to be sent over that night. So, I spent the next approximately 13 hours nonstop after the evaluation filling out assessments and forms and locating different things that needed to be sent over to verify all sorts of things. It was incredibly stressful and overwhelming. I was not sure if I covered things adequately or indicated everything, just by the sheer amount of paperwork that needed to get done. I felt rushed and not fully supported in regard to what I needed in order to have his care ready. I only kept thinking `` why did we run the clock out to the last few hours when I applied months ago back in February?

As far as items being unclear, they were receptive over email and then on the ARD call to questions I would ask. I turned in forms piecemeal throughout the day and night, to at least make sure what I could get over to them made it through in time. They did not rush me during the ARD, so I was able to get all my questions adequately answered and understood.

Jannah

I think it was confusing, but not because of my language, but because the process can be confusing for anyone. I did my due diligence to research on the internet things that parents with special needs children should know, but that was not done by the school. Even now, if my children have a new case manager, they always assume I understand very little and instead of showing me ways in which I can increase my understanding of the process, they skip through important pieces assuming they will be too hard for me to understand. During the

pandemic, they assumed I would not request any help, and it was through my own research that I found out that I could request compensatory services.

(f) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

Aminah

Positively impacted - because I grew up in [xxx] ISD and being in [xxx] ISD now...had the previous experience with special needs peers through Partners PE. Whereas others who have not had the same experience growing up, look down at students and children with disabilities and don't know how to interact with them.

Hadiya

I think that my experiences with my school benefited me. My background from back home and here made me aware of all the differences and helped me walk through this whole situation.

Karima

It's very different between Pakistan and America. The principal and teachers in Pakistan don't really interact with the students. Students never felt comfortable interacting with teachers and admins as compared to here where our kids are comfortable with all staff members. Principals have an open-door policy and let the kids know that they can come in anytime. I've seen this at my kids' schools and it's very encouraging. In Pakistan, the lower your grades and abilities, the further to the back of the classroom you sit. My daughter, who is ID, sat at the

front of the class in a gen ed class. The teachers here seem to encourage kids to speak up and explain their own needs. Can't do that in Pakistan!

Ruby

I don't know if I can really answer this. I didn't have experience with someone in special education in my own education, so I didn't know what to expect. Maybe that was a good thing because it was all new.

Amal

I guess I would say it was positively impacted since I always felt comfortable around those with disabilities. I don't think many people have the same experience and can say that when they found out their child had autism or another disability that they felt it was going to be ok. But I did, I knew that schools were there to help and that kids can be pretty resilient and pretty darn loving towards those that are different. I experienced this and believe in my heart that my daughter will also be welcomed and feel the love of her peers one day. When she's older and can actually understand.

Layla

I can only assume this one- I assume because of my background in higher education, psychology, and me and my husband's experiences going to public schools in America, that this contributed to our overall positive interaction with the school district. While negatively with regards to the private, traditional daycares- they were quick to become defensive of me knowing my son's needs and advocating for them, rather than understanding and looking to include them if possible.

Jannah

I have always been treated as a foreigner, and because I am also a widow, that has negatively impacted my experience with the school system. Due to the biases that exist around my language, my attire, and my gender; I am often ignored from the educational planning of my children's special education planning. I have learned I have to be louder for people to listen, and I am constantly having to claim my space as the primary decision maker when it comes to changes in their placement.

(g) Is there anything else you would like to share to help others or that you would like me to report?

Aminah

My only advice would be to treat each child individually, the needs of each child and family varies even if they share a diagnosis with another child.

Karima

Our community needs to learn how to communicate with the school and staff. We are not showing the manners we should be showing them, you have to be respectful. The teacher doesn't know that the kids eat with their right hand, and don't eat meat; the teacher is not from our culture so they don't understand and know what to expect or what the preferences are. Our parents don't come and talk (to the campus or teacher) and need to do the work of coming and deciding to live in a different culture (living in America). You have to show respect to the culture, you are responsible for educating and informing and staying polite and kind. Sadly, lots of Muslims are very rigid. Parents aren't reading the IEP reports,

goals, not interacting with the teachers and are clueless – they sign blindly.

Teachers can try harder to understand cultures and religious practices. You will always run into people that are not friendly but keep trying and getting people to open up to you. Teaching goes both ways.

Jannah

I think understanding my complete background helps people understand that I'm not just a foreigner that doesn't know enough and can't understand what my kids need. That's the most frustrating part of working with some people the first time they meet me. I was born in the United States but went back to Egypt when I was seven. My education there was traditional and gave me many opportunities to learn in both my native tongue and in English. My school there was on the English side, others were on the French side, so we all learned English along with Arabic. When it was time for college, my parents encouraged me to come back to the U.S. I moved back and completed a bachelor's degree in business administration. This is where I met my husband, who was a student from Jordan. When my youngest of two was only 6 months old, my husband passed away from pancreatic cancer and that shook our family dynamics. It all happened so fast! I went from working part-time to having to work a full-time job that did not give me the flexibility I needed. I noticed my eldest, who was three at the time, did not speak the same way her peers did. Part of me assumed it was due to the loss of her dad. The daycare teachers encouraged me to seek help through my county and I did. Although she received speech therapy consistently, by age five, we couldn't deny that she wasn't meeting milestones. It was then that a more

formal evaluation was completed, and they diagnosed her with Autism. Because of my experience with my daughter, recognizing the same characteristics in my son wasn't as difficult. His journey was not as hard as he was able to get a diagnosis earlier, at 3 years old. His autism is also more severe, and that has affected finding him care when I am working. I hope others can remember that just because someone looks or sounds different, doesn't mean they don't understand.

Participant Verification/Member Checking

Following the method of member checking identified and referenced through Rowlands (2021), post-interview transcripts were emailed to each participant for ITR. Through this back-and-forth communication and edits between participants and the researcher, the third piece of data was finalized and available for analysis. In using ITR, participants were ensured that any information shared would be recorded accurately to present a clear picture of the true experiences.

Summary

This chapter brought together data collected from surveys and interviews conducted between the primary investigator and seven volunteer participants. The participants consisted of all mothers with children currently receiving special education services at their local public schools. All the women who participated were Muslim and held a bachelor's or master's degree. Four participants were educated in the Middle East, North Africa, or South Asia and three participants were educated in the U.S. The researcher collected data from received participant surveys and manually coded the data using Microsoft Excel. This thematic analysis of content enabled the researcher to

discover initial themes that would drive the remainder of the study. Following this initial analysis, the researcher conducted one-on-one interviews with each participant gathering more information into each participant's lived experiences and perceptions since discovering that their child had a disability. Findings gathered between the surveys and interviews were further analyzed through Excel and later through the data analysis software program, NVivo. Results indicated that the initial themes identified carried throughout the study from all data sources (surveys, interviews, and member checking of transcripts).

Summary of the findings from surveys and interviews resulted in three primary themes and six sub-themes. While the small number of participants means a lack of generalizability of the study, all participants shared similar experiences in the overarching themes presented. All participants stressed the importance of understanding their rights and their participation in their child's programming needs and during meetings with the schools. There were shared concerns that communication between schools, teachers, and the parents was a point of contention. Some participants, although able to communicate in English, reported that the schools did not inform them that an interpreter was available; in addition, paperwork received by parents was not offered in the native language of any of the participants.

The final research question focused on currently available research to show the differences and similarities between European-American parents' experiences and perceptions to MENA and South Asian families (from this study). While the theme of native language understanding was not a challenge to native American-born and raised parents, they shared similar challenges of understanding the special education

processes and procedures and ensuring that their voices were heard in the IEP meetings. Parents from all sides believed that they had a responsibility, not just to their own children, but to children of other families who would come after them. The parents believed that it was their responsibility to advocate and advance the rights of their children for the benefit of all children with disabilities.

Finally, an unexpected theme arose during the participant interviews that the researcher did not initially consider at the start of this study. Four of the seven participants commented on the distress they felt from the lack of, or limited community support offered and available to their families. The inclusion of community involvement became apparent post interviews and is considered by the researcher worthy of further investigation in later research. This theme will be described in more detail in the following chapter.

CHAPTER V

RECOMMENDATIONS AND CONCLUSIONS

Introduction

This research aimed to give voice to and explore the lived experiences of Middle Eastern, North African, and South Asian families who had children with disabilities currently being served through a U.S. public school special education program. The primary goal was to introduce and bring about a narrative that is currently underrepresented in available research for this specific minority group. It was the hope of this researcher to provide a new lens of understanding to educators working with CLD students from all different backgrounds. As explained in Chapter 3 of this study, the researcher recognizes the unique privilege of being given the opportunity to conduct a dissertation study on the same (and similar) minority group as the researcher identifies with. Positionality and bracketing of personal experiences were addressed and offered to the reader for complete transparency. While professional ethical standards were met throughout this study, the researcher does not ignore the weight of responsibility in delivering a study focused on this demographic group of individuals. The study was conducted using a qualitative phenomenological design to allow for each participant to share their lived experiences and be given a platform to share their stories and perspectives. The study focused on answering these three questions:

RQ1: What are the experiences working with the LEA of MENA and South Asian parents who have a child with disabilities receiving special education services in U.S. public schools?

RQ2: Is there a difference in experiences with the LEA between minority parents educated in the United States versus those educated in another country who have a child with disabilities receiving special education services in U.S. public schools?

RQ3: How are participants' perceptions and experiences different from European-American parents who have a child with disabilities receiving special education services?

Overview

The idea for this dissertation began 4 years ago when the researcher began discovering limitations to available research studies that focused on MENA and South Asian, Muslim Americans. After participating in two separate student research symposiums, the researcher recognized a theme in recommendations received by visiting faculty. The faculty members advised the researcher to notice that a lack of representation in research paved the way for a study to be conducted. Chapter 1 covered the history of disability laws in the United States, educational practices for children with disabilities, identification of disabilities, and parent rights and involvement in the entirety of their child's special education experiences. A brief summary was also provided to quantify migration numbers into the U.S. and how education agencies work to provide services to culturally diverse populations.

A review of current research was examined in Chapter 2 delving deeper into the historical considerations of special education including laws enacted to guarantee parent rights and students with disabilities' rights to appropriate educational services. To gain a better understanding on culturally diverse individuals, the researcher provided study summaries on ethnic considerations, minority student identification into special

education, as well as historic accounts into Census count information and classifications. Special education, disabilities, and family dynamics in MENA and South Asian countries were examined to provide context into how the families included in this study may perceive disabilities.

Chapter 3 offered rationale for the methodology and framework used in this study. A qualitative phenomenological design was implemented to help make sense of a specific group of individuals' lived experiences, find commonalities, and interpret these findings in a manner that is meaningful and makes sense to readers and future researchers (Bloomberg & Volpe, 2019). Chapter 3 continues with offering researcher positionality in terms of bracketing experiences and offering guidance on how the researcher's own life experiences may have influenced the study. A thorough review of procedures of this study were offered with step-by-step explanations on the process used for study implementation and completion.

The qualitative phenomenological approach to this study meant a non-traditional formatting of Chapter 4, beginning with introducing the reader to the participants as a means of building background knowledge. In Chapter 4, the researcher explained why the use of an initial demographic questionnaire, followed by a survey of participant views and experiences through their child's special education journey was critical in understanding the interviews that would follow. Three themes and six sub-themes were identified and examined to determine how each theme related to the initial research questions. Data was triangulated using an analysis of surveys, one-on-one interviews transcription, and post-interview participant verification (member checking) through ITR to ensure accuracy of transcript reporting. Data were evaluated through manual

transcription of survey results into an Excel program as well as a data analysis program called NVivo. These resources were utilized to code the data, verify dependability, and identify common themes throughout data findings.

Summary of Findings

Themes identified include parent rights and involvement, special education procedures, and native/home language. Six sub-themes were also identified that included how parents experienced the ARD process, understanding of paperwork, understanding of parents' legal rights, ease of communication between parents and the school, parents feeling of being included in the decision-making process for their children, understanding of programming options available to their children, and whether or not paperwork, a translator, or interpreter were offered in the parent's native language. Phenomenological research design allowed for unanticipated themes to arise during interviews which brought about greater understanding of participants' experiences along with a rise in additional themes not initially considered at the start of this study. One such theme that will be discussed further is the focus on community involvement, participation, and support (positive and negative) for families who participated in this study.

RQ1 focused on the experiences working with the LEA of MENA and South Asian parents who have a child with disabilities currently served through special education in U.S. public schools. While RQ2 sought to examine differences in experiences between minority parents educated in the United States versus those educated in another country. Survey findings showed participants educated abroad had a more favorable response to feeling they understood placements and could disagree

with, or question proposed plans. Karima describes her positive outlook on her children's school,

It's very different between Pakistan and America. The principal and teachers in Pakistan don't really interact with the students. Students never felt comfortable interacting with teachers and admins as compared to here, our kids are comfortable with all staff members. Principals have an open-door policy and let the kids know that they can come in anytime.

Those educated in the U.S. had three disagree/strongly disagree responses and only two responded in agreement to the ease of working with the school districts and feelings of understanding procedures and proposed plans. For example, Layla reports:

Working with the school district overall was chaotic...The meeting with the school district representative (a speech pathologist) went fine, but I did not fully understand how things would work- everything was left for "when you have your evaluation and ARD". I tried to get more details from my ECI OT, but there were still large gaps in what I understood...Months went by and I heard nothing. I had no way to follow-up other than asking my ECI OT to see if she could find out what was going on or to try to get ahold of the school district...I asked what happened and they explained that there was staff turnover in the summer, so my son's evaluation request somehow fell through the cracks. I was so outraged and unsure of how something like this could happen.

There was a theme of misunderstandings between parents and the school that appeared to stem around the differences of language and choice of dress (cultural/religious attire). Parents reported that they sometimes were made to feel like

they were not educated enough to be treated as an equal in their child's school. Some of the participants explained that they believed it was also the duty of the parents to help educate teachers on their family values and needs and that it was unfair to expect teachers to know all about your culture and understand your needs. Jannah reports:

I have always been treated as a foreigner, and because I am also a widow, that has negatively impacted my experience with the school system. Due to the biases that exist around my language, my attire, and my gender; I am often ignored from the educational planning of my children's special education planning. I have learned I have to be louder for people to listen, and I am constantly having to claim my space as the primary decision maker when it comes to changes in their placement.

A primary finding in this study was that often, a parent who entered a school and looked different (cultural/religious attire) and spoke with a minor accent was almost immediately treated as though they didn't understand their child's needs. In agreement with research findings that teachers hold less favorable expectations of students from diverse backgrounds as compared to their European-American counterparts (Tenenbaum & Ruck, 2007; Yamasaki & Luk, 2018), Ruby shared that she felt, "because of the way I dress and my head scarf, teachers assume I don't understand English or don't have an adequate education." Most participants who were educated in the U.S. explained that because of their own educational background, they were able to maneuver their way around the school and communicate with teachers easily. Layla explains,

I assume because of my background in higher education, psychology, and me and my husband's experiences going to public schools in America, that this contributed to our overall positive interaction with the school district (while negatively with regards to the private, traditional daycares- they were quick to become defensive of me knowing my son's needs and advocating for them, rather than understanding and looking to include them if possible).

RQ3 used current research to examine how participants' perceptions and experiences differ from European-American parents who have a child with disabilities being served through special education. While current research does not show the same types of challenges faced by minority groups as by European-American groups, there are still challenges that should be addressed. Specifically, regardless of race or ethnicity, parents who have children with disabilities have been made to feel that they are responsible for becoming their children's advocates for their special education programming needs. Many expressed that they feel the need to fight for all their (as the parent) rights as well as their children's and the children that will come after them (Rossetti et al., 2021). "What helps my child will ultimately help yours. Most definitely, we're all in this thing together. We all want the same goal" (Rossetti et al., 2021, p. 449).

A common theme derived from interviews that was not previously considered at the start of this study is the impact of the community of families of children with disabilities. Aminah reported:

When my daughter was initially diagnosed at the age of 14 months, our community was not very welcoming. We did find those in our community and others who have a family member with needs to be very compassionate and

welcoming...Sadly, the general community where we lived was not inclusive and not supportive. Because many didn't understand, there was a lot of mom blaming, "did you do something while you were pregnant?" It all seemed very old school and backwards, just because they didn't understand, they had to find blame.

Karima reported,

...socially, you can sense when people don't like to interact with your child. It takes a long time to get used to people staring and judging you and your child.

Ruby reported,

It's not easy in our community. We are starting to get more support when we go out in public, but it's taken so many years. In the beginning, I felt very alone. I didn't know many other Muslims with a child with a disability.

Layla reported,

This has been a particularly beautiful and painful experience within our social group. It feels like there was almost no middle ground once we found out our son had a disability. We encountered friends who were skeptical of his diagnosis "but he doesn't look like he has autism", who made comments that were insensitive... as if I had to now prove my son's diagnosis...The part that stung the most, was that in these social groups, they were themselves other Middle Eastern or Southeast Asian Muslim physicians, or in one case, a licensed therapist, challenging the discretion of the experts around my son, as well as my own ability to instinctively feel that something was off with my son...I kept wondering if

parents with children diagnosed with cancer or an otherwise “visible” disability, if they were also facing this level of skepticism of the diagnosis.

Four out of the seven participants in this study made mention of and showed distress at the lack of community support offered to them upon discovery of their child’s disability. The researcher’s primary focus at the start of this study was to understand and demonstrate how families from this minority community interacts with and is perceived by their child’s school and teachers. Through these interviews, it became apparent that the importance of feeling accepted by the participant’s community (religious or social) plays a large role in the parent’s overall well-being and acceptance of their child’s needs.

Implications for Teachers

As educators, we enter the field of education understanding the impact we have on students and future generations. This study reiterates the importance of teachers and families working together to ensure appropriate educational opportunities for all students. Through collaboration and mutual understanding, students from all backgrounds have the chance to meet their seen and unseen potential. Parents, being the most important factor in understanding the student’s background and family dynamics, have a critical role in being present and available to help not only their own child, but their child’s teacher. Bringing everyone together for the benefit of the student is the most important factor in ensuring success. As educators, we have roles outside of what is directly stated in our job description; being a teacher is so much more than delivering lessons and meeting state guidelines of what students should be learning. Educators have the responsibility of understanding every student that walks into the

classroom. Part of that understanding is recognizing that the differences of each individual student make them special and unique, not less than just because they do not fit the mold of expectations.

Educators have a responsibility of recognizing in themselves biases held towards individuals who may look and sound different. Acknowledging these biases can be the first step to learning how educational practices can be modified to include culturally responsive pedagogy. Natural human tendencies lead each person to understand others who share similar characteristics to our own; in recognizing this trait, teachers can potentially identify and prevent biases towards students from culturally diverse backgrounds. In acknowledging these differences, teachers can offer students opportunities for learning and succeeding as the students' English language abilities and cultural integration grow.

Recommendations for Future Research

This study was conducted with the primary purpose of gaining deeper understandings into the lived experiences of MENA and South Asian families with children served through special education in U.S. public schools. The experiences of the participants and the reports of specific struggles such as finding support for themselves within their community and the struggles of being judged differently from European-American families could be further studied. Future researchers would benefit from furthering this study to include participants from European-American descent as well as specifically targeting families' sense of community and belonging in social circles. This would allow for more understanding into the differences of treatment and perceptions of special education between minority and non-minority populations.

Future research conducted by multiple researchers of different language and cultural backgrounds can also be considered. This study revealed an unexpected theme of the importance of community among the MENA, South Asian, Muslim participants. Studying the effects of community involvement, sense of belonging, and finding support groups from similar backgrounds can be further analyzed.

While this study did not specifically target participants from the Muslim faith, all participants who chose to volunteer were Muslim. A future research study can consider how religious groups interact with and serve those with disabilities. A study that includes participants from differing faiths can help expand understanding of religious considerations of disabilities.

Limitations

Limitations of this study included a limited number of participants who agreed to take part in the research. The researcher chose to conduct a qualitative study recognizing that members of this community may not be comfortable participating in such a study. The researcher attempted to reach more volunteers to increase participant numbers, but it was quickly realized that there was no more interest available. Due to this small sample size, the overall findings of this study can not be generalized into the overall population of persons from MENA and South Asia.

A second limitation of this study was the lack of inclusion of European-American parents of children with disabilities receiving special education services. In hindsight, the inclusion of European-American participants would have increased the participant size and allowed for comparison between the two groups. Rather than a comparison of the groups only through current research findings.

Lastly, the participants of this study were all fluent English speakers who did not report difficulty understanding documents written in English or how to communicate with schools and teachers. A study that would include more recent immigrants with limited English language abilities can help build a greater understanding on serving minority groups using resources such as language brokers and interpreters.

Final Reflections and Conclusions

A primary limitation to qualitative phenomenological research is the researcher's ability to bracket their own experiences to not be entangled in the interpretation of the data. As described in Chapter 3, interpretation checking between the interviewer and participants through inter-rater reliability was conducted throughout to ensure an accurate account of lived experiences. Also in Chapter 3, the researcher explained her own personal background as a minority, second-language learner when she first moved to the U.S. and how that impacted her views and experiences through public education.

While this entire project was personal in the nature that it impacted the researcher's immediate social and religious community, she was able to ensure that her views and experiences were not impacting the participants and that only their personal journeys were described. As a bilingual diagnostician for a local school district, the researcher works with families every day that are looking for guidance and help for themselves and their children. This study became a way to ensure understanding of the families' struggles came from a lens that was separate from the researcher's professional working lens. The researcher did not have a child with a disability that was served in public school special education. The common theme between participants and the researcher was that of being culturally different and being treated with

misunderstanding in some schools because of the religious hijab worn to cover the hair. Through member checking and interview accuracy checking between the participants and the researcher, the chance of the researcher's personal phenomena coming through in the study was decreased.

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APPENDIX A

INSTITUTIONAL REVIEW BOARD (IRB) APPROVAL LETTER



Texas Woman's University
Institutional Review Board (IRB)

irb@twu.edu

<https://www.twu.edu/institutional-review-board-irb/>

June 1, 2022

Nehal Elramly
Teacher Education

Re: Exempt - IRB-FY2022-188 N. Elramly Parent Perceptions Survey Study

Dear Nehal Elramly,

The above referenced study has been reviewed by the TWU IRB - Denton operating under FWA00000178 and was determined to be exempt on May 31, 2022. If you are using a signed informed consent form, the approved form has been stamped by the IRB and uploaded to the Attachments tab under the Study Details section. This stamped version of the consent must be used when enrolling subjects in your study.

Note that any modifications to this study must be submitted for IRB review prior to their implementation, including the submission of any agency approval letters, changes in research personnel, and any changes in study procedures or instruments. Additionally, the IRB must be notified immediately of any adverse events or unanticipated problems. All modification requests, incident reports, and requests to close the file must be submitted through Cayuse.

On May 30, 2023, this approval will expire and the study must be renewed or closed. A reminder will be sent 45 days prior to this date.

If you have any questions or need additional information, please email your IRB analyst at irb@twu.edu or refer to the [IRB website](#).

Sincerely,

TWU IRB - Denton

APPENDIX B

RECRUITMENT FLYER

The flyer features a top header with a collage of educational icons (lightbulb, gears, puzzle pieces, a person at a computer) and a large teal circle containing the main title and a brief description of the research. Below this, the flyer is divided into two main sections: a white section on the left with detailed text about the study's purpose and logistics, and a dark blue section on the right with eligibility criteria and contact information. The bottom of the flyer features the Texas Woman's University logo and name.

Research Participants Needed!

Help me understand how our local school districts are serving minority students with disabilities and their families.

Middle Eastern, North African, and South Asian parents of children with disabilities. We need your help!

Children and families from MENA and/or South Asian countries have unique experiences with local school districts when they have a child with a disability. The primary purpose of this research is to gain a better understanding of the families' experiences and perceptions. With this knowledge, a report will be published and shared with local education agencies with ideas on how best to serve this under-represented student body.

A 2-page survey will be used and followed with a phone or virtual interview.

There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings, and internet transactions.

Participants will receive a \$20 gift card for participation in the research.

Location:

- All participation will be held in person, through phone interviews, via online platforms such as Zoom, and/or through email communication.

Are you eligible?

- Middle Eastern descent?
- North African descent?
- South Asian descent?
- Child(ren) with disability(ies)

If you're unsure if you meet the requirements, Call, text, or email me at:

- Nehal Elramly (PhD Candidate)
- Principal Investigator
- nelramly@twu.edu
- 214-298-4568

PARTICIPATION IS VOLUNTARY



TEXAS WOMAN'S UNIVERSITY

APPENDIX C

PARENT CONSENT

TEXAS WOMAN'S UNIVERSITY (TWU) CONSENT TO PARTICIPATE IN RESEARCH

Title: Perceptions of Middle Eastern, North African, and South Asian Parents on Special Education in the United States.

Principal Investigator: Nehal Elramlynelramly@twu.edu 214-298-4568
Faculty Advisor: Randa Keeley, PhDrkeeley@twu.edu 940-898-2278

Summary and Key Information about the Study

You are being asked to participate in a research study conducted by Mrs. Nehal Elramly, a Ph.D. Candidate at Texas Woman's University, as a part of her dissertation. The purpose of this research is to understand the perceptions of Middle Eastern, North African, and South Asian families on the Special Education process in the U.S. for their child with disability(ies). As a participant you will be asked to take part in a phone interview, in-person interview, or ZOOM interview to answer questions related to your experiences with local school districts and asked to complete a brief survey. This interview will remain confidential, and we will use a code name to protect your confidentiality. The total time commitment for this study is approximately two-three hours. The greatest risks of this study include potential loss of confidentiality and emotional discomfort.

Your participation in this study is completely voluntary. If you are interested in learning more about this study, please review this consent form carefully and take your time deciding whether or not you want to participate. Please feel free to ask the Principal Investigator (PI) any questions you have about the study at any time.

Description of Procedures

As a participant in this study, you will be asked to complete an initial survey which includes demographic information (parent age, education level, number of children with a disability, ages of children, ethnicity, and language) and a scaled (1-5 rating) questionnaire about your experiences during your child's participation in special education. Questions will include pre-referral understanding, disability understanding, community and school support, language interpretation, and understanding of services. This survey can be completed via email through Google Docs or Fillable PDF forms, via ZOOM interview, via phone interview with the PI, or in-person at a public location such as a park or coffee shop (please see COVID-19 risks below). The PI will ask you questions about your experiences with public school special education services and procedures provided to your child. You and the PI will decide together on a time and platform (via ZOOM, in person, or phone call) where the interview will happen. The interview will be audio recorded and transcribed at the conclusion of the interview. The PI will provide you a copy (electronic or paper) of the completed transcription within two weeks of completing the interview.

Potential Risks

A possible risk in this study is discomfort with questions you are asked. You may stop answering questions at any time and end the interview. If you feel you need to talk to a professional about your discomfort, the PI can provide you with a list of mental health resources (resources can be found at the bottom of this consent form). Confidentiality will be protected to the extent that is allowed by law. The interview will be held via a private platform that you and the PI have agreed upon. A code name, not your real name, will be used during the interview. Only the PI will know your real name. There is potential risk of 'Zoom Bombing' (unwanted participant joining the Zoom meeting). To prevent this from happening, the PI will provide a unique ID for each Zoom call, will set a password to enter the waiting room, and always use the Waiting Room feature to maintain control over who enters the Zoom call.



Initials
Page 1 of 2

COVID-19 has been declared a worldwide pandemic by the World Health Organization (WHO). In person participation of interviews increases the risk of exposure to COVID-19. The PI will take steps to reduce the risk of spread by wearing a KN-95 face mask during in-person interviews. Online/virtual meetings will also be offered at any time during this research study.

The written interview will be stored and saved on an encrypted, password protected flash drive in the PI's possession and stored in a locked safe. Only the PI and her advisor will read the written interview. The written interview will be destroyed within three years after the study is finished. The signed consent form will be stored separately from all collected information and will be destroyed three years after the study is closed. The results of the study may be reported in scientific magazines or journals but your name or any other identifying information will not be included. There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings and internet transactions.

Your written interview and/or any personal information collected for this study will not be used or distributed for future research even after the PI removes your personal or identifiable information (e.g., your name, date of birth, contact information).

The PI will try to prevent any problem that could happen because of this research. You should let the PI know at once if there is a problem and they will try to help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefits

Your involvement in this study is completely voluntary and you may withdraw from the study at any time. Following the completion of the study you will receive a \$20 gift card for your participation. If you would like to know the results of this study we will email or mail them to you.*

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study, you should ask the PI; their contact information is at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the TWU Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at IRB@twu.edu.

Signature of Participant

Date

*If you would like to know the results of this study tell us where you want them to be sent:

Email: _____ or Address: _____

Mental Health Resources:

American Psychological Association Psychologist Locator
<http://locator.apa.org/>
National Register of Health Service Psychologists
<http://www.findapsychologist.org/>

Mental Health of America Referrals
<http://www.nmha.org/go/searchMHA>
Psychology Today: Find a Therapist
<http://therapists.psychologytoday.com/rms/>
National Board for Certified Counselors
<http://www.nbcc.org/CounselorFind>



APPENDIX D

INITIAL DEMOGRAPHIC QUESTIONNAIRE

Perceptions of Middle Eastern-North African (MENA) and South Asian parents who have a child with disabilities on the special education process in U.S. public schools.

1. What gender do you identify as?
 - a. Male
 - b. Female
 - c. Prefer not to answer
 - d. _____ (short answer)
2. What is your age?
 - a. 20-30 years old
 - b. 31-40 years old
 - c. 41-50 years old
 - d. 51+ years old
3. Marital Status?
 - a. Married
 - b. Single
 - c. Widowed
 - d. Divorced
4. How many children do you have currently receiving special education services?
 - a. 1
 - b. 2
 - c. 3
 - d. 4+
5. What is/are the age(s) of your child(ren)
 - a. 0-5 years old
 - b. 6-10 years old
 - c. 11-14 years old
 - d. 15-21 years old
6. Please specify your ethnicity:
 - a. Caucasian
 - b. South Asian
 - c. Middle Eastern
 - d. Other/Prefer not to answer
7. What is your highest level of education?
 - a. High School
 - b. Trade School
 - c. Some College
 - d. Bachelor's Degree
 - e. Master's Degree
 - f. Ph.D. or higher
8. Language most frequently spoken at home?
 - a. English
 - b. Urdu
 - c. Arabic
 - d. Bengali
 - e. Hindi
 - f. Other
 - g. _____ (short answer)

APPENDIX E

PARENT PERCEPTIONS/EXPERIENCES SURVEY

Information on your child(ren) with disabilities

Please answer the following using a scale from 1-5

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
	1	2	3	4	5
Your child's public school has made every effort to help you understand the evaluation process?					
Do you understand what it means to be referred for special education?					
Do you understand why your child was referred for special education?					
Do you fully understand your child's eligibility (disability)?					
Do you fully understand the characteristics associated with your child's disability?					
Do you understand the needs associated with your child's disability?					
Do you understand the services being recommended to your child?					
Have you received a copy of your parent rights, Procedural Safeguards, and Parents Guide to the ARD Process?					
Did you receive a copy of your parental rights written in your native language?					
Have the documents above been fully explained to you?					
Do you fully understand your role in the development of your child's IEP?					
Do you fully understand how decisions are made regarding your child's placement for receiving special education services?					
Do you understand the different classroom settings mentioned during meetings? Such as inclusion and resource settings?					
Do you feel like you can advocate, ask questions, disagree with proposals made for your child as needed?					
Was there an interpreter in your native language available to you if you needed one?					
Do you know who you can contact at your child's school if you have any questions or concerns regarding your child's special education services?					

APPENDIX F

PARTICIPANT INTERVIEW QUESTIONS

- (a) Please describe your own educational background (schooling in the US or overseas, level of education completed, exposure and experience with disabilities in your own schools, etc.) Any background information that you feel would be helpful.
- (b) What type(s) of services did/does your local public school provide to your child?
- (c) Describe your experience (within the school and in your social group) since discovering that your child has a disability.
- (d) Describe the support you receive for yourself and/or your child from family, friends, or community.
- (e) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.
- (f) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?
- (g) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).
- (h) Is there any additional information you would like to add?

APPENDIX G

PARTICIPANT TRANSCRIPTS

Redacted Participant Transcripts:

Aminah transcript with edits:

(a) What type(s) of services did/does your LEA provide to your child?;

She was allowed trips to the nurse as needed for sugar level management. She began with 504 services for diabetes but was evaluated again during the COVID-19 Pandemic and qualified for services under pragmatic language disorder. We take her to an outside counselor and we really feel that her anxiety is much more likely the cause of her struggles at school.

(b) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

(Aminah) transcript revision:

When my daughter was initially diagnosed at the age of 14 months, our community was not very welcoming. We did find those in our community and others who have a family member with needs to be very compassionate and welcoming. Others would make comments to me like, “why are you telling people she has diabetes? She’ll never get married...” This was very hard because we were still mourning for our child knowing the difficulties she will face. Sadly, the general community where we lived was not inclusive and not supportive. Because many didn’t understand, there was a lot of mom blaming, “did you do something while you were pregnant?” It all seemed very old school and backwards, just because they didn’t understand, they had to find blame.

Nehal Notes:

Not welcoming when initially dx at 14 months. Community/people that have a family member with needs is VERY compassionate and welcoming. Others, “why are you telling people she has diabetes, she’ll never get married...” you are mourning for the child – how do we manage the shots and being out in public. ([REDACTED] – supportive [REDACTED] so understood the challenges).

General community, not inclusive, not supportive, lots of mom blaming, did you do something when you were pregnant, etc. Very backwards and old school – don't understand so must find blame.

Example: Mom at prayer – giving out candy (no bad intentions) – but for a child with diabetes can be very dangerous; had to create protocols so kids that have special needs aren't put in danger (such as raising sugars for getting candy).

Had to create your own community within a community – because of the stigma involved, people are not able to be honest about their challenges/medical dx/disabilities (personal or for family members).

Year after year, more community leaders, imams, started joining the JDRF walk and diabetes support. Initial support was for [REDACTED] being a community leader, but eventually grew into a community at large.

JDRF asked [REDACTED] to be on their board – considering, likely will join. Can have huge impact on serving as first Muslim – can help with some scheduling and religious understanding.

(c) Describe the support you receive for yourself and/or your child from family, friends, or community; (answered mainly above)

(Aminah) transcript revision:

We quickly realized that we had to become our own advocates, we couldn't count on help or education from others, so we created our own community inside of the community. Because of the stigma involved, people are not able to be honest about their challenges, medical diagnoses, or disabilities, for themselves or their family members. I became a member of the [REDACTED] Walk and soon, year after year, more community leaders and imams started joining in the walks. Initially, I think it was because I was seen as a community leader and they wanted to support me, but it eventually grew into the community at large supporting the efforts. I think the most important lesson I've learned is that we have to be our own advocates, but many people are just in survival mode. There are lots of abuse cases in families that I've seen and been asked to intervene with just because people are too overwhelmed. They end up

just turning to task-oriented relationships between spouses rather than one of love and support. Resentment then sets in because you don't get a break, you don't have a chance to care for your own personal health and well-being. As a parent of a special needs kid, you can't just drop off the child for a mom's night out or for daycare. You always have to be close by at all times just in case there is an emergency, like I have to be close to her school all the time in case there's an emergency with her sugar levels and I have to run over there. This is where [REDACTED] and the [REDACTED] special needs support group really grew from. This need for support and a network.

Nehal Notes:

Started Muslim FB group for T-1

Started getting calls and communication from overseas, [REDACTED], Europe, etc.

Being able to share experiences, equipment, etc. with others that have T1, mom getting sick ([REDACTED]) – only because [REDACTED] was aware of T1 did she recognize that the lady was having a sugar struggle and was able to help and get her sugars stable and was able to return home.

[REDACTED] Inclusion Network – got [REDACTED] included.

Have to be our own advocates – but many people are just in survival mode. Lots of abuse cases (in families) just because people are too overwhelmed and end up just turning into a task oriented relationship rather than one of love and support. Resentment sets in because you don't get a break – you don't have a chance to care for your own personal health and well-being. A parent of a special needs (medical or disability) cannot just drop off the child for a mom's night out or for daycare. Have to be close by at all times just in case there is an emergency. Ex. [REDACTED] staying close enough to the school in case there's an emergency and she has to go.

[REDACTED] blossomed from [REDACTED] special needs group and the needs of more network.

(d) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

(Aminah) transcript revision:

No, my daughter's was a medical diagnosis.

(e) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

(Aminah) transcript revision:

Our current school is very good. The previous one was very bad. There was so much lack of communication. There were times I had to go ask friends who understood special education for help because I was getting nowhere with the school. It was a very frustrating time.

(f) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

(Aminah) transcript revision:

Positively impacted - Because grew up in [REDACTED] and being in [REDACTED] ISD now – had the previous experience with special needs peers through partners PE. Whereas others who have not had the same experience growing up, look down at students and children with disabilities and don't know how to interact with them.

(g) Is there anything else you would like to share to help others or that you would like me to report?

My only advice would be to treat each child individually, the needs of each child and family varies even if they share a diagnosis with another child.

Why did you choose to participate in this study?

I wanted to participate in because ...this subject is near and dear to my heart; having experienced what we went through following my daughter's diagnosis, I knew things had to change. As a local community leader and mentor to upcoming Muslim leaders, I felt responsible to sharing my experiences and struggles in hopes that others don't face the same.

Hadiya transcript with edits:

Nehal Notes:

Bachelors at Cal State [REDACTED]

Up to HS and 3 yr BA in Pakistan

Came from [REDACTED] – kids initially went through private school there and [REDACTED] was the one that started bringing his therapists to the mosque so he can get therapies.

Para at [REDACTED].

Going through divorce – so split between finding help for after school

Worked at [REDACTED] – had to resign because of childcare for her son's support

Has 4 kids, 19, 18, 17, and son 12 with genetic disorder – chromo 18 - rare – autism dx through private psychiatrist. Smaller stature than most kids his age, bone density issues, (AU, OHI, ID, SI) – [REDACTED]. Still in diapers – very fragile – lots of medication -

When he was 9 months old, development specialist, ECI, speech, etc. that's what she did.

In laws and father did not accept the child had a disability

Father tried explaining to his family about the disability - no matter what they did, they did not accept the disability. Despite the higher levels of education, they all had, they refuse to accept and acknowledge [REDACTED] disabilities.

(a) What type(s) of services did/does your LEA provide to your child?;

Speech, ot, pt, ape – currently in elevate classroom –

Hadiya Transcript Revisions:

Speech [therapy], occupational therapy, physical therapy, Applied PE [Physical Education] – currently in Elevate classroom.

(b) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

When I found out about his diagnosis, he was about 2.5 years old. I had already been doing early intervention and therapies with him since he was 7 months old. People who would find out, stayed neutral. I am not sure it was because it was not something common. At the time he was only diagnosed with tetrasomy18p, and no one knew about

it. People still don't know but now I can often say to them that he is also diagnosed with autism.

(c) Describe the support you receive for yourself and/or your child from family, friends, or community;

Hadiya Transcript Revisions:

The support I received without knowing any diagnoses back in [REDACTED] was excellent. I am not sure why I felt that was, but there was a heart connection with people and the community in [REDACTED]. I missed all that after moving to [REDACTED]. The community here was different. They were nice but different. Seemed like their point of view was, to move on and not worry. Treat and live as if there is nothing. I did not approve of that. I am not sure about the family support. As long as I did what they wanted, they were ok otherwise not.

(d) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

Hadiya Transcript Revisions:

I was often confused. It was all new to me. The early intervention staff that came to my place was very personal. The school was different. I was lucked out. The people, the staff, and everyone were outstanding. The principal at his campus always knew everything about my son. They really catered to his needs and looked out for him. Anytime I had questions or concerns the staff was always there to help and guide me. The Principal for the first 3 years at [REDACTED], even took the initiative to have a meeting with me when music teachers showed her concern about why I did not want him to be in music. And together, we decided on things he could do in music and could not do due to religious boundaries. As I said, I am grateful to Allah for everything.

(e) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

Hadiya Transcript Revisions:

Not really, I made sure I learned all I could very early so I'm not fighting to get my son the service he needs. I'm not afraid to ask for help or to ask questions and the schools have been very understanding.

(f) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

I think that my experiences with my school benefited me. My background from back home and here made me aware of all the differences and help me walk through this whole situation.

Karima transcript with edits:

(a) What type(s) of services did/does your LEA provide to your child?;

Speech, APE, elevate (self-contained), rec center summer program, Tx Workforce summer – ESY only in Kg.

Karima Edits:

Speech therapy, Adapted PE, Elevate [school district's self-contained classroom], and ESY [Extended School Year] but only in kindergarten. We have also attended summer programs for children with disabilities through our local rec[reation] center and programs under the Texas Workforce Commission.

(b) Describe your experience (within the school and in your social group) since discovering that your child has a disability?;

Karima Edits:

Within the school, supportive but not everyone likes the special ed kids.

Social – you can sense when people don't like to interact with your child with a disability. It takes a long time to get used to people staring and judging you and your child. When traveling back to Pakistan, within the family, they kids are accepted, but socially, there is a slight improvement. The govt. does not support sped but there are a

lot of people have begun donating and opening schools specifically serving sped. No laws are in place to support/protect disability.

(c) Describe the support you receive for yourself and/or your child from family, friends, or community;

Close family and friends. Close community group for special needs. [REDACTED], etc. mom's day out and dinner/lunch times.

Karima Edits:

We have great close family and friends. Through [REDACTED] [Islamic Association of [REDACTED] County], we are part of the special needs group and have mom's day out sometimes. We sometimes try to plan dinner and lunch dates just for us moms too.

(d) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

No, not for my kids.

(e) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?
The staff has always stopped the meeting and explained all the points. They send home draft goals three days ahead of the meeting to review. And they always change or update them when I ask during the meeting.

(f) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).
It's very different between Pakistan and America. The principal and teachers in Pakistan don't really interact with the students. Students never felt comfortable interacting with teachers and admins as compared to here where our kids are comfortable with all staff members. Principals have an open door policy and let the kids know that they can come in anytime. I've seen this at my kids' schools and it's very encouraging. In Pakistan, the

lower your grades and abilities, the further to the back of the classroom you sit. My daughter, who is ID, sat at the front of the class in a gen ed class. The teachers here seem to encourage kids to speak up and explain their own needs. Can't do that in Pakistan!

(g) Is there anything else you would like to share to help others or that you would like me to report?

Nehal Notes:

Ways to improve our school system:

Our community need to learn how communicate with the school and staff

We are not showing the manners we should be showing them

You have to be respectful, send a Christmas card

Teacher doesn't know that the kids eat with their right hand, no meat,

Teacher is not from our culture so they don't understand and know what to expect or what the preferences are.

Our parents don't come and talk and need to do the work of coming and deciding to live in a different culture. You have to show respect the culture, you are responsible for educating and informing and staying polity and kind.

Sadly, lots of muslims are very rigid. They never say hi and are not polite.

Teachers can try harder to understand cultures and religious practices. You will always run into people that are not friendly but keep trying and getting people to open up to you. Teaching goes both ways.

Parents aren't reading the IEP reports, goals, not interacting with the teachers and are "clueless" – they sign blindly.

Masters from Pakistan

Karima Edits:

Our community needs to learn how to communicate with the school and staff. We are not showing the manners we should be showing them, you have to be respectful. The teacher doesn't know that the kids eat with their right hand, and don't eat meat; the teacher is not from our culture so they don't understand and know what to expect or

what the preferences are. Our parents don't come and talk (to the campus or teacher) and need to do the work of coming and deciding to live in a different culture (living in America). You have to show respect to the culture, you are responsible for educating and informing and staying polite and kind. Sadly, lots of Muslims are very rigid. Parents aren't reading the IEP reports, goals, not interacting with the teachers and are clueless – they sign blindly. Teachers can try harder to understand cultures and religious practices. You will always run into people that are not friendly but keep trying and getting people to open up to you. Teaching goes both ways.

Ruby Interview Transcripts with edits:

(a) Please describe your own educational background (schooling in the US or overseas?, level of education completed, exposure and experience with disabilities in your own schools, etc.) Any background information that you feel would be helpful.

We grew up in a more well to do area in Jordan. Most of the families were highly educated and had the money to provide their kids with whatever they needed. There were lots of Palestinians who lived near us and I felt very at home. But going to school, I didn't see or hear about disabilities or special education at all. I can't remember anyone in my family talking about someone they knew with a disability. So this was all very new to me. My husband who was born in Jordan too grew up and went to school in the states. He said it was normal for him, but not for me. When our son was diagnosed, I had no idea what to expect. He's the first person I know with autism.

(b) What type(s) of services did/does your local public school provide to your child?;

He gets lots of services it seems. The teachers send home a notebook with him everyday that talks about how his day was. He has a teacher or a teacher assistant with him in most of his classes, I think. He gets overwhelmed with the loud noise in the cafeteria or the gym, so they allow him to wear headphones. He used to get OT service, but he graduated from that.

(c) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

The school has been great. They seem very supportive and understanding even when I ask a lot of questions. [REDACTED] was referred by his pediatrician when he was 3. I didn't know what I was doing and was very confused. I felt guilty because I thought I caused this in my son. But I'm learning more and more and I'm finding more friends. It's not easy in our community. We are starting to get more support when we go out in public, but it's taken so many years. In the beginning, I felt very alone. I didn't know many other Muslims with a child with a disability. Now I know so many and we are like another family together. Alhamdulillah.

(d) Describe the support you receive for yourself and/or your child from family, friends, or community;

Lately we've felt like we have a lot more support. Our community now has some organizations to help families like us. We have [REDACTED] and we have [REDACTED] that seem to really want to make our masjid more kid and family friendly and accepting of those with disabilities. We have some imams even speaking on how to include everyone during their khutbah. It's been nice. Our family has been very understanding. They love our son very very much and are understanding about his needs alhamdulillah.

(e) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

No, we asked the school to test our son after his doctor recommended it. Maybe our culture and language were more of a shock to them because they don't seem to have much experience working with Arabs and Muslims. They asked us as many questions as we asked them it seems.

(f) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

The entire process in the beginning seemed very confusing. There was always so much paperwork and so many forms to complete. It was like we were buying a house again with how many signatures you kept asking for. I didn't know they can give us papers in Arabic. Maybe that would have been nice. My husband and I speak and understand English just fine, but it would have been nice to at least been asked if we wanted it.

(g) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

I don't know if I can really answer this. I didn't have experience with someone in special education in my own education, so I didn't know what to expect. Maybe that was a good thing because it was all new.

Why did you want to participate:

I experienced great difficulties during the initial years of my son's diagnosis and initial start of services. I want to share my story so others can have it easier than I did.

Background:

Pediatrician said that something seemed off and that [REDACTED] looked like he may have autism. The dr recommended that we take him to the school in our neighborhood. So we took him in, this is where the whole thing started.

Amal transcript with edits:

(a) Please describe your own educational background (schooling in the US or overseas?, level of education completed, exposure and experience with disabilities in your own schools, etc.) Any background information that you feel would be helpful.

I was born in Lebanon but I came to America when I was just three years old. So all my schooling has been here in Texas basically. I went to public schools my whole life and we had peers with disabilities in our classes often. It didn't seem weird I guess because that's just the way it was. They were like my little classmates that just seemed to need some more help. My first soccer team when I was 5 even had a little boy with autism on it. I remember him, he had red hair and didn't really speak much. I guess growing up in America and in public schools, I had lots of access to understanding disabilities. I was part of a program in middle school that helped our disabled peers take notes in class and help them go from one class to the other. It's funny because I had thought that when I did that I was going to go to college to be a special education teacher – I didn't think I was going to have my own child in special education. But I guess it was all preparing me for my own kid.

(b) What type(s) of services did/does your local public school provide to your child?;

My baby is just starting this whole special education program thing. She's been offered speech therapy and in class support to help her learn to socialize better. She hates to write so they're helping her with that too. But not officially, like not occupational therapy help, just from her case manager and teacher. She has a choice board and earns rewards too when she does well. I figured there would be more complex services as she grows and needs more. For now, she's pretty easy going.

(c) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

Socially, I guess my friends and I have known each other so long that nothing really shakes us. When my daughter was born and when we started noticing that she was different, it was just, "well this is just her personality." I think we're all pretty western so we don't get scared of disabilities or someone who might look a little different.

(d) Describe the support you receive for yourself and/or your child from family, friends, or community;

We haven't really needed much support from people so I'm not sure I can answer this question. I don't think my daughter's disability has been a hardship on my husband and I at all. Again, maybe when she gets older and it gets harder, it'll be different. But for now, we don't ask for support, and we don't really need it. Our family and friends are there as anyone else's family and friends are there for them. It's just our normal I guess.

(e) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

No, we look pretty much like everyone else so I don't think our culture really played a part in any of this. The only time I think language was really in play was when we told the school that we purposely speak both Arabic and English at home. They thought we were confusing our daughter since language was hard for her. But I'm pretty strong-willed and insisted that I'm not changing my mind. I grew up speaking and understanding both Arabic and English and plan the same for my kids. I want to make sure my children are fluent in our native language. It's a non-negotiable for me.

(f) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

The school was always wonderful, they seem to have so much on their plates though. And there's so much paperwork. It wasn't that it was confusing, per say, it was just a lot. I get that they have to do this to cover themselves from lawsuits, but maybe there's an easier way to not make them have so much paperwork and now have so much paperwork for us too.

(g) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

I guess I would say it was positively impacted since I always felt comfortable around those with disabilities. I don't think many people have the same experience and can say that when they found out their child had autism or another disability that they felt it was going to be ok. But I did, I knew that schools were there to help and that kids can be pretty resilient and pretty darn loving towards those that are different. I experienced this and believe in my heart that my daughter will also be welcomed and feel the love of her peers one day. When she's older and can actually understand.

Why did you want to participate in this study? And is there anything else you would like to share?

I know how little teachers understand about our culture and community and I want to help them understand us better. I've received wonderful support from my child's school but I know they felt overwhelmed when they found out we spoke Arabic. It's still so foreign to them! I'm hoping this study will help more people understand that we're not so different from everyone else.

Layla transcript with edits:

(a) Any background information that you feel would be helpful.

I was born and raised in the US and went through a public school system, K-12. Then I went to a private, elite undergraduate college, then onto a state school for my Master's degree. I remember a girl that was blind in elementary school with me. She was in all our classes and had lunch and recess with us. In my Girl Scout troop, there was a girl with a prosthetic leg (I might've been in 3rd grade). Otherwise, I hardly ever saw individuals with disabilities at school- they were separated from the rest of the school, at least in high school. The only memory I have of them is that they had different schedules than the rest of us. The school bell would ring, we would go to class, and

then I could see through the windows that they would be walking as group through the halls on their own schedule to different rooms around the building. They had classes separate from ours; they had lunch and activities separate from ours; for all intensive purposes, I really didn't see them as far as my memory goes. This is in regards to children with learning disabilities that were severe enough that they were not able to integrate into the traditional classroom. I do remember individuals in my classes, K-12, now looking back and being a little more informed, that were likely disable, but it was never discussed or confirmed, and they must've had ways to self-accommodate in order to be a part of the general classroom. In college I did see more students with physical disabilities, since they are more apparent, as well as my younger sister was diagnosed with type I diabetes during this time, too.

Physical disabilities are usually the ones that I could see or understand first. I didn't have much exposure with disabilities growing up. There were a few family friends in our masjid community with children, of unbeknownst to me of their particular disabilities, but otherwise this wasn't something I was exposed to or that I had much knowledge of prior to studying it a little as a psychology major in undergrad, and then learning a bit more about services required by law for those with documented disabilities in my grad school curriculum. I did have two friends in high school who were on my mock trial team who each had younger brothers with autism, but again, I only saw them briefly in passing and did not spend any time around them.

(b) What type(s) of services did/does your local public school provide to your child?;

His public school system offers speech therapy, occupational therapy, and potentially they will look into feeding therapy. They also have a part time preschool classroom with other children on the spectrum (only this class) with exposure of 10 minutes a day with the general preschool population.

(c) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

This has been a particularly beautiful and painful experience within our social group. It feels like there was almost no middle ground once we found out our son had a disability. We encountered friends who were skeptical of his diagnosis “but he doesn’t look like he has autism”, who made comments that were insensitive, “it’s impossible for a doctor to be able to diagnose him before he’s five” or “doctors are stupid and don’t know what they’re talking about”, said by other doctors, and “doctors are stupid and they always get this wrong”. And the most hurtful phrase, “Are you sure? But are really sure? How do you know? Are you sure? Are you sure?”, as if I had to now prove my son’s diagnosis, in the midst of it being a fresh overwhelming experience I was going through. Needing to become an overnight expert on all things autism and prepare a defense for my son’s disability those were some of the hardest interactions I had, and I repeatedly felt heartbroken and shattered, rather than the kind, reassuring, supportive or helpful words I was looking for. The part that stung the most, was that in these social groups, they were themselves other Middle Eastern or Southeast Asian Muslim physicians, or in one case, a licensed therapist, challenging the discretion of the experts around my son, as well as my own ability to instinctively feel that something was off with my son. I just could not believe the immediate level I was met with argumentation, incredible skepticism, and challenges to what should’ve been a very understandably challenging time. I kept wondering if parents with children with diagnosed with cancer or an otherwise “visible” disability, if they were are also facing this level of skepticism of the diagnosis.

Other things I heard again from these are friends and others in my social circle, “oh don’t worry, he’s going to be fine”, “he’s going to be fine, you’ll see”, as if things could just resolve magically on their own. Or, I kept hearing variations of “oh Einstein (or Elon Musk, or Bill Gates, or Mozart...) has/had autism!” “He’s going to be fine! You’re lucky you have a genius on your hands!” “I have loads of friends who have autism and they’re fine!” I had to educate several of them that there is no way of knowing what my son’s autism will look like- time will unfold and show us if he is one out of 3 autistics who remain nonverbal...or of the 85% who cannot carry a job and need to be supported by their parents into adulthood...or just because he likes numbers and math, does not

mean he hears me when I scream his name as he runs into the street. And that no, things don't just end up being fine on their own, that without massive energies put in to his life now in the form of running back and forth to various doctor's appointments, hundreds of hours of different therapies, dozens of supplements and other medications, finding ways to help regulate his sensory overloads, and help him express his needs...that his entire life trajectory is dependent on what services and therapies we help provide for him now, while his brain is young and developing, before it becomes hardwired and difficult to unlearn and relearn. That was also very upsetting and felt combative from people that were supposed to be allies or the first to be understanding of a health condition as these are individuals who make diagnoses themselves daily as part of their professions, and would surely scorn someone outside of their field for offering their two cents.

On the other side I did have a positive reception from individuals who made sure to come across as concerned or caring and supportive. Friends who would ask how things are going, would send over money, food, or coffee, and check in with us or make play dates so that our kids could have my son included with theirs. These were very meaningful, impactful moments and I felt grateful for being well cared for in those times. But, at the same time, I did feel like I was placing too much weight on these individuals and I was fearful of collapsing their ability to support us by burdening them with our situation too much, and in fact, one such friendship did eventually turn out this way. This other friend who was very close and helpful during my time of need, ended up having a scare of her own for her son's health and her reaction and response for her son was to assume a total hands-off approach. She decided that there was nothing wrong, that there wasn't a need for intervention, that her "role as a parent had no bearing on how my son would turn out", that the situation he faced was not as alarming- even though her son is four years old, had a seizure in his preschool class, and had to be taken to the emergency room in an ambulance in front of his other friends, and she herself is a physician as well as her husband... so once her son's situation came to light and she was dealing with these things, rather than jumping to action or coming up with a plan to address his needs, or even just talk about how he was doing or how she herself was

doing, she inevitably shut down and as a result also shut down in all other aspects. She was no longer sensitive or sympathetic on a whole. She was no longer approachable or someone I could turn to for advice or insight or support as it seemed that talking about my own son's situation drew anger in her, as there was a stark contrast on how she was dealing with her young son's situation. She became combative and insistent that her role as a mother had nothing to do with how her son would turn out- despite her knowing how difficult my parents' toxic treatment of me and my siblings in childhood weighed on me.

When it came to schools- my son was in two different daycares for only one month each, before his diagnosis. Due to Covid, he stayed home most of his ages 0-2. Just a few months before his second birthday, we had to immediately enroll him overnight into full-time daycare, as I was pregnant with my second child and had to be emergency hospitalized for 5 weeks. This was traumatic for my son, as well as myself. He had most of his needs met and his stresses kept at bay when home with me. Now, in the absence of his mother, at the young age of still technically one-years-old, he is suddenly on a tight schedule, around strange adults, in a school full of children, and noise, stimuli, and other things out of his control. He shut down. He spiraled and triggered more and more characteristics of a child on the spectrum.

The first school knew full well what was happening at home, so when they decided to kick him out for biting (which only started after he had been bit several times), I had a very upsetting conversation with the director of his school. We knew and told them of his sensory sensitivities and delayed/non-verbal speech, but they were not willing to do anything to help accommodate his needs. We had an ECI specialist visiting once a week, but the teacher of his class would not implement the recommendations she was passed along. When my son was dismissed, the director said "he was aggressively biting other kids! We have to look out for the well-being of the other kids in the school!", even though I pointed out that my son was a child in her school and that the methods of dealing with him were exacerbating his stress/need to bite. While in my hospital bed, I had camera access to his school and could see that they did not keep him in his class

of just one-year olds, but that they blended the entire school of 1–5-year-olds through most of the day in a chaotic central room for hours. I could see them strap my son into an eight-person cart by himself while others ran around him. I saw them place him in a playpen by himself without any toys, while the rest of the school played on, and other distressing things that had me prepared to pull him out of the school even before they officially kicked him out.

His next daycare was not much better. Now, at just over two years-old, his teacher was a strict disciplinarian (to two-year-olds), and was not understanding of divergent methods of learning or coping with stress. He would dump toys and containers in class, not sit in his seat, or go play off by himself and she'd be angry with him. Around this time, we learned he had a high threshold for pain, so even if his body was getting injured, he was not making noise or crying out for help. He came home multiple times with various scrapes or bruises that the school could not account for, but rather than keep a closer eye on him, they became defensive and accusatory- how do we know he didn't already have that scratch before he got to school? I explained that I bathe and dress my son everyday- that I know what his body looks like before I drop him off in the morning compared to when I pick him up at the end of the day. Well, he only stayed in the class for 4 weeks before contracting multiple serious illnesses that led to his hospitalization for 4 days and being out of school for the entirety of the second month of his enrollment. At this time, we had his appointment with the pediatric neurologist who gave the first official diagnosis of ASD. The same day that he received it, we unenrolled him from his daycare.

(d) Describe the support you receive for yourself and/or your child from family, friends, or community;

I alluded to the kind of mixed support I received from friends and family, who were generally positive in an earlier question, but also at times combative, so I'll include the other kind of support we received in terms of my family after learning of [REDACTED] diagnosis. They generally took his diagnosis well- the adults showered him with more

affection and tenderness, and the children we told of his diagnosis suddenly appeared less bothered by his idiosyncrasies. Our family would ask questions or look into the resources we passed on or allowed me to be the expert in all things [REDACTED], so to speak. Before it would be a lot of questions, like why does he do that or why don't you try this or why don't you try that, but his diagnosis empowered me with the ability to say this is what my son prefers this is how my son works this is what helps my son and this doesn't help my son. I became somebody that could speak without judgment on the needs of my son. Whereas I felt frequently judged as a mother for [REDACTED] behavior before his diagnosis.

In terms of the community, I'm going to refer to the Muslim community. I haven't had too many encounters with other Muslims after [REDACTED] diagnosis (mainly from Covid but also from not being able to figure out logistically how to be able to pray, while one parent watches one son, and the other making sure he doesn't run off). But the few community engagements that I have had, included those other Muslim friends who I mentioned before, who made very abhorrent comments or belittling remarks about his condition. Some of those friends who were dismissive of a two-and-a-half-year-old having a neurodivergent mind, later found out that he also has a coinciding auto immune disorder of inflammation in his brain, and suddenly felt sufficiently explained with what [REDACTED] might be dealing with. It seemed that as long as there was a technically "medical" and "physical" disability for my young son, they were satisfied believing we were challenged in some way. That, since we had a "medical" explanation, that could be "seen" from the outside (on bloodwork and other lab tests), then it might be "ok" to assume there's something in the way he thinks that's different than other kids his age... This was also painful to deal with.

We did have one instance recently, where we took him to a community barbecue at the [REDACTED] Institute. The BBQ was open for kids to run around, so that wasn't as much of an issue, but after the salah (prayer), there was a khutbah (small talk) for a few minutes. It was during this khutbah that we really saw what taking a young child on the spectrum would be like to a large gathering at the musallah. This was really the first time that we brought [REDACTED] out and about because of Covid, and prior to Covid he wasn't much

older than an infant, so he was in our laps or you know, was able to be contained. So, during this khutbah, he was running through the men and women's sections, running between the rows, pushing people, popping men on the head, running by and giving high-fives, and grabbing other people's water bottles, right in front of the speaker, and just overall disrupting the khutbah for all maybe 200 people, sitting quietly with their young kids as well. Now, granted this was at [REDACTED] Institute, rather than a neighborhood masjid, where we felt more comfortable having our son there, understanding their overall mission of inclusivity and accessible Islamic knowledge, rather than some of the stiffer rules on decorum we might expect from other masjids, but it was still salah and a khutbah afterall. But it was what happened during the lecture and right afterwards that really touched my fearful mama heart. The adults held out their hands to give my son high-fives. They extended their arms, if he was trying to climb them for a hug. They acted as another pair of "goalie" hands, trying to scoop him up if I was unable to keep up chasing him. They did not reprimand him or yell at him for "misbehaving".

The speaker was the [REDACTED] organization creator, [REDACTED], and he specifically gave us a lot of grace during and after the khutbah. When [REDACTED] tipped a giant bowl of prayer beads over and made a mess, along with disrupting the congregation, [REDACTED] made comments in his talk not about how to discipline your kids or how to have obedient children- but instead spoke on how "this was his home. This is where children should be allowed to be comfortable," and "this is where they should grow up not feeling isolated, not feeling shunned, or reprimanded for just being children, in a space that they feel comfortable in." Afterwards was an especially pointed experience that will likely remain with me in my life during harder times...because even though [REDACTED] was an acquaintance of ours, we never had any real socializing together, let alone the chance to tell him of our son's diagnosis. But his response was so warm and caring and comforting; he rolled on the floor with [REDACTED], he gave him hugs and tickles, and spoke to him with such honor and respect. He spoke to us with such admiration and respect. He was kind to hear our concerns but also say that "no no, this is his home. He is always welcomed here," and "if there were more [REDACTED] and [REDACTED] [us parents], able to bring their children out, people would learn how to interact with them." He was clearly

knowledgeable on ASD and its effect on an individual and their family, so he was able to speak to the things that would make us all comfortable and feel included. This conversation really spoke volumes to me and made me feel especially at ease, because until this moment, we almost resigned to the idea of taking our son to community gatherings, let alone weekly Friday prayers. Anytime we've attempted to take him in the past, he was sure to be overwhelmed by the large crowd, to certainly try to run away and elope. When there is a large group or when there's a large space (such as the mall or park), he wants to see what's in the other rooms or what is outside of the building...which can be extremely nerve wracking and dangerous, since most of the time these prayer halls leave the doors wide open so people can come and people can come and go, but they lead right out to the street where there's traffic or a parking lot, with no safety measures to contain a child that's running without fear. We still have not brought him back since then, but I do feel comfortable if I should want to. And this feeling, I cannot describe.

(e) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

I honestly felt well respected on the day of my son's evaluation and then his ARD meeting, but I attribute it to my working knowledge and general understating of what they might be looking for in discussing his behaviors and needs (my psych background and work with college students securing accommodations led me to this- not from any preparations made by ECI or the school district). My language was an asset in this case, not just my unaccented English, but my knowledge of medical and psychological terms. They repeatedly commended me on, "being so helpful with what you're sharing with us". I did wonder throughout the process if I hadn't had those exposures or experiences, if I would have felt as clear on what was being discussed for my son.

(f) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

Working with the school district overall was chaotic. We live along the district lines of two school ISDs. We were first told by our ECI OT that we belonged to the [REDACTED] ISD, then no, actually it was the [REDACTED] ISD. We set a time to meet with the [REDACTED] ISD virtually, but a few days before, we are told, no we actually do belong to [REDACTED] ISD. I see the [REDACTED] ISD school buses come down my street, so I still am not sure how they've divided the districts.

The meeting with the school district representative (a speech pathologist) went fine, but I did not fully understand how things would work- everything was left for "when you have your evaluation and ARD". I tried to get more details from my ECI OT, but there were still large gaps in what I understood. I also asked about information in the event that we would like to petition to be in the [REDACTED] ISD- it sounded like it was not common and not promising to consider.

The date of the actual evaluation was also months later instead of it was supposed to have been held- we filed the paperwork through EIC in February, spoke with the school district speech therapist in March, and were told to expect an evaluation date in May, no later than June, as my son's third birthday was in August and we were filling relatively early. Months went by and I heard nothing. I had no way to follow-up other than asking my ECI OT to see if she could find out what was going on or to try to get ahold of the school district. They eventually did contact me (but only days before my son's third birthday) at the end of August. I asked what happened and they explained that there was staff turnover in the summer, so my son's evaluation request somehow fell through the cracks. I was so outraged and unsure of how something like this could happen- people come and go from jobs all the time, how could my son's legal rights to resources be so easily dropped? What about other children about to turn three? There was no way for me to follow-up or be given any information, I was only instructed to wait to hear from them. How could I know this wouldn't keep happening as I dealt with the school

district? I had little trust that this would not be an issue again- they could not ensure anything, since he was already supposed to be in their list to contact.

On the day of his evaluation, it was a bit chaotic. There were just a lot of things happening at once, a lot of people interacting with us at once, and we were hustled from one room to the next to the next. In particular, I didn't feel fully prepared. I tried to get as many details out of my ECI OT (not everything was offered off the bat), but was not informed of the various diagnoses and paperwork that would be required to be sent over to help establish my son's diagnosis or that anything would be required of us before arriving. So far, any time we've had an evaluation (through therapists, schools, doctor's offices), we would only show up and have my son actually evaluated...not use the documentation of others.

Then, afterwards because of the very short window of time to get everything prepared by his third birthday (I think we were literally like four days away, with a weekend in between), they asked for everything to be sent over that night. So, I spent the next approximately 13 hours nonstop after the evaluation filling out assessments and forms and locating different things that needed to be sent over to verify all sorts of things. It was incredibly stressful and overwhelming. I was not sure if I covered things adequately or indicated everything, just by the sheer amount of paperwork that needed to get done. I felt rushed and not feel fully supported in regards to what I needed in order to have his care ready. I only kept thinking of why did we run the clock out to the last few hours when I applied months ago back in February?

As far as items being unclear, they were receptive over email and then on the ARD call to questions I would ask. I turned in forms piecemeal throughout the day and night, to at least make sure what I could get over to them made it through in time. They did not rush me during the ARD, so I was able to get all my questions adequately answered and understood.

(g) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

I can only assume this one- I assume because of my background in higher education, psychology, and me and my husband's experiences going to public schools in America, that this contributed to our overall positive interaction with the school district (while negatively with regards to the private, traditional daycares- they were quick to become defensive of me knowing my son's needs and advocating for them, rather than understanding and looking to include them if possible).

Why did you choose to participate in this study?

I have multiple reasons. Since I was a social science major back in my day, I know the challenges of finding participants for academic research studies and have always tried to make it a point to contribute if I'm able to. Secondly, my husband wrapped up his dissertation a few years ago and I witnessed first-hand the seemingly never-ending obstacles that would pop up along his path, so sympathize with other graduate students looking to wrap their work up and get on to the next phase of their careers. And thirdly, which is what made sure I didn't leave this study out of my time, was to ensure that my son and those that come from our Muslim, minority, and brown communities, would have an included voice in the discussion of disability resources. Research tends to favor the white, male, Christian, participant, and any chance I have to be able to offer a wider consideration of needs, I do feel it a personal obligation to attempt to do so. The fact that it deals with my own son's disorder and his ability to receive resources, just made it that much more personal to pursue. I want the best for him. I want the best for all children and their families that find themselves on this journey in their lives. What we as parents previously imagined for our children before having them is entirely different than the reality of raising them, knowing (or suspecting) developmental or intellectual disabilities...at the very least, we should be ensuring all people in this country receive the information, resources, and legal rights they are supposedly entitled to.

Jannah transcript with edits:

(a) Please describe your own educational background (schooling in the US or overseas?, level of education completed, exposure and experience with disabilities in your own schools, etc.) Any background information that you feel would be helpful.

I was born in the United States but went back to Egypt when I was seven. College was back here in the US.

(b) What type(s) of services did/does your local public school provide to your child?;

My daughter is now in fifth grade. She received speech therapy twice a week for 25 minutes each time, and resource classes for Reading and Language Arts. She does really well in math and other classes, so she has a special education teacher go check on her in her classroom every day for extra help if needed. She also has accommodations so that she can get extra time to finish assignments if needed. She hardly ever uses it, but it is there to help her if needed.

My son, who is in the second grade, receives all his education in a self-contained classroom. He receives speech therapy twice a week and has a social skills classroom. All his classes are adapted to his level, and the focus of his education is to build functional skills. He was unable to care for his own toileting needs until last year, but he is now able to do it most of the time.

(c) Describe your experience (within the school and in your social group) since discovering that your child has a disability;

There is a history of autism in my maternal side of the family, so my family was understanding and helped me with the emotional part. Without having a husband, or a partner to help, working and taking care of my kids is all I do.

Making friends has been difficult. Not only for them, but also for me. If I am not working, I am spending what little time I have left trying to manage the needs of the household. I

found a job that is now remote, and that allows me to have more flexibility when it comes to commuting, but it is also very isolating. Finding care for them when I am off so I can socialize is near impossible due to my son's level of care. My daughter tries to help me with her brother, but he can be aggressive towards her as well. I found a local network of parents of kids with autism, but due to the pandemic, the meetings stopped and I was not able to keep up with the connections I made there. It is a shame because I felt less alone around them.

(d) Describe the support you receive for yourself and/or your child from family, friends, or community;

My family has been supportive, but they live in Egypt so their help is limited. I am not able to make friends due to being a one parent household, and the little community I have is made up of some coworkers who do not understand my home struggles, or friends from church who support me emotionally when I ask for it. Finding care for my children so I can go out is impossible. When my parents come to visit, they encourage me to go out and connect with other adults, but my son doesn't do well with changes in routine, so it becomes easier for me to be there.

Recently, I heard through a parent network that the state offers respite care, and I have been considering applying for that to help me as needed.

(e) Have you felt that culture and language played a part in the referral of your child? If so, please describe your experience and how this was addressed through the evaluation team.

Yes, I think that some people automatically assumed my daughter's speech delay was due to language differences, or they thought she was "confused" by the use of both languages in my household. I also felt like I had a harder time advocating for them, because I was quickly dismissed and told they just needed more time to get used to the system in this country, even though they were born here. Through time, I have learned to be more vocal about their needs, and not let people's misconceptions of my culture

and my accent delay the help my kids need. I was much stronger by the time my son needed the help, and it was me that pushed for finding help early on.

(f) Did any part during the evaluation and later annual meetings for your child seem confusing or unclear? If so, what did the school team do to help in your understanding?

I think it was confusing, but not because of my language, but because the process can be confusing for anyone. I did my due diligence to research in the internet things that parents with special needs children should know, but that was not done by the school. Even now, if my children have a new case manager, they always assume I understand very little and instead of showing me ways in which I can increase my understanding of the process, they skip through important pieces assuming they will be too hard for me to understand.

During the pandemic, they assumed I would not request any help, and it was through my own research that I found out that I could request compensatory services.

(g) Do you feel as though your experiences with your school were positively or negatively impacted by ____ (your own educational experiences in (country of origin)).

I have always been treated as a foreigner, and because I am also a widow, that has negatively impacted my experience with the school system. Due to the biases that exist around my language, my attire, and my gender; I am often ignored from the educational planning of my children's special education planning. I have learned I have to be louder for people to listen, and I am constantly having to claim my space as the primary decision maker when it comes to changes in their placement.

Why did you want to participate in this study and is there anything else you would like to add for me to report?

Simple, ...because I have seen how many people automatically assume I don't understand paperwork, or that I shouldn't understand English, or that I probably don't

really know the needs of my kids...because I wear a scarf and have a little bit of an accent. I want to be a part of the narrative instead of having a narrative written about us that doesn't include us.

I think understanding my complete background helps people understand that I'm not just a foreigner that doesn't know enough and can't understand what my kids need.

That's the most frustrating part of working with some people the first time they meet me. I was born in the United States but went back to Egypt when I was seven. My education there was traditional and gave me many opportunities to learn in both my native tongue and in English. My school there was on the English side, others were on the French side, so we all learned English along with Arabic. When it was time for college, my parents encouraged me to come back to the U.S. I moved back and completed a bachelor's degree in business administration. This is where I met my husband, who was a student from Jordan. When my youngest of two was only 6 months old, my husband passed away from pancreatic cancer and that shook our family dynamics. It all happened so fast! I went from working part-time to having to work a full-time job that did not give me the flexibility I needed. I noticed my eldest, who was three at the time, did not speak the same way her peers did. Part of me assumed it was due to the loss of her dad. The daycare teachers encouraged me to seek help through my county and I did. Although she received speech therapy consistently, by age five, we couldn't deny that she wasn't meeting milestones. It was then that a more formal evaluation was completed, and they diagnosed her with Autism. Because of my experience with my daughter, recognizing the same characteristics in my son wasn't as difficult. His journey was not as hard as he was able to get a diagnosis earlier, at 3 years old. His autism is also more severe, and that has affected finding him care when I am working. I hope others can remember that just because someone looks or sounds different, doesn't mean they don't understand.